



The Future of Medicaid & CHIP Data Use

Assessing the Centers for Medicare
& Medicaid Services Transition to T-MSIS

January 2016

Executive Summary

The American healthcare landscape is rapidly changing. Medicaid and CHIP have grown by nearly 17 million enrollees since the passage of the Affordable Care Act,¹ and enrollment is expected to increase to a total of 91 million Americans by 2023.² At the same time, healthcare leaders are exploring how to increase value in healthcare by improving the experience and outcomes of care while containing or reducing its cost.

This latter effort is especially urgent given the high cost of Medicaid and CHIP for state and federal governments and the importance of creating strong health insurance programs that support the wellbeing of their beneficiaries. However, many state Medicaid agencies lack the ability to adequately evaluate and improve their programs because of a shortage of usable data. The need for higher quality and more timely data to inform decision-making and policy is clear.

To better understand the issue, the Robert Wood Johnson Foundation awarded Nuna a grant to engage with state Medicaid agencies and other stakeholders to learn about their needs with respect to data and data infrastructure.

In this report, we discuss the historical challenges of Medicaid and CHIP's data systems and the issues that stakeholders have identified as inhibiting effective program design, management, and evaluation. The Medicaid Statistical Information System (MSIS) was intended to serve this purpose as a repository of data on eligibility, enrollment, and provider payment. Many stakeholders found that it was inadequate in meeting their needs, primarily because the data was untimely and of poor quality. We then discuss the implementation of a new Medicaid and CHIP data system, Transformed-MSIS (T-MSIS), and identify the ways that it addresses some of the historical challenges we describe.

In the final section, we highlight the opportunities for using Medicaid and CHIP data in T-MSIS to support the goal of high-quality, affordable healthcare for Medicaid and CHIP beneficiaries. We make a number of recommendations that would improve the quality, richness, and availability of Medicaid and CHIP data, enabling stakeholders to leverage the data to its fullest.

1. Kaiser Family Foundation. "Total Monthly Medicaid and CHIP Enrollment." July 28, 2015. Accessed at <http://kff.org/health-reform/state-indicator/total-monthly-medicaid-and-chip-enrollment/> on August 20, 2015; Statista. "Total Medicaid enrollment from 1966 to 2015 (in millions)." 2015. Accessed at <http://www.statista.com/statistics/245347/total-medicaid-enrollment-since-1966/> on August 20, 2015.
2. Kaiser Family Foundation. "How Much Will Medicaid Cost in the Future and Why: A Look At Federal Projections." *Issue Brief*. August 2013. Accessed at <https://kaiserfamilyfoundation.files.wordpress.com/2013/08/8430-how-much-will-medicaid-cost-in-the-future.pdf> on August 20, 2015.

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01

Introduction

As of May 2015, the Medicaid and Children’s Health Insurance Program (CHIP) programs collectively served almost 72 million people—more than one in five Americans. With the Affordable Care Act (ACA) expanding Medicaid coverage to the uninsured, this number continues to grow significantly. Since October 2013, the first open enrollment period for the ACA’s eligibility expansions, the Medicaid and CHIP programs have grown by more than 13 million people.³ In addition to serving tens of millions of Americans, both programs represent major expenditures for both state and federal governments. In fiscal year 2014, total Medicaid spending was close to \$500 billion,⁴ and state contributions to Medicaid and CHIP represent more than 15% of state tax dollars.⁵

At the same time that policymakers have expanded the number of Americans with health insurance coverage, healthcare leaders have sought to improve the experience of care and the outcomes of care while maintaining or reducing its cost. Doing so has the potential to finally realize better value for our nation’s healthcare spending. To support those objectives, the ACA included a host of provisions that advance healthcare value through payment and delivery system reforms. Many of these policies promote the transition of payment policies from fee-for-service to models that make providers accountable to some degree for the quality and cost of the care they furnish. (A list of these models is included in *Appendix A*.)

3. CMS. “Medicaid and CHIP Application, Eligibility Determination, and Enrollment Data.” May 2015. Accessed at <http://www.medicaid.gov/medicaid-chip-program-information/program-information/medicaid-and-chip-enrollment-data/medicaid-and-chip-application-eligibility-determination-and-enrollment-data.html> on August 12, 2015.

4. Kaiser Family Foundation. “Total Medicaid Spending.” June 2015. Accessed at <http://kff.org/medicaid/state-indicator/total-medicaid-spending/> on August 12, 2015. Statistics do not include administrative costs, accounting adjustments, or data for the U.S. territories.

5. Center of Budget and Policy Priorities. “Policy Basics: Where Do Our State Tax Dollars Go?” *Policy Basics*, April 14, 2015. Accessed at <http://www.cbpp.org/research/policy-basics-where-do-our-state-tax-dollars-go> on August 12, 2015.

These two waves of transformation—coverage expansion, and delivery and payment reforms—are important and exciting, but will require careful policy development, resources, and data to execute and evaluate. Yet currently, many state Medicaid agencies lack the ability to adequately examine cost, quality, and access to care with appropriate granularity on patients, plans, or providers. While state Medicaid agencies are cautious not to overburden providers and health plans with more data reporting obligations, the need for higher quality and more timely data is clear.

Generating and disseminating high-quality data for Medicaid and CHIP will have substantial impact; improved data—both on its own and combined with other CMS and non-CMS datasets—will further multiple important policy goals.

First, high-quality data will better inform public policy by ensuring that researchers, governments, and other stakeholders are analyzing and learning from accurate and complete data.

Second, improved data will empower federal and state policymakers to be more informed purchasers of care through better algorithms, enhanced quality metrics, and other high-value analyses to advance Medicaid and CHIP delivery system and payment reforms. This data will support the transition to more accountable healthcare reimbursement payment models.

Third, there is an expanded opportunity to improve other safety net programs that rely on Medicaid and CHIP service utilization.

02

Purpose & Methods

The Robert Wood Johnson Foundation (RWJF) recognized the importance of creating a high quality, nationwide data repository for Medicaid and CHIP. RWJF awarded a grant to Nuna Health, a San Francisco-based data analytics company, to make a set of recommendations to help maximize the use of Medicaid and CHIP data by stakeholders and enable the use of the data to support payment and delivery system changes in our nation's healthcare delivery system.

With this funding, Nuna set out to understand the challenges with, and opportunities from, assembling and using Medicaid and CHIP data. In conducting our report, we took seriously the complexities associated with building such a repository to hold data that travels from health plans and providers to states and ultimately to the Centers for Medicare and Medicaid Services (CMS).⁶

Nuna Health interviewed staff at five state Medicaid agencies and 12 stakeholders in the policy and research communities between February 2015 and July 2015. We learned how Medicaid agencies currently use Medicaid data for program design and what their needs are with respect to making data-driven policy decisions. We also spoke with researchers and policymakers about how CMS could better support their efforts through improved access to data.⁷ (See Appendix B for the complete list of interviewees.) The following are reports of the difficulties stakeholders encountered, descriptions of implemented improvements to the state of Medicaid data and data infrastructure, as well as recommendations for future development.

6. Separately, Nuna Health was subcontracted to a large IT vendor to CMS to build a new data warehouse for Medicaid (known as T-MSIS). Nuna's dual roles—writing the report and building the T-MSIS data warehouse—enabled Nuna to fold feedback obtained during the RWJF interviews into the T-MSIS project development.

7. Nuna Health thanks all participants for contributing their time and expertise.

03

Challenges with Today's Data Systems for Medicaid and CHIP

In Section 1, we described how data can help Medicaid and CHIP advance several critical policy goals. In this section, we evaluate Medicaid and CHIP's current data offerings based on a review of the programs' structural challenges and our interviews with key stakeholders.

Need for Better Medicaid and CHIP Data

The Medicaid and CHIP programs are jointly funded and administered by the state and federal governments to provide a set of benefits to certain eligible population groups. States have the flexibility to apply for a waiver of federal law in order to expand these health benefits. States maintain a public account of their general program features (eligibility, benefits, administration, financing, waiver programs, etc.) through their Medicaid and CHIP state plans. This cross-state variation represents both a great opportunity for research and comparative analysis, and some substantial challenges.

- **Opportunity:** As key features of the programs differ across states and time, researchers and other stakeholders can more easily learn about the effects of implementing policies by comparing states across time.
- **Challenge:** Because states play a key role in setting policies for and administering the programs—and therefore the programs frequently differ from state to state—it is more difficult to collect high-quality and comparable national data from Medicaid and CHIP than it is for programs that are solely administered by the federal government, such as Medicare.

In part, as a consequence of the joint federal-state nature of the programs, Medicaid and CHIP data takes several different forms and often resides in separate systems at the state level that historically have not always been interoperable.

With funding and guidelines from the ACA, states and CMS are moving from these disparate, stovepiped systems to interoperable, enterprise systems.⁸ The types of data that Medicaid and CHIP collect include: consumer and provider eligibility and enrollment data; benefits and claims data from fee-for-service programs administered by the states; and encounter data, which is essentially the claims data that health plans gather and report to states.

8. "Balanced Budget Act of 1997." August 5, 1997. Accessed at <http://www.gpo.gov/fdsys/pkg/PLAW-105publ33/pdf/PLAW-105publ33.pdf> on August, 10, 2015.

For many years, CMS used a system known as the Medicaid Statistical Information System (MSIS) to store and aggregate data on eligibility, enrollment, and provider payment. This data is submitted by states to CMS and the source data is derived from the states' Medicaid Management Information Systems (MMIS) and Eligibility and Enrollment Systems. Unfortunately, as we document below, MSIS data has long-standing issues with completeness, accuracy, and timeliness, making the data unusable for meaningful empirical analysis and program design.

To remedy these problems, Medicaid and CHIP are in the processes of adopting a new data system, the Transformed Medicaid Statistical Information System (T-MSIS). T-MSIS is intended to rectify the problems with MSIS, enabling much more complete, complex, and timely analysis for both programs.

Key Challenges with Existing Systems

Based on our interviews and our experience as a data warehouse developer, we outline several critical gaps.

Data Timeliness

Stakeholders who were interviewed repeatedly raised concerns about the timeliness of Medicaid and CHIP data. Historically, quarterly data was submitted to CMS, then went through further edits to properly adjust all claims, and was finally transformed into MAX data (the research extract for MSIS data). Only when transformation of data into MAX data was complete was it made available for researcher use through a CMS data portal. Late and incomplete reporting was common. This, combined with the delay needed to adjust the files and transform MSIS to MAX, meant data had a two- to three-year lag, making real-time or near real-time monitoring of program and policy changes virtually impossible.

Poor Data Quality and Reliability

Stakeholders indicated that they were concerned about the reliability of data given that a number of entities may have modified the data—especially during quality validation processes—before it is sent to CMS. The issue of inconsistent data extends from the state level down to the health plan level. States did not always adhere to the submission standards (e.g., specified file formats and data schema) when submitting fee-for-service claims data and health plan encounter data. Furthermore, before reaching the state's MMIS, health plans often report and transform data in ways that state Medicaid agencies are unaware. One example was an instance where plans used different patient identifiers on the eligibility, claims, and encounter files.

Ambiguity in the Data Dictionary

Interviewees raised concerns about their ability to accurately analyze the data due to ambiguity in the data dictionary, which is the file that accompanies the data set and explains the meaning of the data fields. In order to integrate MSIS data with other files and systems, researchers must be aware of, and control for, idiosyncrasies of the data.

Lack of Transparency Around Provider Payments

One of the challenges with the current Medicaid and CHIP data is the limited information regarding provider reimbursements. This makes analyses of utilization and spending more difficult and inhibits states and CMS's ability to engage in program integrity activities.

Challenges in Accessing the Data

Stakeholders raised significant concerns about the difficulty and costs associated with gaining access to Medicaid and CHIP data. Researchers noted that there were challenges to working with CMS's legacy systems and that the Virtual Research Data Center (VRDC), the platform by which researchers access data, was difficult to navigate. For some researchers, the best option was approaching states directly for use of their data. Use of states' data, however, requires time-consuming negotiation with separate state health officials, sometimes has additional costs, and, in some cases, requires researchers to invest time harmonizing data across different state programs. This process essentially replicates much of the work that could be done as part of the creation of T-MSIS.

Limited State Resources and Poor Incentives

In addition to the technical and operational challenges limiting the usefulness of Medicaid and CHIP data, there has been a historical lack of funding for modern systems and the lack of incentives to states for submitting their data to the federal government. Prior to 1999, state submission of MSIS data was voluntary. The Balanced Budget Amendment of 1997 made the submission of this data mandatory,⁹ but did not give states the technical assistance or resources to make this a reality. CMS also lacked the necessary authority it needed to enforce the new data submission requirements.

9. CMS. "RE: Transformed Medicaid Statistical Information System (T-MSIS) Data." August 23, 2013. Accessed at <http://www.medicaid.gov/Federal-Policy-Guidance/Downloads/SMD-13-004.pdf> on August 12, 2015.

04

Recent Improvements to Medicaid and CHIP Data Systems

In Section 1, we described how data can help Medicaid and CHIP advance several critical policy goals. In this section, we evaluate Medicaid and CHIP's current data offerings based on a review of the programs' structural challenges and our interviews with key stakeholders.

Provisions of the ACA—specifically the delivery system, payment reforms, and enhanced program integrity requirements—made having an effective and high quality national Medicaid and CHIP data collection tool even more important than before. Partly motivated by these provisions, CMS developed a Transformed-MSIS (T-MSIS).¹⁰

In this section, we evaluate the extent to which recent improvement to Medicaid and CHIP data systems will address many of the shortcomings of the previous system.

10. To enable a seamless feedback loop between data providers, states, and CMS, T-MSIS will include an Operations Dashboard where states can go see the status of files that they have submitted and dynamic error reports with drill downs available for every error.

Timeliness

Under the previous data delivery system, states had to wait for a manual confirmation (effectively, an email from CMS or its contractor) that the file was received; no information about the file was available prior to that point. Under T-MSIS, file processing will be implemented in an automated manner such that states will have the capability to track the transmission of a file throughout its various processing stages. Additionally, states will be required to submit all files on a monthly, rather than quarterly, basis. These improvements will accelerate the pace of data exchange and increase the availability of more current data.

Data Quality and Reliability

One obstacle to more current data availability has been the lack of processes to verify data accuracy. In T-MSIS, this verification process will be automated. Standardized fields such as diagnosis codes, procedure codes, and medical claim form fields will be validated against a set of canonical values. Along with data, states will submit source-to-target mapping documents, which indicate data sources and deviations from the T-MSIS format. This will also be visible within the Operations Dashboard,¹¹ allowing CMS stakeholders to understand where the data originated (e.g., state MMIS, a state data warehouse, etc.) and data anomalies.

Under T-MSIS, CMS and states can monitor the data as it is submitted and view real-time feedback about file errors. Non-conforming data issues are communicated quickly, thus providing states to opportunity to make decisions about how to address quality concerns soon after they have submitted data, rather than months later.

Resources for States

The ACA provided substantial amounts of federal funding to states in order for them to bring their Eligibility and Enrollment Systems up to date to support the ACA-mandated eligibility and enrollment changes to the Medicaid and CHIP programs. CMS also made funding available for changes to states' MMIS to support gathering higher quality data on their Medicaid and CHIP programs. In contrast, as a negative incentive to states to that do not submit timely claims and encounter data, the ACA permits CMS to withhold federal matching payments.¹²

Even with the expanded resources for states, the quality and timeliness of data submitted by healthcare providers to states and health plans may continue to be an issue until states begin to more aggressively enforce the contract provisions they currently have with providers and health plans. Some states are doing this with more success than others. All of the states we interviewed that made data submission contract enforcement a priority have seen definitive results. States that tied health plan data submission to either rewards or penalties have seen even quicker results. Non-health plan care (i.e., fee-for-service arrangements with the state) may still be a challenge; this is a complicated issue tied to reimbursement and provider IT infrastructure, among other things, and varies state by state.

11. "Patient Protection and Affordable Care Act." March 23, 2010. Accessed at <http://www.gpo.gov/fdsys/pkg/PLAW-111publ148/content-detail.html> on August 10, 2015.

12. CMS Medicaid. "Reducing Early Elective Deliveries in Medicaid and CHIP." Accessed at <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Quality-of-Care/Downloads/EED-Brief.pdf> on August 10, 2015.

05

Recommendations for the Future State of Medicaid and CHIP Data

Our stakeholder interviews shed light on a broad range of ideas for how the vision for a robust, high-quality Medicaid and CHIP data environment could function. Many have been addressed in the improvements included in T-MSIS, but others reach beyond the T-MSIS scope. Some of these important stakeholder insights could be included in future improvements to T-MSIS while others fall outside of the T-MSIS purview.

THE OPPORTUNITIES ARE DIVIDED INTO TWO CATEGORIES:

1. Those that would improve the quality and richness of Medicaid and CHIP data
2. Those that would make Medicaid and CHIP data more accessible and useful

We make recommendations for each. We stress that that none of these issues are easy to tackle and that our recommendations may not fully solve the problem.

Opportunities to Improve the Quality and Richness of Medicaid and CHIP Data

Setting Minimum Standards for the Claims Data

ISSUE

A database that is able to support CMS and states' program design, management, and evaluation activities and advance the goals of improved health and healthcare delivery must meet a minimum set of data standards.

RECOMMENDATION

In summary, data should be:

Comprehensive. It must begin with information on beneficiaries' medical claims (inpatient, outpatient, long-term care, and prescription drugs). Furthermore, it must contain the universe of fee-for-service claims and health plan data, including payment associated with each claim. Because the majority of Medicaid beneficiaries receive their care through a managed care plan, it is essential that a dataset include data from health plans, including the dollar amounts that they pay to providers. T-MSIS will require the amount paid for a service (in addition to the amount billed, that which is usually reported).

Up-to-date. Given the impact of policy reform on the Medicaid and CHIP programs, it is critical that policymakers and other stakeholders be able to evaluate potential decisions with the help of up-to-date information. While stakeholders had different points of view on the exact definition of "up-to-date," the consensus opinion was that data should be no more than approximately six months old.

Easy to use, including detailed documentation. Given the inherent complexity in combining data from different state programs, it is essential that data be well-documented.

Comparable across states. The Medicaid and CHIP programs differ substantially across states in many of their key features, such as eligibility, payment values, and payment models used. This variation represents a valuable opportunity for states to learn from each other, but for these cross-state differences to be valuable, it is critical that the data set be comparable across states.

Comparable with historical data. One of the benefits of cross-state variation is the creation of "natural experiments." An example of a natural experiment is the study of the effect of an intervention, such as a benefit variation or healthcare delivery model, in one state by comparing outcomes to a similar population in another state that did not have the intervention. To be able to accomplish this, it is important for researchers and other stakeholders to be able to compare the programs over time. The migration from MSIS to T-MSIS will play a key role in meeting this need. Any database must, as much as possible, facilitate tracking of data over time. At first, T-MSIS data will be available separate from MSIS data. However, taking into account the need for longitudinal research, in the next several years, T-MSIS data will be merged with MSIS data in the future.

Comparable within and between delivery systems. When clean and timely encounter data is available with payment information, state policy makers will gain new insight into providing services under a managed care and fee-for-service delivery systems and begin to better evaluate the value of such care. Examples of the usefulness of such comparisons are: 1) Benchmarking cost and quality between states; or 2) Better evaluating the effectiveness of care management and accountability-oriented programs.

ISSUE

CMS uses a data dictionary to define the data elements that states are submitting to T-MSIS. Over the course of the project—yet still prior to implementation—continual changes to the data dictionary have upset states' ability to make progress on their systems. In fact, this was a subject of great consternation for many interviewees. With general recognition that the current data dictionary is not perfect, further changes make state systems fall even further behind. CMS has committed to no new updates to the data dictionary until after the initial system is launched. Once launched, however, it is essential that updates to the data dictionary be transparent and predictable.

RECOMMENDATION

T-MSIS will come with a fully dynamic and searchable data dictionary which we recommend that CMS make publicly available. Any change to a data element will easily be seen and its history visible. In order to make the best use of the data over time, and also not upset state progress, we recommend that CMS have regularly scheduled data dictionary updates. This way states can plan with their vendors and within their contracts for systems modifications, as well as communicate changes to the providers and health plans who are submitting most of the data. Upon discussing this issue with CMS, there was broad agreement about an organized approach.

Detailed, Standardized Coding on Claims

ISSUE

Several stakeholders raised concerns about the limited amount of information available on claims and how that may prevent state Medicaid agencies from monitoring adherence to clinical guidelines. For example, a number of states have tried to reduce early elective deliveries (EEDs), which are generally expensive and harmful procedures.¹³ However, there is not enough information on claims to determine the gestational age of the child and therefore to determine when a delivery was early. One state noted that it became almost impossible to monitor adherence to the Medicaid guidelines on early elective deliveries. A number of state agencies responded by creating codes for gestational age that physicians can add in manually, allowing the state to assess quality improvements in these payment reform programs.

RECOMMENDATION

Working with states and other stakeholders, CMS should oversee development of a set of claim modifiers and standardized codes for episodes, which contain information about a commonly associated set of procedures and diagnoses. Such modifiers and codes could provide greater clinical nuance to the claims and enable states and other stakeholders to monitor and advance healthcare quality goals.

13. David Card, Raj Chetty, Martin Feldstein, Emmanuel Saez. "Expanding Access to Administrative Data for Research in the United States." 2010. Accessed at http://papers.ssrn.com/sol3/papers.cfm?abstract_id=1888586 on August 14, 2015.

Pursuing Deeper Understanding of Value-Based Payment Systems and Innovative Care Models

Issue

As mentioned above, many state, federal, and commercial healthcare payers are actively engaged in efforts to reform their payment systems to improve the value of the care provided and to encourage innovative care models as a means to achieving that goal of better value.

While current claims reimbursement systems work well with fee-for-service, they are not yet well equipped to handle bundled payments, bonus payments, and other alternative compensation arrangements.

The mechanics of how to pay providers on a non-fee-for-service basis are imperfect and pose a substantial hurdle for health plans, as one state Medicaid agency reported. Plans and providers remain unsure of whether they were paid fairly in alternative payment structures because the existing claims system is rooted in fee-for-service and poorly adapted for other arrangements.

Similarly, several stakeholders raised concerns about states' abilities to measure cost, value, and effectiveness of services or items provided that are not traditionally covered by Medicaid. As an example, some healthcare leaders argue that it is more cost effective to purchase an air conditioner for a beneficiary with COPD who lacks one in their home than to pay for repeated inpatient stays when the hot weather exacerbates their condition. It is believed that substitute services can provide better value for the payer and patient. However, this is a difficult empirical argument to make in the absence of formal claims for these services (e.g., there is no healthcare claim for an air conditioner) and no counterfactual (e.g., it is unclear that an air conditioner would certainly avoid an inpatient stay for an individual with COPD in this case).

RECOMMENDATIONS

While this issue certainly goes beyond Medicaid and CHIP, purchasers and providers need a new data infrastructure that can better assess and assign value. When designing such a system, CMS and the states should balance the desire for more information and types of data with a concern for states' reporting burden.

In some cases, it may be useful to have data on all the processes and inputs involved in a new care model. In others, payers may be more interested in simply measuring outcomes. For example, one could argue that adding reporting requirements around social supports such as air conditioners may provide important insights about the interplay between a beneficiary's social situation and her health outcomes. On the other hand, others might argue that the payer's concern is the outcome, e.g., fewer emergency department visits or hospitalizations, so we should restrict our reporting to those most important measures.

Improving Provider Directories

ISSUE

CMS maintains the National Plan and Provider Enumeration System (NPPES), which allows providers and health plans to apply for and receive a National Provider Identifier (NPI), consistent with HIPAA requirements. NPPES collects data about the providers, but there are only general responsibilities that providers update their records with changes and no triggering event (e.g., annual recertification). This results in spotty and often inaccurate data on the providers that serve Medicaid and CHIP enrollees.

RECOMMENDATION

Having accurate provider directories is important for both health plans (in building provider networks) and consumers (who may rely on Medicaid programs and health plans to provide information with which to choose their physicians). The data associated with an NPI is critical to understanding providers' delivery of service, scope of practice, taxonomy, and location. Furthermore, providers often change practice features, accepted payers, composition, and languages spoken. These are all important details of provider practices, yet we currently lack reliable primary sources for this information.

While in theory, T-MSIS will hold some of this information, there is room to improve the source information and potentially create a more reliable national provider directory that is easy to use and current.

Opportunities to Make Medicaid and CHIP Data More Accessible and Useful

Expanding Data Access

ISSUE

High-quality data will help improve Medicaid and CHIP only if key stakeholders can access the data in a manner that facilitates their ability to conduct meaningful statistical analyses.

RECOMMENDATION

We begin our discussion of data access by touching on how stakeholders should access the data. As emphasized by researchers,¹⁴ direct access to raw micro-data (e.g., individual claims, with information about patients and providers) rather than aggregated statistics is critical. Alternatives, such as access to "synthetic data" (simulated micro-data that is constructed to mimic some features of the actual data) or submission of computer programs to agencies to run analysis, are poor substitutes for giving stakeholders access to the micro-data itself. Moreover, it is critical that stakeholders be able to access the data with tools that match their objectives and level of technical expertise. At the same time, a data environment that enables access must protect the security and privacy of Medicaid and CHIP data.

14. U.S. Department of Health and Human Services National Institutes of Health. "To Whom Does the Privacy Rule Apply and Whom Will It Affect?" February 2, 2007. Accessed at http://privacyruleandresearch.nih.gov/pr_06.asp on August 10, 2015.

These needs justify the creation of a secure and functional data center that allows qualified stakeholders to access the data. In particular, given that the guiding principle of T-MSIS is to centralize, harmonize, and learn from data from state programs, it would be wasteful if the data were not available in a form that allows stakeholders to conduct their research. Given the challenges raised with the VRDC, we encourage CMS to continue to think creatively about how data can be shared in more ways that promote the dual aims of data privacy and security on the one hand and data access on the other. A good example might include Amazon Web Services (AWS), which includes Elastic Map Reduce (EMR) as a tool that allows data scientists and researchers to quickly access and process large data sets at minimal costs.

Determining who should have access to data requires balancing the tangible gains from open data access with the risks and costs associated with granting this access to a wider group of stakeholders. The purpose of this report is not to resolve this tradeoff; instead, we briefly document how access to high-quality data could benefit the Medicaid and CHIP programs, and their beneficiaries. The following is a list of stakeholders who have meaningful interests in accessing and using the Medicaid and CHIP data:

Policymakers at the state and federal levels. Individuals who are responsible for setting policy for the Medicaid and CHIP programs can benefit from a better understanding of their programs, beneficiaries, and providers, and from having the ability to learn from policy reforms that were implemented in the past. Moreover, some interviewees stressed the importance of granting data access to individuals who set policy for other social programs (such as public education and foster care). Giving these individuals access could improve the coordination between their programs on the one hand and Medicaid and CHIP on the other. Critically, several stakeholders raised the importance of being able to combine data from these various social programs in a manner that is secure and protects the privacy of beneficiaries.

Researchers.

The research community, both inside and outside of universities, can help identify ways to improve the efficiency of these programs.

Providers.

Information contained within claims data can help providers optimize their treatment plans for beneficiaries, which, in turn can lower cost and improve healthcare outcomes. This data, for example, can help providers identify beneficiaries who do not adhere to their prescribed drug regimen. Understanding this information can inform and improve communication between providers and beneficiaries.

Under some conditions, for-profit entities such as managed care plans.

Because the majority of Medicaid beneficiaries receive most or all of their care from managed care organizations, there may be value in using Medicaid data to help these plans reduce costs and improve outcomes. Giving a plan access to Medicaid data has the potential to help those plans operate more efficiently, such as identifying high-quality providers or flagging at-risk beneficiary populations.

Protecting Privacy while Reducing Barriers for States and Researchers

Issue

The HIPAA Privacy Rule limits the transmission of health information, even among entities permitted to possess and transmit identifiable data, so called “covered entities,”¹⁵ such as state Medicaid agencies and other public service agencies. State Medicaid agencies may feel discouraged from undergoing the HIPAA approval process due to a lack of time, resources, and financial incentives. As a result, they seldom try to obtain and integrate education, housing, prison, and public health data with their own Medicaid data, even with entities in the same jurisdiction that may or may not have their own mandates to share health information.

Researchers may face similar and more pronounced challenges than covered entities when accessing Medicaid data. They too must comply with HIPAA rules, and do not have the same mandates to access and utilize identifiable data. They may also require different types of technology in order to transfer data securely; the data pull for these users might be more labor intensive. In addition to these privacy and technological hurdles, the know-how, time, and money required to navigate bureaucratic and technological conduits may further inhibit researchers from obtaining data. Research entities may not know how to apply for permission, stumble while navigating different guidelines surrounding identifiable and de-identified data, and struggle to know which gatekeepers of data to turn to—state Medicaid agencies or CMS, among others.

RECOMMENDATION

Amending the HIPAA rule to more easily combine Medicaid data with other covered entities’ data would be immensely helpful for policymakers and researchers alike. Additionally, a grant system or other financial awards may incentivize covered entities to share and combine data for the betterment of public health.

These administrative and technological processes for obtaining and transmitting Medicaid data are complex, perhaps prohibitively so. In the longer run, we recommend that CMS look not just for technological solutions, but also to provide administrative assistance. Medicaid data users would benefit if CMS created simplified processes for approval, and low-cost, streamlined solutions for sending HIPAA-protected data, such as limited datasets, securely across permitted entities.

15. Gerard Anderson, Karen Davis, and Stuart Guterman. “Medicare Payment Reform: Aligning Incentives for Better Care.” The Commonwealth Fund, June 2015. Accessed at <http://www.commonwealthfund.org/publications/issue-briefs/2015/jun/medicare-payment-reform-aligning-incentives> on August 10, 2015.

Addressing States' Reporting Burden

ISSUE

State Medicaid agency interviewees repeatedly expressed concerns about the administrative and financial burden of reporting data to the federal government. At the time of the interviews, most state stakeholders perceived T-MSIS as a distinct federal reporting burden with no direct benefit to the states. Most felt very disconnected from CMS's vision for a more streamlined and efficient data collection and aggregation system. Several states also mentioned that other federal reporting requirements, such as the Payment and Error Rate Measurement, were duplicative, and therefore unnecessary.

RECOMMENDATION

We encourage CMS to be proactive in engaging and educating states and other stakeholders about the vision and the plan for implementing T-MSIS. Many states were unaware that some of their concerns relating to reporting burden will be addressed by T-MSIS. This could include hosting regular conference calls or webinars, or issuing regular memoranda about the progress and plans for T-MSIS.

Looking beyond better communication, there may still be opportunities for CMS to find more efficient and accurate ways to gather and report data. Examples of reporting burdens that could be resolved through more streamlined data collection and reporting include: program integrity, budget and expenditure, and adult and child quality metrics.

Improving Opportunities for Insight by Facilitating Merging Medicaid and CHIP Data with Other Data Sources

ISSUE

There was broad consensus about the public policy opportunities when merging Medicaid and CHIP health data with other data sets. In fact, some states have already been combining Medicaid data with other types of data on other programs including: housing; Early and Periodic Screening, Diagnostic, and Treatment (EPSDT); lead screening; immunizations; managed long term support services assessments; corrections; and financial and nutrition assistance to low income families. While many of these data sets are not protected by HIPAA, they are still difficult to obtain and state-to-state comparisons are not yet possible. Integrating these various data sources, especially data from electronic health records, would require a substantial investment of IT resources. Our purpose here is not to resolve the question of how to allocate IT resources between competing priorities but instead to briefly summarize the non-claims data elements that interviewees felt should be part of a functioning high-quality data warehouse.

Beneficiaries:

demographics, basis of eligibility, enrollment information

Providers:

location, facility size, licensing information

State policies:

state's eligibility requirements, benefits, delivery systems, and administrative policies and procedures.

Health plans:

plan name and information that would allow researchers to import other plan characteristics such as for-profit status and regional scope.

Electronic health records (EHR):

detailed information from providers' medical records

RECOMMENDATION

We recommend that CMS work with the federal agencies overseeing the state programs to further reduce the burden by making widely available common, certified sets of de-identified T-MSIS data with standard data use agreements.

Data sets could include:

- Temporary Assistance to Needy Families (TANF) and Supplemental Nutrition Assistance Program (SNAP) data
- Criminal justice data
- Geographic information such as: locations of parks, grocery stores, fast food restaurants, public transportation routes, different types of healthcare providers, schools, etc.
- Public health data
- Federal and State-based Marketplace enrollment data
- EHR/clinical data

CMS should also consider integrating better sources of various data that are included in T-MSIS. For example, using data from the Federal Data Services Hub used to confirm data on applications for healthcare through Medicaid and CHIP could improve the accuracy of certain fields, such as eligibility.

Two principal types of de-identified datasets would serve as a huge boon to the research and policy community: "Safe Harbor" data and statistically de-identified information. The Safe Harbor method of de-identifying data strips direct and fine-grained temporal and geographic information from the dataset. While these data may be useful for certain research enquiries, they are somewhat limited in their utility given the amount of information omitted from the data. Statistically de-identified information does not have unique identifiers but does contain metrics on geography and time. It may be the best balance between privacy and data usability.

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Conclusion

There is increasing consensus that Medicaid and CHIP program data is critical to transforming how we monitor, evaluate, and pay for care within these two programs, and also within the broader context of health system transformation. Timely availability of high quality Medicaid and CHIP operations data is critical and the time is now.

This is a significant undertaking. CMS and states have contributed an enormous amount of effort to wrangling this complex topic over the last five years—and during a time of many competing priorities.

We have demonstrated where CMS and states have made significant progress in reducing the gap between data needs and the IT systems to support this. Many opportunities remain for improving the systems, the policies governing them, and how both evolve over time. With commitment, collaboration, and open communication, we believe CMS, the states, and other stakeholders can help advance the cause of better data, and ultimately, better health and healthcare for Americans enrolled in the Medicaid and CHIP programs.

Appendix A: Current and Recent Activity Supporting New Models of Care

In the last five years, there has been a flurry of activity in the public and private payer space to test and implement new ways of paying for high quality care. These activities are not exclusive to payer type—meaning that multiple payers are likely to participate in multiple models with one another. Here are some examples of activity:

Medicare and Commercial Payer-Led Payment Reforms.

Medicare and the commercial health insurance space have been implementing and testing models such as (but not limited to): episodes of care and bundled payments, systems of care accountability under risk arrangements (e.g., Accountable Care Organizations under Medicare), global payments, reference-based pricing, narrow networks, and Centers of Excellence.¹⁶ CMS' Center for Medicare and Medicaid Innovation (CMMI) was established under the ACA and was well-funded with approximately \$10 billion for developing and testing new models of care delivery and payment in Medicare and Medicaid. Many of the Medicare initiatives listed above have flowed from the CMMI programs.¹⁷

Health Information Exchange.

Building on the foundational work of the Health Information Technology for Economic and Clinical Health (HITECH) portions of the American Recovery and Reinvestment Act (ARRA) of 2009, states, payers (including Medicare and Medicaid), and providers have been busy building the health IT infrastructure needed to meaningfully report, store, and exchange clinical health data (e.g., health information exchanges, EHR incentives, and roadmaps to achieve these things). In an effort to eventually promote transparency around healthcare pricing, as of August 2015, 14 states have established All-Payer Claims Databases.¹⁸ Although, very few of these states have been able to achieve goals around transparency with the data in these databases.¹⁹

16. US Department of Health and Human Services. "CMS Center for Medicare & Medicaid Innovation Budget Overview." June 4, 2014. Accessed at <http://www.hhs.gov/about/budget/fy2015/budget-in-brief/cms/innovation-programs/index.html> on August 10, 2015.

17. All Payer Claims Database. "Interactive State Report Map." 2015. Accessed at <http://www.apcdouncil.org/state/map> on August 10, 2015.

18. Catalyst for Payment Reform and Health Care Incentives Improvement Institute. "Report Card on State Price Transparency Laws." July 2015. Accessed at http://www.hci3.org/sites/default/files/files/2015_Report_PriceTransLaws_06.pdf on August 10, 2015.

19. Alexandra Gates, Robin Rudowitz, and Jocelyn Guyer. "An Overview of Delivery System Reform Incentive Payment (DSRIP) Waivers." *Kaiser Family Foundation*, September 29, 2014. Accessed at <http://kff.org/medicaid/issue-brief/an-overview-of-delivery-system-reform-incentive-payment-waivers/>

Delivery System Reform Incentive Payment Program (DSRIP).

DSRIPs are part of the section 1115 demonstration waivers in California, Texas, Massachusetts, New Jersey, Kansas, and New York. Oregon also received federal funds under a similarly structured feature of its section 1115 demonstration. The general purpose is to include sizeable investments in the delivery system infrastructure needed to achieve medium- and longer-term gains for value-based purchasing.²⁰

State Innovation Model (SIM) Grants.

The purpose of the State Innovation Model SIM grants —established by CMMI in 2013—is to develop and test models that bring together efforts of multiple payers for market alignment, hopefully yielding consistent program requirements and ultimately improved outcomes. CMMI has since awarded almost \$1 billion to 38 states, territories, and the District of Columbia.²¹

Financial Alignment Initiative (also known as “the duals demos”).

CMMI and the Federal Coordinated Health Office at CMS has led a broad effort that is targeted at integrating the Medicare and Medicaid programs better in order to improve outcomes for the nearly 10 million individuals enrolled in both Medicare and Medicaid.²² This population is particularly frail and their costs exceeded \$284 billion in 2010, or approximately 34% of the Medicare costs and 35% of Medicaid costs.²³ Currently 12 states are actively under agreement with CMS to share in savings resulting from better coordinated care between the two programs, which is measured by improved health outcomes.

Innovation Accelerator Program (IAP).

Announced in July 2014, the IAP is a non-grantmaking federal effort to offer technical resources to states to accelerate progress in the area of delivery and payment reform.²⁴ CMS will supplement the efforts with technical resources such as learning collaboratives, analytics, and program/policy analysis. States need this federal leadership to enhance their own projects, learn from other states, and evaluate vendor contributions.

20. CMS CMMI. “Health Care Innovation Awards.” August 6, 2015. Accessed at <http://innovation.cms.gov/initiatives/Health-Care-Innovation-Awards/> on August 10, 2015. at August 10, 2015.

21. CMS. “Financial Alignment Initiative.” July 30, 2015. Accessed at <https://www.cms.gov/Medicare-Medicaid-Coordination/Medicare-and-Medicaid-Coordination/Medicare-Medicaid-Coordination-Office/FinancialAlignmentInitiative/FinancialModelstoSupportStatesEffortsinCareCoordination.html> on August 10, 2015.

22. CMS Medicare-Medicaid Coordination Office. “People Enrolled in Medicare and Medicaid.” March 2015. Accessed at https://www.cms.gov/Medicare-Medicaid-Coordination/Medicare-and-Medicaid-Coordination/Medicare-Medicaid-Coordination-Office/Downloads/MMCO_Factsheet.pdf on August 10, 2015.

23. CMS Medicaid. “Medicaid Innovation Accelerator Program (IAP).” Accessed at <http://www.medicaid.gov/state-resource-center/innovation-accelerator-program/innovation-accelerator-program.html> on August 10, 2015

Appendix

B: List of Interviewees

State Medicaid Programs

Arkansas

Florida

Illinois

New Jersey

New York

Oregon

Pennsylvania

Texas

Virginia

Washington

Italics denote state Medicaid programs that Nuna staff visited on site in addition to conducting phone interviews.

Other Researchers and Stakeholders

Center For Children and Families at

Georgetown University

Centers for Medicare & Medicaid Services

Catalyst for Payment Reform

George Washington University

Kaiser Family Foundation

Medicaid and CHIP Payment and Access Commission

National Association of Medicaid Directors

National Governors Association

NORC

Stanford Medical School

University of California at San Francisco

Urban Institute