



AcademyHealth

**The AcademyHealth Listening Project:  
Improving the Evidence Base for Medicaid Policymaking**



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# Executive Summary

*AcademyHealth is a leading national organization serving the fields of health services and policy research and the professionals who produce and use this important work. Together with our members, we offer programs and services that support the development and use of rigorous, relevant, and timely evidence to increase the quality, accessibility, and value of health care, to reduce disparities, and to improve health. Launched in 2013, AcademyHealth's Translation and Dissemination Institute helps move health services research into policy and practice more effectively. It undertakes activities that help research producers better understand the needs of research users, and serves as an incubator for new and innovative approaches to moving knowledge into action. This report is the second in a series focusing on the short- and long-term research needs of policymakers and leaders in health care delivery systems.*

The Listening Project, a signature activity of AcademyHealth's Translation and Dissemination Institute, seeks to identify the most pressing research needs of leaders in health policy and health care delivery for the coming three to five years. Its goal is to foster greater interaction among the producers, funders, and users of health services and policy research (HSR) and spur the production and use of timely, relevant evidence to improve health and health care. As such, it supports AcademyHealth's vision to improve health and health care by generating new knowledge and moving that knowledge into policy and practice. The first report in the Listening Project series was released in early 2014 and focused on research and data, to support Medicare policymaking.

During the summer and fall of 2014, AcademyHealth staff conducted semi-structured telephone interviews with 53 state and federal policymakers, non-governmental experts, and other stakeholders regarding knowledge gaps and research needs related to Medicaid. Our interviewees included Medicaid agency staff from four states representing a diversity of sizes, geographic regions (Northeast, South, and West), political perspectives, and decisions on Medicaid expansion. To maintain the anonymity of our respondents and in keeping with our Institutional Review Board exemption,<sup>i</sup> we do not provide more specific information about the states included in the interviews. Staff used qualitative data analysis techniques to identify and synthesize major themes, which were validated by an external review committee comprised of interviewees and content experts. The analysis that follows draws heavily on the use of verbatim quotes to illustrate each finding; in some cases, quotes were edited for grammar and length. While we do not identify interviewees by name or organization, we precede the verbatim quotes with information about the respondent's role relative to Medicaid, for example, as a state or federal policymaker, advocate, or researcher.

The final analysis organized respondents' comments along four major themes: (1) research needs, (2) data gaps, (3) use of evidence to inform Medicaid policymaking, and (4) advice for researchers. As with the first Listening Project report, this document is not intended to be a research agenda nor the sole effort of its kind,<sup>ii</sup> but rather a starting point for discussion among the producers, users, and funders of research about opportunities to strengthen Medicaid research and policy moving forward.

The full narrative of the 2015 Listening Project report, with expanded samples from respondent interviews, is available online at: [www.academyhealth.org/listeningproject](http://www.academyhealth.org/listeningproject).

## 1. Medicaid Policy Needs: Gaps in Research

The research topics identified most often and most forcefully in the interviews reflect the changing structure and composition of some state Medicaid programs in the context of payment and delivery system reform and implementation of the Patient Protection and Affordable Care Act (ACA):

## Medicaid Expansion

Interviewees' comments suggest that issues surrounding Medicaid expansion are top-of-mind for many state policymakers. Respondents consistently identified the need for evidence on the impact of expansion versus non-expansion on enrollee health outcomes, providers, and state budgets. They also cited the need for additional information about the different approaches used by states to expand Medicaid coverage, from more traditional approaches that follow federal rules established by the ACA, to alternative models that use demonstration waivers from the federal government to expand Medicaid eligibility while making broader changes to the way coverage is structured.<sup>iii</sup> Respondents raised a number of questions about the impact of "premium assistance models" in place in Arkansas and Iowa as well as similar initiatives that move Medicaid programs in some states more toward providing coverage through private insurance. A state-based policy analyst was among the respondents who raised this issue.

*There's a lot of interest in what Arkansas has done, what Iowa has done... What is Arkansas seeing in terms of utilization of services? With the focus now on increasing patient responsibility and cost sharing, what are we seeing? Is that a positive for health outcomes? Is that a negative? Are people foregoing services because they have a high cost burden? What implications does it have on cost?*

-Interviewee

In order to make decisions about Medicaid expansion, policymakers also need information about the health status and health-seeking behavior of individuals who would be newly eligible for coverage under Medicaid expansion. This information could also help inform decisions about benefit design.

## Payment and Delivery System Reform

The interviews suggest that state Medicaid programs are actively involved in the types of payment and delivery system reforms that are gaining traction elsewhere in the U.S. health care system. In particular, respondents expressed significant interest in how state Medicaid programs might structure payments to managed care plans in a way that incentivizes quality improvement while controlling costs. A stated obstacle to these efforts is a lack of understanding about how payments from a state move through a plan to providers and how this process affects the care enrollees receive. Value-based purchasing was commonly cited as a promising strategy that is limited somewhat by the continued challenges associated with measuring plans' quality performance. Respondents also identified the need for additional research on accountable care organizations (ACOs), medical homes, and other models that aim to provide coordinated, integrated care to Medicaid enrollees while controlling costs. The key question is "What works?" A federal policymaker was among the respondents who raised this issue.

*...how can the researchers still help call out things that are worthy of continued testing or scaling? That would be, I think, the greatest help for these types of demonstrations in new care models and ways of doing Medicaid differently.* -Interviewee

## High-Need Medicaid Enrollees

Respondents noted that Medicaid policymakers are focusing particular attention on enrollees with complex health care and social service needs, such as dual eligibles, individuals with disabilities, and individuals with mental illness and substance use disorders.

*I would love to see an analysis of the high-cost, high-need populations and how they're being served and to think about how to better serve them and focus resources there. I mean, we have some sense of that, but I haven't seen a good sort of analysis of who they are and what they cost today and what their patterns of care are.*

-Interviewee

A common challenge is determining the specific set of services that are appropriate for different patient populations, including the setting in which care should be delivered and by whom. This issue was frequently raised in the context of behavioral health, where respondents cited the need for additional research on the appropriate locus of care for enrollees with different types and severity of mental illness. Respondents also expressed high interest in the growing use of Medicaid managed care for populations such as dual eligibles and individuals with developmental and physical disabilities, raising questions about how managed care compares to fee-for-service payment in terms of access to care, patient satisfaction, and state costs.

## Other Issues of Interest

Interviewees identified a number of other areas where they believe new or better research could help inform Medicaid policy, including studies to understand:

- effective strategies for enrolling eligible individuals in Medicaid coverage and keeping them enrolled;
- effective strategies for incentivizing enrollees to engage in behaviors that improve their health and reduce program costs;
- whether Medicaid enrollees, particularly the newly-eligible, have adequate access to care and how states might measure access;
- how to balance benefit and cost considerations when making decisions about high-cost pharmaceuticals;
- how best to deliver services to children with special health needs, including those with developmental disabilities or severe and persistent mental illness;
- how to improve service delivery and payment for maternity care and reduce rates of poor birth outcomes; and
- the cost effectiveness of peer support specialists, community health workers, and other non-physician providers in serving Medicaid enrollees.



## Service Integration and Coordination

Our interviews suggest that Medicaid policymakers are increasingly interested in evidence to help design effective strategies for integrating services and coordinating care among the multiple systems that serve Medicaid enrollees, such as mental health, social services, and criminal justice.

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*“I think there are [all] sorts of widely-recognized shortcomings as people move across health care systems, across insurance products, across settings for care. The better coordination of those could yield big returns, both in terms of improved outcomes and more efficient use of resources.”*

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Respondents identified several research needs related to the integration or coordination of services for Medicaid enrollees, such as the need for evidence on:

- cost-effective models for integrating behavioral health and physical health services;
- measures for assessing the level of primary care-public health integration occurring in local communities; and
- effective strategies for ensuring continuity of care through periods of incarceration.

Some respondents raised questions about the role of Medicaid in addressing social determinants of health—factors such as access to housing, transportation, and other resources that may impact an individual’s health. Comments on this topic suggest that while policymakers in some states are interested in providing services that help address social determinants among Medicaid enrollees, many are unlikely to act in the absence of financial incentives.

## 2. Medicaid Policy Needs: Gaps in Data

Respondents frequently cited challenges that can make the collection and analysis of Medicaid data difficult. These issues include significant variation across states in program structure, data collection and reporting practices, data-use requirements, and churn within the enrollee population. In addition to these challenges, respondents identified four main data issues that limit the ability of researchers and policy analysts to use Medicaid data to help inform policymaking. Respondents consistently cited the need for (1) improved data quality; (2) comparable data across states; (3) detailed Medicaid managed care encounter data; and (4) better measures of access to care, quality of care, and health outcomes.

### Improved Data Quality and Timeliness

Respondents indicated that the lack of high quality, timely Medicaid data limits the ability of researchers and policy analysts to conduct research to help inform policy decisions. Many noted that Medicaid data are complex and require significant resources and expertise in order to conduct useful analyses in a timely manner.

*In most states, claims lag in terms of when publicly available data files are available...Historically, Medicaid claims have been extremely 'dirty' and very hard for researchers to clean and make useable. I would say that data lag and the quality of what is going in and how hard it is to make that [data] useable coming out continues to be the biggest problem from a researcher perspective.*

-Interviewee

### **Comparable Data Across States**

Respondents frequently commented on the usefulness of studies that compare various aspects of Medicaid programs across states. However, the lack of uniform data collection and reporting practices across states makes conducting comparative studies extremely complex and resource-intensive. A state policy expert was among the respondents to raise this issue.

*If you want to do something in Medicaid, almost everything you would need to gather would be state by state. There are very few data sources that are comparable across states that you could use for anything of interest.*

-Interviewee

Although interviewees noted recent efforts by the Centers for Medicare & Medicaid Services (CMS) to improve data systems via the Transformed Medicaid Statistical Information System (T-MSIS) and the creation of a national data repository,<sup>iv</sup> most did not indicate whether or not they thought these changes would help address data reporting and collection issues.

### **Detailed Medicaid Managed Care Data**

Interviewees in both state and federal government expressed frustration with the limited and often low-quality data provided by Medicaid managed care plans. Encounter data are submitted by plans to the state Medicaid agency and include summary information on the total amount of enrollee interactions or “encounters” with the health care system through the services received, such as physician office visits or prescriptions. Managed care plans are paid on a pre-determined, capitated basis and as a result, encounter data does not include individual level utilization or cost per service provided. Without more detailed data, states are limited in their ability to track trends in utilization, access to care, and actual costs.

*We run into the problem of gaining access to encounter data...When we ask [Medicaid managed care plans] how they're spending the dollars, we're getting very little information back. The response we get is that it's proprietary and that it can't be shared with us. The converse of that is we're paying for the care so we feel like we ... should be able to access that information to analyze it and get data [on] utilization, cost, trends, et cetera.*

-Interviewee

### **Better Measures of Access to Care, Quality of Care, and Health Outcomes**

A number of respondents raised research needs regarding measurement, in particular, the need for better measures of Medicaid enrollees' access to care, quality of care, and

health outcomes. In one line of comments, respondents described the need for more and better measures of access to care, particularly access to specialty care among high-cost, high-need populations. A researcher was among those respondents to raise this issue.

*While there seems to be pretty good measures of access to primary care, there are not particularly good measures or understanding of access to specialty care. We hear anecdotally from health plan medical directors that access to specialty care is an enormous challenge for them, particularly in rural areas, but even in some urban areas.*

-Interviewee

Interviewees also noted that access measures should account for the new and emerging ways patients receive care outside of the traditional primary care visit with a physician, such as telemedicine and utilization of non-physician providers. In addition, respondents reiterated the need for better measures of the quality of care Medicaid enrollees receive, particularly high-cost, high-need populations enrolled in Medicaid managed care.

### Quality Measurement: A Cross-Cutting Theme

Across the interviews, many respondents described the difficulty of assessing the quality of care Medicaid enrollees receive. Citing the need for continued work on this issue, respondents identified a few key areas where additional evidence on quality measurement could help inform Medicaid policy moving forward.

#### **In relation to pay-for-performance and other payment approaches that reward providers for quality:**

*“So the plans report these HEDIS measures, but...most of them are process measures and they’re not outcome measures...how do we get beyond the HEDIS cycle and actually improve quality? What is [the state’s] role vis-à-vis the managed care plans?”*

#### **In relation to behavioral health services:**

*“There just aren’t real great tools about assessing patient experience or quality of care, and more specifically within behavioral health, we found a real poverty of data or metrics around measuring the quality of behavioral health services...in general, but more specifically within Medicaid.”*

#### **In relation to dual eligibles and other enrollees with complex needs:**

*“With these types of populations, we are desperate for information about how to truly measure quality impact and we’re stuck with a lot of process measures. We don’t have a very good understanding of how to measure a patient’s care coordination or integration of care. They don’t lend themselves well to NCQA [National Committee for Quality Assurance] or other nationally-endorsed measurement sets that have been tested for years and years.”*



## 4. Use of Evidence to Inform Medicaid Policymaking

In addition to asking about gaps in existing research and data, we also asked respondents about the ways in which they access and use analytic evidence to inform their Medicaid-related work. Interviewees consistently identified three influences that affect whether and how policymakers use evidence in Medicaid decision-making. These three factors are well-documented in the existing literature on how evidence is used in policymaking.<sup>v</sup>

### Politics

Many respondents cited politics as a widely-recognized factor influencing Medicaid policymaking, including the perception and use of evidence. Interviewees noted that briefs and reports supplied by stakeholders may present potentially biased or one-sided perspectives on policy issues, though respondents suggested that the majority of policymakers, particularly those within Medicaid agencies, are adept at taking information from stakeholders with the appropriate “grain of salt.”

In addition, election cycles and turnover among political leadership can limit the ability of analysts in state government to conduct internal research and analyses over long time frames. Politics may also influence the policy options available to decision makers on a given issue.

While some respondents expressed frustration with the challenges that politics present to the policymaking process, others encouraged researchers to consider highly-partisan environments as an opportunity instead of an obstacle.

*Oddly, I think in some ways the politicization is the opportunity and not the problem. I think in a very highly-politicized and polarized environment, people who can come forward and enter into that debate who are independent and not driven by ideology but instead by evidence...actually have a unique platform.*

-Interviewee

*If a researcher is not advocating for a particular interest [and] can actually figure out a way to get in front of these legislators...they are so grateful to have a third party present some of this information, particularly if that researcher is willing to step out on a limb, translate, and talk about the implications.*

-Interviewee

### Experiences of Other States

The interviews suggest that many Medicaid policymakers look to the experiences of other states to help inform key policy decisions. These experiences may help policymakers build the case for certain policy decisions, and often carry significant weight when compared to other forms of evidence. A state policymaker was among the respondents who cited this practice.

*Information from other states is very useful and it's one of the first things usually that people want to know. When you're talking about a particular issue, it's 'what's happening out there in other states on this?' It's not that we don't have access to [that information]...we've been able to get some information from what other states have done. There are sources for that, but I think that there is still a void and a need for more comparative information for policymaking.*

-Interviewee

These comments reflect a theme heard across the interviews regarding states' strong interest in learning from each other as they grapple with shared opportunities and challenges.

## State Capacity

Respondents expressed broad recognition of the time, budget, and staffing constraints that impact the ability of policymakers and their support staff to understand and use data and other information from both internal and external sources. As one state policymaker observed, policymakers at both the state and federal level are “drinking through the fire hose” when it comes to the volume of information received on a daily basis, making it difficult to process, prioritize, and use evidence to inform key policy decisions.

*I know there is obviously new research, new ideas coming out all the time and for somebody in my shoes, when you're getting 250 emails a day or more, it's hard to sift through it all to deal with it.*

-Interviewee

Several respondents suggested that there is significant variation in the ability of state Medicaid programs to access and analyze data to inform Medicaid policy. Some programs experience significant “brain drain” and loss of institutional knowledge as highly-skilled analysts leave to pursue more lucrative positions in the private sector. While some respondents noted that working with external researchers can help address this issue, others countered that sharing data with individual researchers often does not alleviate capacity issues, as program staff must help the researcher navigate the unique and complex details of their Medicaid program and dataset.

Some respondents noted the emergence of partnerships between states and universities or other state-based research organizations, calling these partnerships helpful for building trust between states and researchers, addressing internal staffing and capacity issues, and facilitating increased access to data for researchers.

## 5. Advice for Producing and Communicating Policy Relevant Research

In another line of questions, we asked respondents to provide advice for researchers interested in producing policy relevant work. Suggestions for researchers pointed to the importance of:

- developing relationships with policymakers and other research users early in the research production process;
- producing timely analyses;
- communicating research findings in clear, concise language that is free of jargon;
- disseminating research findings in multiple formats, such as a peer-reviewed publication accompanied by a two-page brief; and
- drawing on past experience or the best available evidence when questions from policymakers don't have a definite answer or sound evidence base.



In addition, many respondents noted the importance of understanding states' unique political environments, budget constraints, and other contextual factors that can affect the production and use of research—a point that is not unique to Medicaid research.<sup>vi</sup> Respondents described the importance of aligning study topics with state policy priorities and structuring research in a way that will produce tangible, actionable findings. For researchers working with agency staff on data acquisition, analysis, or other work, respondents emphasized the importance of being a good research partner, including being mindful of the time, budget, and other resource constraints facing those working in state government.

In another piece of advice, several respondents encouraged researchers to put study findings in the context of existing literature as a way of helping policymakers and other audiences understand the study's contribution to the current evidence base. These comments are supported by existing literature on effective practices for communicating research findings to decision makers.<sup>vii</sup> A state policy expert was among the respondents who offered this suggestion.

*The biggest mistake researchers make is thinking that their one study standing alone should be a big media story. Really what you want is to put your work in the context of the broader literature and figure out how to move the body of thought in a certain direction and not try to isolate your own work.*

-Interviewee

These comments reflect existing literature on the role of systematic reviews in providing policymakers with summary information on the key findings and strength of an existing body of evidence.<sup>viii</sup>

## Conclusions and Next Steps

The results from AcademyHealth's Listening Project show that there are many opportunities for health services research to help inform Medicaid policymaking, including decisions regarding ACA implementation and payment and delivery system reform. The interviews suggest that Medicaid policymakers have high interest in the health and budgetary impacts of coverage expansion; effective strategies for driving cost and quality goals through payment and delivery system reform; and targeted approaches to serving high-cost, high-need Medicaid populations. Respondents also emphasized the role of research in helping state policymakers learn from one another as they address similar challenges in unique contexts. Importantly, interviewees identified Medicaid as an important area for research that has implications for health care financing and delivery in the U.S. more broadly.

We found that there were some topics interviewees did not mention or emphasize as much as we expected. For example, given the media coverage during the time of the interviews of expensive pharmaceuticals like Sovaldi,<sup>ix</sup> a new treatment for hepatitis C, we expected to hear greater discussion of drug costs and the nature of Medicaid pharmaceutical benefit design. Other topics that received only limited mention in the interviews included waste, fraud, and abuse; opiate abuse; and issues specific to access to care in non-expansion states. Additionally, we heard relatively few comments about parents, children, and individuals with HIV/AIDS enrolled in Medicaid relative to other

populations such as dual eligibles, individuals with disabilities, and individuals with high behavioral health needs.

Following the lead of our first Listening Project report, AcademyHealth intends to share findings from the Medicaid interviews through a variety of channels, including discussion at the 2015 Annual Research Meeting. We also plan to follow this report with additional releases in our “Evidence Roadmap” series, an attempt to address the extent to which perceived research gaps identified in the Listening Project reflect a true lack of evidence or a failure to translate and disseminate effectively. Through these and other activities, we hope to help inform discussion among the producers, funders, and users of research about the opportunities and challenges facing the field moving forward, particularly in the area of research translation and dissemination.

# Introduction



The Listening Project is an AcademyHealth effort to help health services researchers proactively identify the most pressing research needs of leaders in health policy and health care delivery for the next three to five years. Its goal is to foster greater interaction among the producers, funders, and users of health services and policy research (HSR) and to spur the production and use of timely, relevant evidence to improve health and health care.

The Listening Project is a signature activity of AcademyHealth's Translation and Dissemination Institute, an initiative that addresses the challenges of getting the best health services research to the right audiences, at the right time, and in a form useful to decision makers. Launched in 2013, the Institute undertakes activities that help research producers better understand the needs of research users, and serves as an incubator for new and innovative approaches to moving knowledge into action. This work involves testing new technologies and media as well as the application of practices from other fields.

The idea and some of the methods used in the Listening Project are informed by similar efforts to elicit HSR needs in Canada and the United Kingdom as well as prior work undertaken by Evidence-based Practice Centers in the United States.<sup>x</sup> The first report in the Listening Project series was released in 2014 and focused on research and data needed to support Medicare policymaking. This report features findings from a second round of interviews focused on Medicaid, a program undergoing significant change in some states in the context of payment and delivery system reform and implementation of the Patient Protection and Affordable Care Act (ACA). Many of the research needs raised in the report are cross-cutting issues relevant not only to Medicaid but to health care payment and delivery more broadly. With Medicaid covering more people, the program becomes an even more important window into the nation's health care system. As with the first Listening Project report, this document is not intended to be a research agenda nor the sole effort of its kind,<sup>xi</sup> but rather a starting point for discussion among the producers, users, and funders of research about opportunities to strengthen Medicaid research and policy moving forward.



## Methods

During the summer and fall of 2014, AcademyHealth staff conducted semi-structured key informant interviews with 53 state and federal policymakers, researchers, research funders, and representatives of other organizations with interest and expertise in Medicaid policy.

## Sample Population

We developed a list of potential interviewees based on input from AcademyHealth staff as well as external partners with Medicaid expertise. Because of the broad reach of AcademyHealth programs, the resulting list represents diverse perspectives and significant knowledge of the Medicaid program. Interviewees fall into four broad categories: (1) staff in executive and independent federal agencies tasked with supporting the



development or implementation of Medicaid policy; (2) leadership and analytical support staff from four state Medicaid agencies; (3) staff from associations, advocacy organizations, and other stakeholder groups relevant to Medicaid; and (4) Medicaid researchers and experts employed by universities, think tanks, or other organizations, some with expertise on specific Medicaid populations. Of the total interviewees, approximately half are employed in the federal government or with associations, consulting firms, or other organizations interested in Medicaid policy across states. The remaining half of interviewees are employed in state government, state-focused research centers, or research funding entities focused on state health policy. The four states where we drew interviewees from Medicaid agencies represent a diversity of geographic regions, political perspectives, and decisions on Medicaid expansion. We included Medicaid agency staff from large and small states from the Northeast, South, and West, though other states were referenced in comments by federal policymakers, researchers, and others. To maintain the anonymity of our respondents and in keeping with our Institutional Review Board exemption,<sup>xiii</sup> we do not provide more specific information about the states included in the interviews.

### Instrument and Interviews

With input from AcademyHealth leadership, staff, and project partners, we designed a semi-structured interview guide reproduced in Appendix A. Before each interview, we provided the interviewee with a list of questions that focused on three broad areas: (1) interviewees' expected research and data needs over the next three to five years; (2) the ways in which interviewees accessed and used analytic evidence, including HSR, to inform their Medicaid-related work; and (3) interviewees' perspectives on how HSR could be more useful to Medicaid policy. For those interviewees employed outside state or federal government, we asked them to draw on their Medicaid expertise and experience working with policymakers to reflect on the most pressing issues facing policymakers now and into the future.



We conducted all interviews by telephone. Two AcademyHealth staff participated in each interview and shared in posing questions to interviewees and taking notes. With the consent of interviewees, all interviews were audio recorded.

### Qualitative Analysis

AcademyHealth staff developed an a priori codebook and used qualitative data analysis software NVivo 10 to code verbatim transcripts of each interview for complex concepts as well as stated Medicaid research and data needs. The analysis focused on identifying key themes and diverse points of view that emerged within the semi-structured design of the study. Two AcademyHealth staff members blind-coded each transcript. Throughout the process, staff deliberated inconsistencies in transcript coding and added emergent codes based on discussions between coders. As a result, the code list was refined iteratively throughout the coding process. Appendix B reproduces the final code list. The report that follows draws heavily on the use of verbatim quotes to illustrate each finding. In some cases, quotes were edited for grammar and length. To ensure candor in the interviews, we do not identify interviewees by name, nor do we attribute comments to interviewees' specific agencies or organizations. However, wherever possible,

## Listening Project Interviewees' Stated Research Needs

- *Medicaid Expansion*
- *Enrollment, Retention, and Engagement*
- *Benefit Design*
- *Payment and Delivery System Reform*
- *Service Coordination and Integration*
- *Specific Enrollee Populations*
- *Behavioral Health*
- *Access to Care*

we precede the verbatim quotes with information about the respondent's role relative to Medicaid, for example, as a state or federal policymaker, advocate, or researcher. Throughout the report, we use the term "policymaker" to refer to individuals employed in state or federal government. We also attempt to indicate the general frequency with which particular points or themes arose over the course of the interviews. The final analysis organized respondents' comments along four major themes: (1) research needs, (2) data gaps, (3) use of evidence to inform policymaking, and (4) advice for researchers.

## Results

### I. Medicaid Policy Needs: Gaps in Research

The primary purpose of this project was to help researchers direct their efforts toward topics that are relevant and timely to Medicaid policy. Respondents identified eight areas where they believe new or better research is needed to help inform Medicaid policymaking. With the exception of Medicaid expansion, a topic cited across the interviews, the research areas that follow are not listed in priority order.

#### Medicaid Expansion

When asked about pressing issues facing Medicaid policymakers, nearly all respondents pointed to states' decisions regarding Medicaid expansion. Some respondents suggested that questions about whether and how to expand Medicaid will remain top-of-mind over the next several years as state policymakers assess the experiences of other states and potentially revisit their initial decisions. While some interviewees expressed the opinion that states' decisions regarding Medicaid expansion depend more on political will than the available evidence base, most respondents identified areas where new or better research could help inform decision-making on this issue.

#### Impact of Expansion

Nearly all respondents expressed high interest in comparative information on expansion and non-expansion states, particularly the impact of expansion versus non-expansion on enrollee health outcomes, providers, and state budgets.

*I think that is a key decision that governors and legislators are still grappling with in their states...I think the information they need tends to revolve around both short-term and long-term financial implications of expanding Medicaid as well as benefits to providers [and] the people who are currently insured and will be enrolled should the state expand. I think that's probably one of the most important decisions that's coming out in the next few years.*

-Interviewee

*I think the question of whether or not to expand Medicaid is going to loom very large in state capitals across this nation in the coming years. I think having an evidence base, really foundational evidence about what the impacts are of expanding or not expanding ... [is] going to be critical for understanding the fiscal impacts and the impacts on people's lives in our communities.*

-Interviewee

In regard to expansion states, nearly all respondents described the need for research on the different approaches used by states to expand Medicaid coverage. These range from more traditional approaches that follow federal rules established by the ACA, to alternative models that use demonstration waivers available under Section 1115 of the Social Security Act to expand Medicaid eligibility while making broader changes to the way coverage is structured. Several respondents pointed to Arkansas and Iowa's use of a Section 1115 waiver to purchase coverage for newly-eligible enrollees from qualified health plans in the Marketplace.<sup>xiii</sup> Respondents raised a number of questions about the impact of these "premium assistance models" as well as similar initiatives that move Medicaid programs more toward private insurance coverage. A state-based policy analyst was among the respondents who raised this issue.

*There's a lot of interest in what Arkansas has done, what Iowa has done... What is Arkansas seeing in terms of utilization of services? With the focus now on increasing patient responsibility and cost sharing, what are we seeing? Is that a positive for health outcomes? Is that a negative? Are people foregoing services because they have a high cost burden? What implications does it have on cost?*

-Interviewee

A few interviewees also raised questions about the level of administrative burden that alternative expansion models create for states, as well as the implications for program accountability when payment and service delivery are no longer tied to a single state agency.

### Evaluations of Section 1115 Demonstrations

In commenting on alternative expansion models, a few interviewees raised broader policy questions about the Section 1115 demonstration waiver, which allows states to experiment with new ways of paying for and delivering care under Medicaid, provided the changes stay true to the goals of the program and are budget neutral to the federal government.<sup>xiv</sup> Respondents emphasized the need for strong evaluations that illuminate what components of various demonstrations work and why.

*...the research has to be robust and done as quickly as possible because we are working in a demonstration project authority and at some point, [the Center for Medicaid and CHIP Services] has to be able to say, 'Okay, well, this was tried and it didn't work' or 'This was tried and it worked; you might want to try this.' That's really the underlying assumption of the 1115 authority, but right now it's going out there with hypotheses that are kind of all over the place.*

-Interviewee

Other respondents noted that information regarding the structure and effectiveness of different demonstration models will be crucial as some states consider applying for waivers under Section 1332 of the ACA that will allow them to bypass certain key provisions of the law and implement their own alternative health reform frameworks starting in 2017.<sup>xv</sup>

### Newly-Eligible Enrollees

In another line of comments, many respondents identified the need for additional information about the health status and health-seeking behavior of individuals newly eligible for coverage under Medicaid expansion. Respondents suggested that more specific



information on this topic is needed to help inform policymakers' decisions regarding expansion.

*To be able to make that decision, you have to know things about the prospective Medicaid expansion population that...are often guessable but not really knowable. These people have not historically been very connected to the health care system. When they have been connected to the health care system, it's been through charity care and free clinics and federally qualified health centers, and they don't have an insurance history...so trying to figure out what is the size of that population? What are the health needs of that population?*

-Interviewee

Respondents also noted the usefulness of this information for making decisions about benefit design and estimating costs to state budgets. Other stated areas for research include comparisons of the health needs of newly-eligible enrollees versus those previously enrolled; assessment of newly-eligible enrollees' use of preventive care; and examination of the extent to which individuals who were previously eligible for Medicaid but not enrolled choose to enroll under Medicaid expansion, known as the "welcome mat effect" or "woodwork effect." Policymakers are interested in the impact this effect may have on state budgets particularly because states receive a higher federal matching rate for newly-eligible individuals than they do for previously-eligible individuals.

## Enrollment, Retention, and Engagement

Across the interviews, respondents expressed significant interest in effective strategies for enrolling eligible individuals in Medicaid coverage, keeping them enrolled, and incentivizing them to engage in behaviors that improve their health and reduce program costs.

A few respondents raised questions about factors that prompt individuals to seek Medicaid coverage. For example, one Medicaid researcher questioned whether advertisements for Marketplaces and a general "culture of coverage" in some states have affected Medicaid enrollment. Another respondent, a federal analyst, noted the need for research to help predict the effects of employment and labor market trends on Medicaid enrollment.

*As we look at what's happening in the economy, can we project what is going to happen to Medicaid enrollment? Can we look historically and see how Medicaid enrollment has been affected by upswings and downswings in the economy? That's one whole set of issues—the interaction with the labor market and employment.*

-Interviewee

Several respondents mentioned states' continued efforts to develop streamlined Medicaid eligibility and enrollment systems, indicating that this work will largely require policy and technology decisions rather than new research. Where many respondents cited the need for additional research was in relation to churn—the phenomenon in which Medicaid enrollees cycle in and out of the program based on fluctuations in their income. Respondents suggested that issues around churn have become more complex with the advent of the Marketplaces, where individuals must seek coverage through private plans if an increase in income disqualifies them from Medicaid.

*We know that there's historically been a lot of churn between the Medicaid patient population and the uninsured population. Now we expect that we're going to see that churn continue with folks moving between Medicaid, getting coverage on the exchange, maybe being uninsured, and moving around.*

-Interviewee

Respondents cited the need for additional research on the population of Medicaid enrollees who are susceptible to churn. One Medicaid researcher noted the usefulness of knowing the differential rates of churn among different population groups, such as children, parents, and adults without children. Other respondents expressed interest in effective policies for reducing churn.

In another line of comments, some respondents raised questions regarding enrollees' understanding of their coverage and cost-sharing requirements, particularly in those states that are experimenting with new cost-sharing models as part of their Medicaid expansions. An advocate for underserved populations was among those who raised this issue. Respondents also expressed interest in effective strategies for communicating with Medicaid enrollees and their families, noting that while states are experimenting with a variety of tools such as text messaging and social media, more evidence is needed on what does and does not work.

*A lot of folks [who] are newly insured for the first time don't have a very good understanding of what a premium is versus [a] cost-sharing obligation...you can imagine how challenging it would be for an individual who is just paying for coverage for the first time and trying to understand how all this works.*

-Interviewee

*I think states tend to try everything and anything that they think might work. That's why it's hard research to do because I think it's hard to tease out which particular interventions might actually have an impact or even whether it is the totality of multiple things that has the impact.*

-Interviewee

Similarly, some respondents described the need for research on effective strategies for incentivizing enrollees to seek preventive care and engage in other behaviors that may help improve health and control costs.

*We really need a lot of economic behavioral outcomes research. What works in this population? How do you engage? What helps people want to engage and change their behavior?*

-Interviewee

One federal policymaker noted that more information is needed on how to effectively enroll Medicaid enrollees in accountable care organizations (ACOs), medical homes, and other integrated care models, particularly those individuals with complex health care needs who previously had limited contact with the health care system.

*We're all doing a great job of talking about developing new care models and new payment models and how to evaluate them effectively, but if nobody can figure out how to engage the beneficiaries, it's not really going to matter.*

-Interviewee

## Benefit Design

Respondents identified benefit design as an area of significant interest to Medicaid policymakers, particularly in the context of health care reform. The majority of comments on this topic focused on the need to match specific populations of high-cost, high-need Medicaid enrollees with the appropriate set of benefits and services. Respondents identified several areas where new or better research could help inform states' decisions regarding benefit design moving forward.

### Newly-Eligible Enrollees

Several respondents described the challenge of making decisions about Medicaid benefit design given the lack of information regarding the baseline health status, service needs, and health-seeking behavior of newly-eligible enrollees. One federal policymaker suggested that benefit packages will continue to evolve as additional information about this population and their service needs becomes available.

*We are getting those populations that maybe have never had health insurance before and therefore have a lot of unmet health needs that need to be addressed. I think we're going to see...some refinements of our areas of focus in terms of benefits and delivery systems.*

-Interviewee

Several respondents pointed to the broader issue of affordability and the ability of enrollees, particularly the newly-eligible, to maintain coverage over the long-term. One respondent described an interest in additional evidence about the use of health savings accounts by some state Medicaid programs, including the extent to which enrollees understand and make effective use of this feature.

*I think what's going to be interesting is to see how those folks are able to retain coverage, specifically around questions of affordability, over time. So can people continue to afford to pay their premiums? Can they afford to pay their cost-sharing obligations?*

-Interviewee

### Behavioral Health

Respondents suggested that state policymakers are paying particular attention to benefit designs for mental health and substance use disorder services, due in part to an ACA provision that requires states to enroll new Medicaid enrollees in benefit plans that are compliant with federal parity protections. States may choose whether or not to provide parity-compliant benefits to individuals already enrolled in Medicaid.

*States are having to take a look at their underlying benefit designs as they think about both what's mandatory, but also what might be good policy even where it's not a requirement...I think that's going to be an area of very high attention, particularly substance use because that's an area that has sometimes gotten a short shrift in Medicaid.*

-Interviewee

Several respondents, including a federal policymaker, identified the need for additional evidence on the types of services and care settings that are most appropriate for enrollees with varying types and severity of mental illness.

*I don't think we know how to look at different types of focused serious mental illness and understand what the [best] type of interaction would be, whether it would be better by social workers or by peer support specialists or by more clinical professionals, whether it should be done in a home, what the frequency should be...* -Interviewee

These comments were echoed by a respondent from a state-focused research organization.

*What we're trying to do is find that line between the...folks who probably should be getting coordinated care in the primary care setting with mental health services, versus those [individuals with] serious and persistent mental illness...who probably should be getting core care from a specialist mental health provider with the physical health services wrapped around.* -Interviewee

Additionally, one federal policymaker questioned how benefits might be structured to promote transitions into community-based care.

*I think there are a lot of questions about what does good benefit design look like and how does a system operate effectively to help people move out of more intense treatment and into the community and be maintained successfully in community settings...* -Interviewee

### Coverage of High-Cost Pharmaceuticals

Several respondents described the challenges state policymakers face in making coverage decisions about high-cost pharmaceuticals, what one respondent, a research funder, called “the issue of the season.”

*What is the effectiveness of these drugs, which is more of a comparative effectiveness study...How are prices determined and how are Medicaid agencies to balance efficacy and cost when they're trying to deal with limited resources?* -Interviewee

In particular, several respondents noted the current debate in some state Medicaid programs over whether to place coverage restrictions on the high-cost specialty drug sofosuvir (sold under the brand name of Sovaldi), a treatment for individuals with hepatitis C. Respondents expressed a need for more information on the comparative effectiveness of the drug, as well as how to determine which patients should receive it.

*What is the impact of a breakthrough drug like Sovaldi that is also a budget buster? There are more drugs that are going to be coming that are going to be targeted to various discrete groups of individuals. How do we pay for those? How are we to decide who ought to receive those drugs? I think the questions about drug management, drug program management are beginning to shift pretty dramatically with some of the new drugs that are coming forward.* -Interviewee

## Payment and Delivery System Reform

In addition to Medicaid expansion, payment and delivery system reform was the topic most commonly cited by respondents as an area where new or better research is needed to support Medicaid policymaking. Respondents suggested that while these reforms are taking shape in different ways across the country, there is a common need—particularly at the state level—for better information on payment strategies and care delivery models that incentivize quality improvement, control costs, and promote high-value care. One state policymaker noted that states’ decisions about payment and delivery system reform are often happening in tandem with decisions about coverage expansions under the ACA.

*How do we expand access to care while coupling it with reforms in the way we pay for care and the way care is organized and delivered?... I don't think you can really look at one without the other.*

-Interviewee

### Medicaid Managed Care

Respondents noted that while Medicaid managed care penetration varies across states, managed care is a predominant approach for delivering services to the Medicaid population, with more than half of all enrollees receiving services in comprehensive risk-based plans.<sup>xvi</sup> Many respondents expressed high interest in how states might make more strategic use of Medicaid managed care to drive cost and quality goals, particularly among specific high-cost, high-need patient populations.

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*“Medicaid has used managed care for a very long time, but in the last few years there’s been growing reliance on managed care for [senior citizens] and people with disabilities who were historically carved out from managed care programs. We’re now far enough into some of those new areas that I think we’ll start to see evidence about what the health implications are, what the cost implications are.”*

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Several respondents noted that while there is high interest in Medicaid managed care there are significant knowledge gaps about how managed care plans work on the inside. This theme mirrors comments from the Medicare-focused Listening Project report regarding the workings of Medicare Advantage plans. In regards to Medicaid managed care, one researcher described a lack of information about how payment from a state moves through a plan to a provider and how that process affects enrollees’ access to care.

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*“So in that sort of step-like progression between the Medicaid department and right down to the person who’s actually caring for the patient, what do we know about what’s happening to that payment and how that affects the Medicaid provider’s willingness and ability... to add Medicaid patients to his or her practice?”*

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In these and other comments, respondents expressed significant frustration with the quality and usefulness of Medicaid managed care encounter data currently available to help inform Medicaid policy— an issue discussed in greater detail in Section II of this report, “Medicaid Policy Needs: Gaps in Data.”



## Payment Reform

The interviews suggested that Medicaid policymakers have significant interest in how states might be better purchasers of health care services, particularly through managed care organizations. A state Medicaid policymaker was among several respondents who cited value-based purchasing as a promising strategy for driving quality improvement among both plans and providers.

*I think that what we're interested in is, what are the best value-based payment systems that both create incentives around appropriate cost containment, but also really are designed in ways that reward quality and avoid some of the potential downsides of things like sub-capitation?*

-Interviewee

While respondents expressed high interest in using payment to incentivize quality, some noted the continued difficulty in assessing Medicaid managed care plans' quality performance and suggested that research on better quality metrics is needed as a starting point for implementing value-based payment.

*So the plans report these HEDIS measures, but...most of them are process measures and they're not outcome measures... how do we get beyond the HEDIS cycle and actually improve quality? What is [the state's] role vis-à-vis the managed care plans?*

-Interviewee

*If you don't have good measurement, it is really hard to say whether you're getting value.*

-Interviewee

Another respondent noted that this issue is particularly acute for non-traditional managed care populations, such as dual eligibles and individuals with disabilities.

*For those groups, I think one of the challenges that state decision-makers face is the lack of good performance metrics or outcome measures or even sometimes structure and process measures. To the extent that they want to behave like an effective purchaser and pay based on performance...I think identifying what those good measures are and getting that data in a timely way is a key challenge.*

-Interviewee

In related comments, one state policymaker described the difficulty of implementing payment reform initiatives across a range of plans with varying resources and capabilities.

*So trying to find that balance with how do you achieve [payment reform] with all these different plans, keep administrative burden low, and not be overly prescriptive or find out just those minimal areas that you need to be prescriptive...A lot of research in that area, I think, is needed for us to better understand what's going on [in other states] so we can use that information in order to compel movement.*

-Interviewee

The issue of quality measurement was a cross-cutting theme across the interviews, raised here in relation to pay-for-performance and elsewhere in regards to understanding the health outcomes associated with different policies, health care services, and enrollee populations.



## Quality Measurement: A Cross-Cutting Theme

Across the interviews, many respondents described the difficulty of assessing the quality of care Medicaid enrollees receive. Citing the need for continued work on this issue, respondents identified a few key areas where additional evidence on quality measurement could help inform Medicaid policy moving forward.

### **In relation to pay-for-performance and other payment approaches that reward providers for quality:**

*“So the plans report these HEDIS measures, but...most of them are process measures and they’re not outcome measures...how do we get beyond the HEDIS cycle and actually improve quality? What is [the state’s] role vis-à-vis the managed care plans?”*

### **In relation to behavioral health services:**

*“There just aren’t real great tools about assessing patient experience or quality of care, and more specifically within behavioral health, we found a real poverty of data or metrics around measuring the quality of behavioral health services...in general, but more specifically within Medicaid.”*

### **In relation to dual eligibles and other enrollees with complex needs:**

*“With these types of populations, we are desperate for information about how to truly measure quality impact and we’re stuck with a lot of process measures. We don’t have a very good understanding of how to measure a patient’s care coordination or integration of care. They don’t lend themselves well to NCQA [National Committee for Quality Assurance] or other nationally-endorsed measurement sets that have been tested for years and years.”*



## New Care Models

Many respondents raised research questions about accountable care organizations (ACOs), Medicaid health homes, patient-centered medical homes, and other models that aim to provide integrated, coordinated care while controlling costs. Across the interviews, respondents often described the need to identify what works, for which populations, and why. One federal policymaker pointed to the opportunity for researchers to help address these questions.

*...how can the researchers still help call out things that are worthy of continued testing or scaling?*

*That would be, I think, the greatest help for these types of demonstrations in new care models and ways of doing Medicaid differently.*

*-Interviewee*

Regarding ACOs, several respondents pointed to statewide ACO initiatives in place in Oregon, Minnesota, and several other states, noting that comparisons of states’ differing approaches would be useful for assessing what has worked, where, and why. Similar to comments we heard regarding Medicaid managed care organizations, some respondents suggested there is a continuing need for basic information on how ACOs work,

particularly how ACOs move payments to downstream providers while maintaining overall accountability for cost and quality goals.

While there are existing evaluations of Medicaid health homes and patient-centered medical homes, some respondents cited the continued need for evidence on the effectiveness of these models, particularly the extent to which they can improve care and reduce costs among Medicaid populations with complex health care needs. One researcher questioned whether there are key differences between medical homes as defined by the National Committee for Quality Assurance (NCQA) and Community Care of North Carolina (CCNC), North Carolina's statewide medical home and care management system.

*I think there are a lot of questions still about what's in the secret sauce of medical homes. If you look at the NCQA definition versus the CCNC definition in North Carolina, are there essential elements that really lead to better outcomes and lower costs in patients? I think there's still a lot of research that needs to be done in that regard.*

-Interviewee

## Service Coordination and Integration

Many respondents expressed high interest in effective strategies for coordinating the services and systems utilized by Medicaid enrollees, particularly individuals with complex health care and social service needs.

*I think there are [all] sorts of widely-recognized shortcomings as people move across health care systems, across insurance products, across settings for care. Better coordination of those could yield big returns, both in terms of improved outcomes and more efficient use of resources.*

-Interviewee

Most comments on this topic addressed the following areas for research: (1) dual eligibles; (2) public and population health; and (3) social determinants of health.

### Dual Eligibles

Respondents often discussed care coordination in the context of dual eligibles, a population mentioned in many of the interviews. Several people described the issue of how to coordinate the financing and delivery of care for dual eligibles as a significant policy concern.

*What do we really know about...how the long-term care services, the nursing home services, really integrate with the standard physical and behavioral health services that these people would otherwise receive from both programs? Just being able to connect the data dots on that in a way that tells a comprehensive story, I think, is a struggle...that people should really be focused on.*

-Interviewee

In particular, respondents described the need for evaluation of the duals demonstrations currently underway in approximately a dozen states. These three-year demonstrations, authorized under the ACA, seek to test new approaches to financing and delivering care for dual eligibles.<sup>xvii</sup> One state health policy expert noted that while a federal evaluation of the demonstrations is forthcoming, it would be useful to have information available sooner.



*[They've got] high hopes for it in terms of cost savings, in terms of better care coordination, in terms of better health quality, better life satisfaction, etcetera. There is no research yet that I'm aware of, but that's crying out as an area of opportunity. There is an evaluation of it...five years from now they will be telling you things. Is there [something] that can be done more quickly than that?*

-Interviewee

Several respondents, including policymakers and researchers, noted the data challenges associated with the duals population, namely, the difficulty of linking Medicaid and Medicare claims data at the individual level to inform care coordination activities. Respondents acknowledged that while some progress has been made in this area, lags in data—particularly Medicaid claims data—is a persistent problem.

*It doesn't help you a lot when you're trying to manage care of a dual eligible today. [The data] can inform you about what they looked like two years ago and what their issues were, but you really can't use it for real-time care coordination.*

-Interviewee

One federal policymaker reiterated the difficulty of measuring the level of care coordination or integration enrollees receive, particularly for dual eligibles and others with a range of service needs.

*With these types of populations, we are desperate for information about how to truly measure quality impact and we're stuck with a lot of process measures. We don't have a very good understanding of how to measure a patient's care coordination or integration of care. They don't lend themselves well to NCQA or other nationally-endorsed measurement sets that have been tested for years and years.*

-Interviewee

Respondents raised a number of research needs related to care coordination more broadly, including how to incentivize care coordination through the payment system; how to promote care coordination among providers with varying data-sharing capabilities; and how to document the benefit of investing in care coordination activities. One respondent, a state health policy expert, suggested that more research is needed on the impact of care coordination on costs.

*If your approach is not changing rates or reducing who's eligible or reducing services, where's the evidence that just applying more coordination is going to actually reduce our costs over the long term? There's very mixed evidence about that in the Medicaid program or even outside the Medicaid program.*

-Interviewee

## **Public and Population Health**

Beyond care coordination, many respondents expressed broader interest in how Medicaid services might be better integrated with those provided by other systems such as social services, mental health, and criminal justice. A number of respondents raised research questions regarding the integration of primary care and public health services, namely, how to assess the level of integration occurring in local communities.

In addition, some respondents suggested that while state policymakers have high interest

*There are lots of examples where you see public health working with primary care, but there are other examples where there might not be a strong primary care-public health linkage yet, but they're still on this continuum in terms of developing that partnership...so how to measure and evaluate what that level of integration looks like using that IOM framework<sup>xviii</sup> is something that I think a lot of health officials would benefit from.*

-Interviewee

in incorporating population health goals into their delivery system reforms, more information is needed on how to do this effectively and measure impact. A few respondents mentioned population health in relation to the State Innovation Models (SIM) Initiative, a CMS program that provides support to selected states to develop and test models for multi-payer payment and health care delivery system transformation.<sup>xix</sup> One interviewee noted that while states are required to develop strategies for improving population health and integrating community health and prevention into delivery systems as part of their SIM work, many states are still figuring out what those strategies should look like.

### Social Determinants of Health

In related comments, some respondents raised questions about the role of Medicaid in addressing social determinants of health—factors such as access to housing, transportation, and other resources that may impact an individual's health. A few interviewees, including a state policymaker, spoke passionately about the need to address these social determinants in order to improve enrollee health and control Medicaid costs.

*We have this very siloed approach [to] how we address those issues such as unemployment, poverty, low educational attainment, and lack of opportunity. We don't address those as a health issue or possible health issue and...the ongoing failure to do that will jeopardize the ability of policymakers to really control costs in the way they want as it relates to Medicaid.*

-Interviewee

Other respondents noted that CMS has rejected proposals from states to use waiver funds to pay for supportive housing. These interviewees suggested that while policymakers and providers in some states are interested in addressing social determinants among Medicaid enrollees, they are unlikely to act in the absence of financial incentives. Multiple respondents cited the need for a business model that demonstrates the financial benefit to states and the federal government of paying for non-health care services under Medicaid. A Medicaid-focused researcher was among the respondents who articulated this issue.

*[It's] going to be really important to look at what works, what's the best way to provide care and link [enrollees] to the services they need. How do you document—I guess that's a big research question—the return on investment for spending money on care management that links some to housing and jobs and mental health...rather than just an acute care model that [serves] people when they show up?*

-Interviewee

Respondents described a number of challenges in doing this type of research, including a lack of data sharing between many state Medicaid and social service agencies. As one respondent noted, studies examining the relationship between supportive services, health outcomes, and costs may also require longer timeframes.

*In health care, I always say we do this strategy du jour and then when we don't get the results in a budget year, we go on to something else, and I think some of these investments are going to require a longer time horizon and I think trying to track the return, the ROI, is going to be critical...*

-Interviewee

While a number of respondents expressed interest in addressing social determinants of health among Medicaid enrollees, a few interviewees noted that this issue is not on the minds of policymakers in their states at this time.

## Specific Enrollee Populations

Nearly all respondents noted the need for more evidence on effective strategies for providing care to specific patient populations within Medicaid. In particular, respondents pointed to enrollees with complex health care and social service needs, such as dual eligibles, individuals with disabilities, and individuals with mental illness and substance use disorders, noting that targeted approaches are needed to meet the needs of each group.

*I would love to see an analysis of the high-cost, high-need populations and how they're being served and to think about how to better serve them and focus resources there. I mean, we have some sense of that, but I haven't seen a good ... analysis of who they are and what they cost today and what their patterns of care are.*

-Interviewee

Respondents also noted a particular need for information on how managed care plans are caring for specific patient populations that are relatively new to managed care, such as dual eligibles, individuals with developmental and physical disabilities, and children with special health care needs. Managed long-term services and supports, including the impact on access to care, patient satisfaction, and state costs, was cited by many respondents as an area of high interest. A federal policymaker was among those who pointed to this issue.

*Increasingly, states are looking at people with chronic and disabling conditions and including long term services and supports in managed care arrangements. How to do that [and] how to do that effectively is a question not only for states, but for stakeholders and also frankly the health plans.*

-Interviewee

Many respondents identified data challenges as a significant barrier to understanding the service needs of certain complex populations within Medicaid. Some respondents described a lack of basic information about enrollees who are transient and may lack a consistent insurance history. Others noted that some high-need Medicaid enrollees receive services across a range of state agencies and systems that may or may not connect with one another. Respondents expressed high interest in how communication and data sharing might be strengthened across systems to provide a more comprehensive view of an enrollee's needs.

*It would be interesting to get a better sense of...not just Medicaid spending and service needs, but what are the other state-funded services that they're getting through other agencies...what is the full picture of their service needs?*

-Interviewee

One respondent, an advocate for vulnerable and underserved populations, suggested that a lack of information about certain enrollees may result in those groups being left out of policy decisions.

*Populations that don't necessarily come with a good set of data or information get forgotten in the process of formulating new policy. [They are forgotten not] because we don't care about them, but simply because we don't know enough about them to craft the right policy.*

-Interviewee

In addition to dual eligibles and other populations mentioned elsewhere in this report, respondents identified a number of other groups of Medicaid enrollees about whom new or better evidence could help inform policymaking:

### Children

A number of respondents raised research needs related to children who receive health care coverage under Medicaid. Some interviewees noted that while children have relatively high rates of insurance coverage, there is a continued need to track access to care and health outcomes for this population. One state health policy expert expressed concern that children's access to care might be compromised given the current focus on high-cost adults.

*A lot of our focus is on high-cost utilizers of the system, which are generally not children, so there's a real concern that there's not going to be a lot of focus on kids. In fact, as more people come into the system, [children's] access could suffer as perhaps family physicians or health centers begin to serve this influx of the newly eligible.*

-Interviewee

Multiple respondents suggested that policymakers are increasingly focused on improving care and reducing costs among children with complex conditions.

*There's obviously always going to be a focus on kids, but I think that focus moving forward will be on the higher cost, higher need, special needs kids, and there's a lot of developmental disability in that category.*

-Interviewee

Interviewees described the need for additional information on how care is being delivered to children with special health needs and how continuity of care might be better preserved through adolescence into adulthood. In addition, respondents expressed significant interest in issues around children's mental health, indicating that more research is needed about how best to serve children with severe and persistent mental illness, including those who may have other high-priority health care needs.

*We need to know an awful lot more about childhood mental health...and how Medicaid benefits can be best configured to treat those kids with severe mental illness with or without medical comorbidities. I think those are fairly different populations with different kinds of service packages and I think we still don't know too much about them.*

-Interviewee

Some interviewees also expressed high interest in children's interactions with other service systems, reflecting a theme heard elsewhere in the interviews in relation to adults. One federal policymaker noted the need for information on the quality of care

received by children in the foster care system, including proper diagnosis and treatment for emotional and behavioral issues. Another federal policymaker questioned how best to address developmental delays in children that may have later implications for school and employment. Similarly, one respondent, a Medicaid-focused researcher, cited the importance of considering children in the context of their families.

*So you have, perhaps, a mom [who] is dealing with depression with a very young child. We know there are consequences for that young child, but we don't really have a system that necessarily identifies that both mom and child may need treatment to address underlying problems...I think there's going to be more and more attempts to think about people in their families and match up service needs with how people live and how they interact with the world.*

-Interviewee

It is worth noting that while the Children's Health Insurance Program (CHIP) was outside the scope of the interviews, a number of respondents mentioned CHIP renewal as a significant area of interest to state and federal policymakers.

### Individuals with Disabilities

Several respondents raised research questions regarding Medicaid enrollees with physical, developmental, and intellectual disabilities, noting the wide range of health care and social service needs among this population.

*I think we have only begun to scratch the surface [of] looking at individuals with disabilities in the [Medicaid] program... That is a broad population, from somebody in a wheelchair who maybe doesn't have many more health care needs than anyone else to people that are highly medically fragile...*

-Interviewee

Echoing a theme heard elsewhere in the interviews, some respondents noted the difficulty of identifying an enrollee's full range of care needs and matching that individual with the correct set of services delivered in the most appropriate setting. One state health policy expert raised this issue in the context of long-term services and supports, noting that more information is needed about what services should be delivered to what populations and in what settings.

*Over the past probably 10 to 15 years, we've thrown a ton of money at home and community-based services as a way to get people out of institutionalization, which is great from a big picture policy perspective. I'm not sure that we've ever really looked at...what [are] the right home and community-based services for these people? How are they being delivered? Is it efficient? Who really does belong in an institution?*

-Interviewee

In related comments, one respondent noted that variation in enrollees' service needs leads to differences in spending on individuals with disabilities across state Medicaid programs. This respondent, a policy analyst, suggested that many states do not understand the reasons behind the variability in spending or the impact this spending has on health outcomes.

*There is really a huge amount of variability in the resources devoted to serving people with disabilities and there should be a variability, but we don't know much about it. We don't know about it...from a health effects perspective. We don't really know about it from a spending benchmarks perspective. I think it is so poorly understood that there is almost no question you could ask that wouldn't be helpful to answer to give us more insight...*

-Interviewee

Finally, one respondent pointed to gaps in understanding about how best to measure the quality of care delivered to individuals with disabilities and reiterated the need for quality benchmarks for specific populations of enrollees in both fee-for-service and managed care environments.

## **Immigrants**

Some respondents raised research questions regarding the health care needs and service utilization of immigrants, both lawfully present individuals who qualify for Medicaid services,<sup>xx</sup> as well as undocumented immigrants who utilize safety net systems that also serve Medicaid enrollees. Respondents described a need for additional information on immigrants' health status compared to the general population; their health-seeking behavior; and cultural differences that may impact immigrants' use of services. One state policymaker interested in health disparities suggested that research on Latin American immigrants needs to go beyond current political debates to provide a better understanding of this population's health care needs.

*I think we need to know more and plan more regarding care of the Latino community in a way that's not really caught up with the political question of whether or not they should be here, but rather, how do we really get to their needs given what we're already seeing in that population from their chronic disease rates?*

-Interviewee

Other respondents expressed concern about undocumented immigrants, who may qualify for emergency Medicaid programs in some states and largely rely on safety net hospitals and community health centers for care. These comments largely focused on the ability of safety net systems to care for undocumented immigrants and other uninsured populations, particularly given cuts to states' Disproportionate Share Hospital (DSH) payments.

## **Justice-Involved Individuals**

Several respondents expressed interest in the interplay between Medicaid and the criminal justice system, particularly issues around the provision of coverage to justice-involved individuals. Under federal rules, Medicaid enrollees remain enrolled in the program during periods of incarceration, but coverage of services is suspended until after release, a policy that is unchanged by the ACA.<sup>xxi</sup> However, interviewees noted that Medicaid expansion will still have implications for many members of the incarcerated population, a group that is predominantly male with a high prevalence of mental illness and substance use disorders. One respondent, an advocate, noted that additional information about the demographic and health characteristics of the nation's incarcerated population is needed to help inform states' decisions around health care reform.

*So on a research level, we don't know anything other than these brief data bits on the characteristics of this population... States now have to make massive decisions ranging from benefit packages, enrollment strategies, 1115 waivers—I mean, the level of state decision-making in this is humongous and there's almost no research base [about this population] to guide them.*

-Interviewee

Respondents also described significant care coordination issues in relation to the incarcerated population, noting a lack of information about the services individuals received before and after jail to help inform decisions about care following incarceration.

*Jail is a black box. Once [someone] enters it, whatever happens to [them] doesn't circle back. What happened beforehand doesn't circle back.*

-Interviewee

Multiple respondents identified the need for evidence on effective strategies for enrolling individuals in coverage after they leave jail—whether that's facilitating a person's previous Medicaid enrollment, enrolling them as a newly-eligible, or helping them connect with Marketplace coverage—and ensuring access to services in the community. While some respondents cited existing research on this topic,<sup>xxii</sup> they described it as an important area for further exploration.

*I think that is just going to be very, very important research to continue—to look at the enrollment process, [what] states are doing to get people enrolled at the point of leaving jail, what are the best practices there, what's working and what's not working, are there policy changes that need to be made to facilitate that?*

-Interviewee

## Women

Respondents suggested that policymakers at the state and federal level have high interest in improving maternity care for Medicaid enrollees and reducing rates of poor birth outcomes. Medicaid has historically provided coverage for pregnant women, including prenatal care through delivery and 60 days post-partum, financing nearly half of all births in the United States.<sup>xxiii</sup>

Some respondents cited the need for more information on strategies for providing prenatal care that address factors that contribute to poor birth outcomes. One respondent pointed to the Strong Start for Mothers and Newborns Initiative—a joint effort of CMS, the Health Resources and Services Administration, and the Administration on Children and Families—that aims to test new approaches to reducing premature births among enrollees at risk for preterm births. This respondent, a federal policymaker, noted that more of this type of research is needed to understand the non-clinical factors affecting birth outcomes, as well as viable approaches for addressing these factors.

*When we look at the problems with low birth weight infants or certainly the problem of infant mortality, we have a sense of the clinical care issues...that might affect the outcomes or that we know affect outcomes, but we know very little about other issues like stress or the extent to which social support,...home visiting or other kinds of outreach strategies can really make a difference...*

-Interviewee

Some respondents also raised questions about how best to pay for maternity care, including how payment models might be structured to facilitate access to contraception or enhanced prenatal care. One Medicaid researcher questioned how states might help women navigate available insurance options following pregnancy so that coverage is maintained.

## Behavioral Health

Respondents suggested that the financing, organization, and delivery of services for mental health and substance use disorders is a high-priority Medicaid issue that will remain top-of-mind for policymakers over the next several years.

*I think that's a huge issue coming forward with the recognition that there is so much comorbidity and that...the highest cost patients tend to have both physical health and behavioral health issues.*

-Interviewee

As noted in the “Benefit Design” section, many respondents commented on behavioral health in relation to benefit design and the anticipated needs of newly-eligible enrollees. In addition, several interviewees described the need for evidence on cost-effective models for integrating physical and behavioral health services. One federal policymaker noted that while evidence suggests offering physical and behavioral health services at the same site is a promising strategy for integrating care, providers have struggled to do this in a cost-effective way. Respondents suggested that both providers and policymakers need to see the business case for service integration, as well as specific information about how integrated care should be structured.

*I think the models have a lot of variability. Integration in some places means bringing a full-time psychiatrist on staff. In other places it means a Masters-level counselor who may not have the same range of treatment that they can offer and may only be part-time in a particular clinic. So there's a lot of staffing issues and effectiveness issues that are still waiting to be resolved in that area.*

-Interviewee

In a number of interviews, respondents expressed interest in the use of community health workers, peer support specialists, and other non-physician providers to deliver services to Medicaid enrollees. This issue was frequently raised in the context of behavioral health, an area where several respondents cited a shortage of providers, particularly in rural areas. Multiple interviewees noted that it would be useful to examine health outcomes and costs in states in which Medicaid pays for services delivered by alternative care providers.

*I'd love to see an analysis of the return on investment because it certainly sounds like a great idea, but I think people are going to need to see the return for paying for those services, what you're getting out of that.*

-Interviewee

*I think it would be very helpful to Medicaid agencies to know where there is evidence of [these providers'] efficacy, of the impact on cost of delivering care, various aspects of utilizing those kinds of providers.*

-Interviewee



Respondents also identified a number of data challenges associated with behavioral health services, including privacy concerns that can make data sharing difficult. Reflecting respondents' interest in quality measurement more generally, some interviewees, including a state-focused researcher, noted the difficulty of assessing the quality of behavioral health services.

*There just aren't real great tools about assessing patient experience or quality of care, and more specifically within behavioral health, we found a real poverty of data or metrics around measuring the quality of behavioral health services...in general, but more specifically within Medicaid.*

-Interviewee

## Access to Care

Several respondents noted that as some states expand coverage under the ACA, there is a particular need for evaluations of enrollees' access to care. Interviewees raised questions around key measures of access such as workforce adequacy and the impact of payment rates on provider willingness to accept Medicaid patients.

*...a lot of attention is turning to the access that covered folks actually have to care and whether it is sufficient. Even [without talking about the quality of care provided], are there sufficient providers? Are they the right kind of providers? Are people actually able to get to them and be part of their caseload? Those, again, I think are very challenging things to evaluate and to measure.*

-Interviewee

In related comments, respondents reiterated a longstanding concern that inadequate payment rates may deter providers from accepting Medicaid patients. Consequently, interviewees expressed interest in the impact of the ACA's primary care payment increase during 2013 and 2014 on provider willingness to accept Medicaid patients. While a number of states have already chosen to extend the payment increase beyond 2014 using state funds, one interviewee suggested that research on the impact of this increase on access would be helpful for other states who may be deciding whether to continue the payment increase or apply it to other types of care.<sup>xxiv</sup>

*There is the question of what impact did [the payment increase] have, if any, as well as whether there is a take up more permanently on the part of states, and if not, why not? So some of those questions around that primary care bump and whether that might be a relevant strategy to pursue for access to other kinds of care or if it's going to be maintained long-term.*

-Interviewee

Respondents made a number of other comments related to measuring access to care that are included in the next section of this report.

## Other Research Needs

In addition to the research needs described above, respondents identified a few additional areas where new or better research could help inform Medicaid policy decisions. While these areas were mentioned less frequently than those in the sections above, they provide additional insight into current and future areas of interest to policymakers. Respondents noted the need for more research to understand:



- the value of using emerging technologies such as telehealth to deliver services to Medicaid enrollees;
- the impact of current efforts to define, identify, and address health disparities;
- the provision of non-clinical support services to enrollees with HIV/AIDS and their role in promoting enrollee engagement and care-seeking behaviors; and
- efforts at the state and federal level to reduce waste, fraud, and abuse within the Medicaid system and how these efforts might be strengthened.

## II. Medicaid Policy Needs: Gaps in Data

In addition to identifying research gaps, many respondents cited challenges that can make the collection and analysis of Medicaid data difficult. These issues include significant variation across states in program structure, data collection and reporting practices, data-use requirements, data privacy restrictions, and churn within the enrollee population. In addition to these challenges, respondents highlighted four main data issues that impact the ability of researchers and policy analysts to use data to inform policy decisions. Many respondents noted the need for (1) improved data quality and timeliness; (2) comparable data across states; (3) detailed Medicaid managed care data; and (4) better measures of access to care, quality of care, and health outcomes.

### Improved Data Quality and Timeliness

Respondents indicated that a lack of high quality, timely Medicaid data limits the ability of researchers and policy analysts to conduct research to inform policy decisions. Many respondents noted that Medicaid data is complex and requires significant resources and expertise in order to produce useful analyses.

*In most states, claims lag in terms of when publicly available data files are available...Historically, Medicaid claims have been extremely 'dirty' and very hard for researchers to clean and make useable. I would say that data lag and the quality of what is going in and how hard it is to make that [data] useable coming out continues to be the biggest problem from a researcher perspective.*

-Interviewee

*I do think that one of the big challenges that researchers in general face is that Medicaid data are complex and difficult to use if you're dealing with the administrative data. It requires a level of analytic sophistication that some researchers just are not exposed to or don't have any training and background in.*

-Interviewee

Respondents noted that issues around timeliness can be compounded by the sometimes lengthy process of accessing data from state agencies.

*It must take more than a year for some researchers to get data agreements signed, to actually obtain the data, to clean the data, and to go back and forth with the states to understand anomalies in it...* -Interviewee

### Comparable Data Across States

A primary data gap articulated by a majority of respondents was the need for uniform data collection and reporting practices in order to facilitate studies comparing aspects of state Medicaid programs. Respondents noted that conducting research across states is difficult due to the lack of a centralized data set, a barrier that leads to the resource-intensive process of requesting data from each state individually.

*If you want to do something in Medicaid, almost everything you would need to gather would be state by state. There are very few data sources that are comparable across states that you could use for anything of interest.* -Interviewee

*There are 50 states and they all do things differently. It is not like Medicare where there is one big happy data set that everybody can dig into and do their own thing.* -Interviewee

Several respondents noted recent efforts by CMS to improve data systems through the current transition from the Medicaid Statistical Information System (MSIS) to the Transformed-MSIS (T-MSIS). The new data system aims to streamline reporting processes, provide states with an increased ability to analyze their own data, and create a nationwide data repository.<sup>xxv</sup> It is interesting to note that while some respondents mentioned this transition, most were largely unclear as to whether the changes would effectively address data reporting and collection issues.

In an earlier section of this report, one respondent noted that populations on which policymakers have limited data may be left out of policy decisions. One Medicaid researcher echoed this sentiment in regards to state-level research, suggesting that states with more restrictive data sharing policies may be studied less often than states where data is easier to access, resulting in a potential imbalance in the research.

### Detailed Medicaid Managed Care Data

As indicated earlier in this report, interviewees in both federal and state government expressed frustration with the limited encounter data available for enrollees in Medicaid managed care plans. This finding mirrored comments from the Medicare-focused Listening Project regarding the difficulty of accessing encounter data from Medicare Advantage plans. Encounter data is submitted by plans to the state Medicaid agency and includes summary information on the total amount of enrollee interactions or “encounters” with the health care system through the services received, such as physician office visits or prescriptions. Managed care plans are paid on a pre-determined, capitated basis and as a result, encounter data does not include individual level utilization or cost per service provided.

In the Medicaid interviews, respondents at the state level noted that the data submitted by plans is often limited and of low quality. Though plans have reporting requirements to the states, the lack of detail in the data provided makes it challenging for Medicaid agencies to monitor the patient care experience at the individual level, identify utilization trends, and track access to care for specific populations across different plans and geographic regions.

*We run into the problem of gaining access to encounter data...When we ask [Medicaid managed care plans] how they're spending the dollars, we're getting very little information back. The response we get is that it's proprietary and that it can't be shared with us. The converse of that is we're paying for the care so we feel like we...should be able to access that information to analyze it and get data [on] utilization, cost, trends, et cetera.*

-Interviewee

Interviewees suggested that many state policymakers want to know what data they should be requesting from plans in order to better track plans' performance. Respondents noted that, while this issue remains a broad concern, some states have made significant progress in working with plans to develop additional reporting agreements and improve the quality of the encounter data they receive.

*[States have] examined [data] and how variable it is in quality and quantity from so many health plans out there that work with Medicaid....So the [the Medicaid agency] has to ask itself 'how far can we go with the health plans at this time in requiring newer [levels of] encounter data accuracy and how often do they need to be shipping it back to us?'*

-Interviewee

In states where high-needs populations are being transitioned into Medicaid managed care, this lack of detailed data raises questions about whether the benefits provided are both adequate and appropriate.

*Since the majority of beneficiaries and particularly the newly eligibles are going to be in managed care health plans, our knowledge of their utilization and services is going to be quite limited for some time.*

-Interviewee

### **Better Measures of Access to Care, Quality of Care, and Health Outcomes**

A number of respondents raised research needs regarding measurement, in particular, the need for better measures of Medicaid enrollees' access to care, quality of care, and health outcomes. In one line of comments, respondents described the need for more and better measures of access to care, particularly access to specialty care for high-cost, high-need populations.

*While there seems to be pretty good measures of access to primary care, there are not particularly good measures or understanding of access to specialty care. We hear anecdotally from health plan medical directors that access to specialty care is an enormous challenge for them, particularly in rural areas, but even in some urban areas.*

-Interviewee

In related comments, one interviewee described the need for more research on measures of access to care that account for the new and emerging ways patients receive care outside of the traditional primary care visit with a physician, such as telemedicine and utilization of non-physician providers.

*People are getting care in a number of different ways, whether it is through self-care, pharmacists and allied health professionals or via telemedicine, e-mail consults, and phone visits. We don't really measure that when we ask people [about] when they last sought care at a physician's office and whether they had any trouble making an appointment. It is very focused on the in-person care with the physician. That's an area that we see where more work needs to be done.*

-Interviewee

In addition, several respondents identified the need for better household survey data that captures information about Medicaid enrollees' access to care and other measures of the patient experience. One respondent noted that while CMS planned to implement a Medicaid-focused survey through the Consumer Assessment of Healthcare Providers and Systems (CAHPS) program, the survey may be conducted only periodically and more regular assessments are needed in order to create benchmarks and track progress for important measures such as access to care.



As noted throughout this report, many respondents cited the need for improved measures of quality of care, both as a basis for rewarding quality through the payment system and for understanding the quality of care associated with different types of services and care models, particularly those serving enrollees with complex needs.

Respondents also reiterated the need for better measures of Medicaid enrollees' health outcomes, in part, to evaluate the effectiveness of particular interventions or policy changes. While several respondents acknowledged the challenges in developing appropriate outcome measures and collecting necessary data, particularly for complex and high-need populations, respondents noted that data on outcomes continues to be an area of significant interest.

*Of course data on outcomes is always a big question. To what extent do these policy interventions actually make people healthier? That's probably the hardest question to answer, but it's the one everyone's working towards...*

-Interviewee

### III. Use of Evidence to Inform Medicaid Policymaking

In addition to asking about gaps in existing research and data, we also asked respondents about the ways in which they access and use analytic evidence to inform their Medicaid-related work. In some cases, we asked respondents outside of government to draw on their experience to reflect on the use of evidence by state and federal policymakers. Respondents' comments on this topic confirmed that policymakers must make decisions amid a host of competing pressures and priorities. One respondent summarized these influences by suggesting that most state policy decisions are "either programmatically-, ideologically-, or budget-driven." Policymakers also face the added challenges of short

timeframes and a lack of “just-in-time” evidence. Beyond these factors, respondents identified three influences that affect whether and how policymakers use evidence in Medicaid decision-making: (1) politics; (2) the experiences of other states; and (3) state capacity. These three factors are well-documented in the existing literature on how evidence is used in policymaking.<sup>xxvi</sup>

## Politics

Nearly all respondents cited politics as a widely-recognized factor influencing Medicaid policymaking, including the perception and use of evidence. Interviewees noted that briefs and reports supplied by stakeholders often present potentially biased or one-sided perspectives on policy issues, though respondents suggested that the majority of policymakers, particularly those within Medicaid agencies, are adept at taking information from stakeholders with the appropriate “grain of salt.”

*I think in general, policymakers are pretty smart [to understand] that when they get materials from an advocacy organization or a lobbyist, they're going to have some sort of an agenda behind that most likely, but it does make it tough...to separate through and really put a critical eye to some of the information that's out there.* -Interviewee

Several respondents noted that policymakers may choose to use specific evidence due to political influences, in the absence of opposing research, or as a result of time constraints within the state political or budget cycle.

*[Policymakers] certainly recognize that getting information from a biased source or on weak methodological foundations is not valuable, but if you had to pick one, they'd go for the quicker and dirtier rather than the 100 percent validated.* -Interviewee

*I think [policymakers] decide [evidence] is good enough to use when it suits their political purposes...generally speaking, if they have a legislator or governor or consensus building within their administration that X needs to happen, they are going to look for research that supports X. If it is validated, so much the better. They are going to use it. Do they take research and say 'Oh look at this' and de novo, start a new process? Probably not all that often.* -Interviewee

One respondent also pointed to changing political leadership at the state level as a factor that limits the ability of policy analysts within Medicaid programs to produce their own research and conduct internal studies over longer timeframes.

*They are making decisions in the context of governors and legislatures that are turning over all the time. So the ability to dig into issues is not there. There is not this 'let's take the long view and study this' the way there might be with Medicare or commercial insurance.* -Interviewee

While some respondents expressed frustration with the challenges that politics present to the policymaking process, others encouraged researchers to consider highly-partisan environments as an opportunity instead of an obstacle.

*Oddly, I think in some ways the politicization is the opportunity and not the problem. I think in a very highly-politicized and polarized environment, people who can come forward and enter into that debate who are independent and not driven by ideology but instead by evidence... actually have a unique platform.*

-Interviewee

*If a researcher is not advocating for a particular interest [and] can actually figure out a way to get in front of these legislators...they are so grateful to have a third party present some of this information, particularly if that researcher is willing to step out on a limb, translate, and talk about the implications.*

-Interviewee

## Experiences of Other States

Several respondents pointed to the tendency among state policymakers to look to the experiences of other states to help inform key policy decisions. These experiences may help policymakers build the case for certain policy decisions, and often carry significant weight when compared to other forms of evidence. These comments reflect a theme heard across the interviews regarding states' strong interest in learning from each other as they grapple with shared opportunities and challenges.

*Information from other states is very useful and it's one of the first things usually that people want to know. When you're talking about a particular issue, it is 'what's happening out there in other states on this?' It's not that we don't have access to [that information]... we've been able to get some information from what other states have done. There are sources for that, but I think that there is still a void and a need for more comparative information for policymaking.*

-Interviewee

Several respondents noted that state policymakers often find value in anecdotes or case study experiences from other states with similar demographics or program structures. One interviewee suggested that this anecdotal evidence tends to get the attention of policymakers more effectively than published research.

*Policymakers want to adopt the same policy because one of their neighboring states is adopting it or it's the latest greatest thing a medical society is talking about. They don't say, 'We're going to adopt this because 25 research studies have shown that it's cost-effective or improves outcomes.'*

-Interviewee

## State Capacity

Respondents expressed broad recognition of the time, budget, and staffing constraints that impact the ability of policymakers and their support staff to understand and use data and other information from both internal and external sources. One of the main issues identified by respondents was the sheer volume of information received by policymakers and their support staff on a daily basis through emails, phone calls, and long meetings. As one respondent observed, policymakers at both the state and federal level are "drinking from the fire hose" when it comes to receiving information, and frequently struggle to process, prioritize, and use data and information to effectively address key policy issues.

*I know there is obviously new research, new ideas coming out all the time and for somebody in my shoes when you're getting 250 emails a day or more, it's hard to sift through it all to deal with it.*

-Interviewee

As noted in the section on data needs, several respondents indicated that there is significant variation in the ability of state Medicaid programs to access and analyze data to inform Medicaid policy. While some states have advanced analytic capabilities and adequate staffing, others may not have dedicated funding to effectively meet the data and policy analysis needs of the agency.

*It has been very challenging for states to have the capacity to accept [data] and then link, cleanse, and validate it, much less have a set of people who can actually use it to help put information in the hands of policymakers.*

-Interviewee

One respondent also noted that some Medicaid programs experience significant “brain drain” and loss of institutional knowledge as highly-skilled analysts leave to pursue more lucrative positions in the private sector.

*I don't think the state can be as competitive with private industry in retaining good staff, so there is a lot of turnover. People will go work for the state for a couple of years and then their knowledge and expertise is very appealing to private sector employers and so they'll often get offers there.*

-Interviewee

While many respondents noted that working with external researchers can help address some of these concerns, several state-based respondents countered that sharing data with individual researchers on projects often does not alleviate capacity issues, as some states must spend a significant amount of time helping the researcher navigate the unique and complex details of their Medicaid program and data set.

*States are not as free with their data as they would otherwise be because often when they give out their data, they either find themselves having to correct what [the researchers] have done or spend a lot of time investing in educating the researchers on the data.*

-Interviewee

Some interviewees noted that the emergence of partnerships between states and universities and other non-partisan research organizations has helped to address these challenges in some states. These partnerships were described as helping build trusting relationships between states and researchers, addressing internal staffing and capacity issues within the state, and facilitating increased access to state data for researchers.

*States now have state-based think tanks, state-based policy organizations that are really strong and play a key role in the state, both in sharing information and then thinking about important issues.*

-Interviewee



## IV. Advice for Producing and Communicating Policy Relevant Research

In addition to asking about research and data needs, we also asked respondents to provide advice for researchers interested in producing policy relevant work. Responses included familiar comments about the importance of timely analyses, including the need to carefully consider the tradeoffs between rigorous “gold-standard” methods versus alternative approaches that may produce faster results. In addition, respondents encouraged researchers to develop strong relationships with policymakers early on in the research production process, a practice that some interviewees characterized as key to connecting with policy audiences at the dissemination stage.

*It's not getting it published. It's not talking about it on Twitter. It's often not even getting it in the local health policy journal or the national health policy journal or even the bigger picture newspapers. It's really having a connection with the policy-makers [so] that you can go and effectively present [findings] one-on-one.*

-Interviewee

*If you can put a researcher in front of a group of peers to talk about what's going on, it increases the likelihood of take up and the richness of the exchange.*

-Interviewee

Interviewees reiterated the need for dissemination of research findings using clear, concise language that is easily digestible and free of jargon.

*We don't have the luxury to plow through lengthy articles and papers. That's not to say there isn't a place for them, but brevity and really good writing - that is my bias. Say it in English. If you have to rely on jargon, that signals to me that you really don't understand the concept yourself well enough to explain it.*

-Interviewee

Another interviewee encouraged researchers to draw on past experiences and the best available evidence when questions from policymakers don't have a definite answer or a sound research base.

*It is about bridging the gap and saying: 'Yes, we need to do some research but this is what we know at the time. Given that, here is what I would suggest ...' Policymakers are very much in the here and now, and we have to do something quick. So, what is your best guess of what is going to work given other things that have been done in the past? It is just a different way of thinking and it is going to be a challenge.*

-Interviewee

A number of these comments echo themes heard in the Medicare-focused Listening Project report. Respondents also offered two additional pieces of advice to help guide researchers seeking to produce policy relevant research, Medicaid-related or otherwise: (1) consider the unique circumstances affecting evidence production and use in each state, and (2) frame research findings within the existing body of evidence.

## Consider State Context

Several respondents noted that in order to produce useful Medicaid research, it is crucial for researchers to understand the unique circumstances of the state in which they're working. These comments are supported by existing literature on the importance of considering the perspective of the intended audience when conducting research and disseminating findings to decision makers.<sup>xxvii</sup> Many interviewees noted the influence of a state's political climate on policy decisions. A few expressed strong opinions about the importance of understanding the political forces at play within a state in order to effectively inform the policymaking process.

*I think that those who do not understand the political agenda of the party that is in control are doomed to not actually have any of their priorities or any of their issues addressed effectively.*

-Interviewee

Others emphasized the importance of having a broader awareness of how state governments operate and the issues policymakers care about.

Interviewees noted that understanding a state's particular context includes being mindful

*I think it's making sure that you really understand the context that the policymakers are operating within so if it's at the state level, really understanding that state and the structures both in government and the key issues that are happening. [Researchers need to] know the context in which their research is being released, and then releasing it and discussing it at multiple levels...*

-Interviewee

*I'm always asking, 'What do you need to know? What are the policy questions where you're really frustrated because you don't have good data to make decisions?' I think sometimes it's hard as the researcher to know what areas are actually up for decisions, what are up for grants, and what areas [are there where] it doesn't really matter what the data show because the decision is going to be made on a different basis.*

-Interviewee

of the time, budget, and resource constraints facing analysts and others working in state government. It also means being sensitive regarding the release of study findings, for example, by giving state partners advanced notice before results are widely disseminated, particularly findings that address politically sensitive issues. One Medicaid researcher described this as a way to build trust while still maintaining autonomy throughout the research production process.

*I think we also in return try to be sensitive to not making demands on [a state's] time or money because they have very little of either to spare. [We were] sure to give them a heads-up on our findings before they were widely disseminated while not giving them any right of editing or censorship. We wanted to be sure that they weren't surprised by anything...*

-Interviewee

Similarly, some respondents suggested that researchers should strive to convey research findings in a way that makes them meaningful to state policymakers and offers tangible takeaways for informing policy.

*For us to partner with a research entity or a researcher, we want to see that there is going to be something of real tangible value to us, and tangible value is findings that are actionable.*

-Interviewee

## Put Research Findings in Context

Several respondents noted the usefulness of studies that frame results within the larger body of research as a way to help policymakers understand the unique contribution of the work and the evolution of the evidence base over time. These comments are supported by existing literature on effective practices for communicating research findings to decision makers.<sup>xxviii</sup>

*The biggest mistake researchers make is thinking that their one study standing alone should be a big media story. Really what you want is to put your work in the context of the broader literature and figure out how to move the body of thought in a certain direction and not try to isolate your own work.* -Interviewee

Multiple respondents noted that putting one's study findings in the context of existing research is particularly important as a way of maintaining a type of "institutional memory" of the policies that have been implemented in the past and the evaluations of those initiatives.

*I think researchers have an obligation to talk about what is similar and what is dissimilar and try to make a link to the studies that have been done in the past that still can be relevant, even though the acronyms or the particular features may have changed.* -Interviewee

*It takes some discipline to be able to continue to pull that thread over five years so that we actually get some accumulation of learning. I think that there's a tendency to not have a lot of patience with that [approach] and I think we need more help with holding that thought over multiple years.* -Interviewee

One federal analyst noted the usefulness of studies that have negative findings or findings of no impact, suggesting that these studies make an important contribution to existing literature despite being less desirable to journal editors.

*They don't like publishing findings of no outcome or no impact. That's not nearly as interesting, they think, to readers, but it is really important to us and I think it is really important to policymakers...[It] is really critically important information for policymakers to know that 10 times something has been tried and produced nothing rather than the one time it was tried and did produce...a statistically significant effect...* -Interviewee

In related comments, respondents suggested that syntheses of existing research are very useful for helping policymakers and analysts gain a better understanding of work on a given topic. These comments reflect existing literature on the role of systematic reviews in providing policymakers with summary information on the key findings and strength of an existing body of evidence.<sup>xxix</sup>

*I could go and find a study but how would I know it's the right study? Or there might be five ones that say different things. So I think if there is more work to synthesize a field or different perspective within a field that would be helpful.* -Interviewee

## Conclusions and Next Steps

The results from AcademyHealth's Listening Project show that there are many opportunities for health services research to help inform Medicaid policymaking, including decisions regarding ACA implementation and payment and delivery system reform. The interviews suggest that Medicaid policymakers have high interest in the health and budgetary impacts of coverage expansion; effective strategies for driving cost and quality goals through the payment system; and targeted approaches to serving high-cost, high-need Medicaid populations. Respondents also emphasized the role of research in helping state policymakers learn from one another as they address similar challenges in unique contexts. Importantly, interviewees identified Medicaid as an important area for research that has implications for health care financing and delivery in the United States more broadly, as well as spending in other areas.

*It's just really hard to ignore the fact that Medicaid is an increasing percentage of state budgets but also the federal budget... how do we make the program more sustainable and as efficient as it can possibly be? That's just a huge overarching question that's not going to change, especially as the population ages.*

-Interviewee

Not surprisingly, the interviews suggest that politics can be a driving factor in Medicaid policymaking, particularly in regards to Medicaid expansion and other decisions related to ACA implementation. However, the interviews also indicate that contentious political environments can provide an opportunity for researchers to step forward as a source of objective, unbiased information, helping policymakers make sense of different policy options. Some respondents encouraged researchers to “be brave” in the face of political, data, or other challenges that might deter their work.

*This population demands your attention...just because it isn't easy to study doesn't mean you shouldn't study it.*

-Interviewee

We also noted that there were some topics interviewees did not mention or emphasize as much as we expected. For example, given the extensive media coverage of the hepatitis C drug Sovaldi during the time of the interviews,<sup>xxx</sup> it is somewhat surprising that the costs of pharmaceuticals or the nature of pharmaceutical benefit design in Medicaid were not discussed more frequently in the interviews. Other topics that received only limited mention in the interviews included waste, fraud, and abuse; opiate abuse; and issues specific to access to care in non-expansion states. Additionally, we heard relatively few comments about parents, children, and individuals with HIV/AIDS enrolled in Medicaid relative to other populations such as dual eligibles, individuals with disabilities, and individuals with high behavioral health needs.



Following the lead of our first Listening Project report, AcademyHealth will share findings from the Medicaid interviews through a variety of channels, including discussion at the 2015 AcademyHealth Annual Research Meeting. We also plan to follow this report with additional releases in our “Evidence Roadmap” series, an attempt to address the extent to which perceived research gaps identified in the Listening Project reflect a true lack of evidence or a failure to translate and disseminate effectively. Through these and other activities, we hope to inform discussion among the producers, funders, and users of research about the opportunities and challenges facing the field moving forward, particularly in the area of research translation and dissemination.

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## Endnotes

i AcademyHealth received an institutional review board exemption determination for the Listening Project from the Western Institutional Review Board on March 27, 2013 per criteria outlined in 45 CFR §46.101(b)(2).

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# Appendix A

## Instrument Used for Semi-Structured Interviews

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1. Tell us how your work relates to the financing and delivery of care under Medicaid. What else does your agency, office, or organization do?
2. Which communities or stakeholders do you represent or interact with most often? Do you expect your relationships with these groups to change in the future? In what way?
3. What is your role within your agency, office, or organization? How long have you been in this role?
4. What Medicaid-related decisions do you expect to make (or expect policymakers to make) in the next few years? What information do you need to make these decisions?
5. What other issues related to Medicaid are you personally most concerned about? Why?
6. Is there information about particular Medicaid populations that would be useful to you in your work (e.g. individuals with disabilities, working adults, dual eligibles, etc.)?
7. What research would be useful to federal and/or state policymakers that is not already being done?
8. Have you been involved in Medicaid research or evaluation projects (or know of research or evaluation projects) that did not come to fruition for some reason? If so, what were the barriers to completing the project? What could the research community have done differently?
9. To what extent is collecting, reviewing, and assessing research part of your work? How often do you engage in these types of activities?
10. What Medicaid data is currently available to you and how useful is this data in your organization's decision-making? To what extent do you use data or information from other states or organizations? How do you access this information?
11. What level or quality of research or evidence do you need in order to make decisions about Medicaid policy? What would reassure you that a particular intervention or policy change is a good idea? How do you assess when the evidence base is good enough to inform decision-making?
12. Are there key sources you rely on for information about the health care system?
13. Who/What do you consider trusted sources of technical information? Are there common sources you consider untrustworthy in some way? Why?
14. To what extent do you currently work with researchers or other external technical analysts, either off-site or embedded? If so, how has that experience gone?
15. To what extent do politics or ideology play a role in what evidence is used in the policymaking process? In how evidence is used?
16. What do you think is the most useful format for receiving information about the results of a research study (e.g. journal article, brief, research synthesis, etc.)?
17. What are your frustrations with the current academic literature on Medicaid coverage, provider payment, and/or service delivery? What advice would you give to researchers and funders seeking to enhance the policy relevance of the research they undertake or support?



## Appendix B

### Final Codebook Used to Analyze Interviews

Parent Code	Child Code	Definition
Access		Issues or research questions related to enrollee access to care including physician willingness to accept Medicaid patients.
Advice		
	Research production	Advice to health services researchers related to the research production process.
	Research communication	Advice to health services researchers related to the communication of research findings to policymakers and other audiences.
Behavioral Health		Issues or research questions related to behavioral health including mental illness and substance use disorders.
Enrollee Behavior		Issues or research questions about enrollee behavior including engagement with the health care system as well as responses to various benefit designs.
Benefit Design		Issues or research questions related to the structure and coverage of benefits for Medicaid enrollees.
Care Coordination		Issues or research questions related to the coordination of care for Medicaid enrollees. Does not include specific comments regarding accountable care organizations or health homes.
Cost		Issues or research questions around the cost of treating Medicaid enrollees.
Data and Measurement		
	Data availability and quality	

	Comments about access to Medicaid data and the quality of Medicaid data sets.	
	Measurement	
	Comments about the measurement of quality, outcomes, or other concepts for research or management purposes.	
	Medicaid data systems	
	Comments about the quality or capacity of Medicaid data systems including any reporting issues or updates to data systems.	
Eligibility and Enrollment		
	Exchanges	
	Issues or research questions related to state, federal, or partnership exchanges including the interface with Medicaid eligibility systems.	
	Churn	
	Issues or research questions related to the fluctuation of Medicaid populations between various types of coverage including private plans, Medicaid, or lack of coverage.	
Evidence Use		General comments about the use of evidence in policymaking and policy analysis (Medicaid or otherwise).
Expansion		
	Alternative expansion models	
	Issues or research questions related to alternative models used by states to expand Medicaid using waivers or other legislation distinct from the Affordable Care Act.	
	Expansion decision	

	Comments, issues, or research questions related to states' decisions to expand or not expand Medicaid eligibility as a result of the Affordable Care Act.	
	Newly eligible population	
	Issues or research questions related to the new population eligible for Medicaid coverage under the Affordable Care Act.	
Frustrations		Comments about frustrations, concerns, or limitations of academic health services research for policy analysis or policymaking.
Innovations in Payment and Service Delivery		
	ACOs	Issues or research questions related to accountable care organizations (ACOs) or other similarly structured models piloted with Medicaid populations.
	Health homes	Issues or research questions related to health homes or other similar care models.
	State Innovation Models	Issues or research questions related to the Centers for Medicare & Medicaid Services State Innovation Models Initiative including implementation and evaluation.
Long-term Services and Supports		Issues or research questions related to the delivery, payment, and/or cost of long-term services and supports provided to Medicaid enrollees.
Medicaid Managed Care		Comments, issues, or research questions related to Medicaid managed care including recent trends toward utilization of managed care organizations to cover Medicaid populations.
Miscellaneous		Comments worth noting that do not fit in any other category.

Pharmaceuticals		Issues or research questions related to development, cost, or coverage of drugs and the general role of pharmaceuticals in health care.
Politics/Ideology		Comments about the role of politics and ideology in Medicaid policymaking and policy analysis.
Program Sustainability		Comments, issues, or research questions related to the long-term financial sustainability of the Medicaid program.
Provider Payment		
	DSH payments	Comments, issues, or research questions regarding reductions in Disproportionate Share Hospital (DSH) allotments under the Affordable Care Act.
	Primary care payment increase	Issues or research questions related to the effect of the temporary primary care payment increase under the Affordable Care Act.
	Risk adjustment	Issues or research questions related to appropriate risk adjustment to account for treating complex and/or vulnerable populations.
Public/Population health		Comments, issues, or research questions related to public or population health.
Social Determinants of Health		Comments, issues, or research questions about the impact of social determinants such as education and housing on health outcomes and health care costs.
Special Populations		
	Children	Issues or research questions related to children in the Medicaid program. Includes comments regarding the Children's Health Insurance Plan (CHIP).
	Dual eligibles	Issues or research questions related to the population eligible for both Medicare and Medicaid.

	Formerly incarcerated individuals	Issues or research questions related to individuals released from jail or prison including transition challenges and coverage concerns.
	Immigrants	Issues or research questions related to the immigrant population including legal immigrants, refugees/asylees, and undocumented individuals.
	Non-elderly disabled	Issues or research questions related to the non-elderly disabled population including adults under age 65 and children/adolescents.
	Women	Issues or research questions related to women's health including maternal health.
	Individuals with HIV/AIDs	Issues or research questions related to individuals with HIV/AIDs.
State Capacity		Comments or concerns related to states' internal capacity to interpret, use, or conduct research and policy analysis to aid in policymaking.
State-specific Anecdotes		State-specific stories, experiences, programs or initiatives not covered by other categories.
Quotes		Text from interviews we may want to reproduce as quotes in the report.
Workforce		Comments, issues, or research questions related to the health care workforce including adequacy, capacity, and scope of practice.