



AcademyHealth

**The AcademyHealth Listening Project:  
Improving the Evidence Base for Medicare 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. 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 report is the first in a series focusing on the short- and long-term research needs of policymakers and leaders in health care delivery systems.*

In 2013, AcademyHealth's Translation and Dissemination Institute launched its first major activity, a "Listening Project" aimed at identifying the most pressing health services 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, users, and funders of health services research to spur the development and use of more relevant and timely evidence. 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 Listening Project draws on two separate audiences annually, the first round of interviews focusing on policymakers and the analysts who advise them, and the second on health care delivery system leaders. The Translation and Dissemination Institute's Advisory Committee reviews and recommends topics for each round of interviews.

During the summer of 2013, AcademyHealth staff conducted telephone and in-person interviews with 24 government agency analysts, non-governmental experts, and other health care policymakers regarding knowledge gaps and research needs related to Medicare. 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 final analysis organized respondent needs and feedback along five major themes: (1) research needs, (2) data gaps, (3) research process improvements, (4) political context and (5) improved dissemination.

The full narrative of the 2014 Listening Project Report, with expanded samples from respondent interviews, is available online at: [www.academyhealth.org/listeningprojectmedicare](http://www.academyhealth.org/listeningprojectmedicare)

## **1. The Most Frequently Cited Research Needs Address New Organizational Structures and Persistent Problems Like Costs.**

The research topics identified most often and most forcefully in our interviews relate to both emerging trends and long-standing, complex issues in Medicare policy:

### **Help Policymakers Understand Accountable Care Organizations (ACOs), Medicare Advantage Plans, and Consolidated Markets**

Policy initiatives like the Affordable Care Act (ACA) as well as recent trends in local health care marketplaces have brought about new types of organizations that provide Medicare services that policymakers seek to understand better. While policymakers know how ACOs are paid and their intended impact, little is known about how they are internally structured, whether and how they actually coordinate care, how they compensate participating providers, or what unintended consequences they may have for providers and patients. Research is needed to shed light on these issues. Interviewees similarly pointed to the need for research to understand the inner workings of Medicare Advantage (MA)

plans, including their ability to coordinate care and realize any efficiency. Respondents also questioned how the recent trend of hospitals directly employing physicians or acquiring entire physician practices may be impacting access, costs and quality of care.

*If any [ACOs] are able to actually reduce the growth of service use, that would be fascinating. The interesting thing would be which ones. What services are they reducing? Is it inpatient acute care? Physicians? What is it that is changing? Is it the result of patient choice or is that a result of provider behavior? What's going on?*

-Interviewee

### Answer Persistent Questions Related to Medicare's Costs

A variety of topics concerning the costs of care financed by Medicare continue to require further study. Examples include the impact of technology on costs (a longstanding and recognized research gap), how best to manage traditionally high-cost beneficiaries, what makes some provider organizations deliver greater value, and, as part of the research described above, the cost impacts of new forms of provider organizations. Respondents also requested more information on trends in overall Medicare costs, particularly the causes and implications of the recent slowdown in the program's rate of growth.



### Illuminate Medicare's Role in End-of-life Care

While acknowledging the topic is politically charged, interviewees identified end-of-life care as an area in need of additional research. Of particular interest is research on the Medicare hospice benefit, including a better understanding of who uses it, for how long, and with what impact on costs and quality of care/life.

### Examine Other Issues

Less frequently, interviewees mentioned other areas where they believe new research would help inform Medicare policy, including studies to understand:

- how beneficiaries make decisions about their health care and health insurance;
- the impacts of recent pharmaceutical trends including the growth in the number of medications beneficiaries take and the growth in high-cost “specialty drugs” that treat conditions affecting small numbers of patients;
- the impact of new restrictive benefit designs in Medicare Advantage and Medicare Part D on beneficiary access; and
- the effectiveness of different approaches to eliminating waste, fraud, and abuse.

## 2. Data Gaps Impede the Study of Quality of Care, Medicare Advantage, and Physician Practice.

It is no surprise when researchers clamor for more and better data. We found policymakers equally vocal about the need to fill data gaps relevant to Medicare.

*I'm not so much frustrated with the topics that are chosen by academic researchers. I'm most frustrated with their lack of data. They just don't have the data available to answer the questions we're interested in, the way we would like for them to answer [those questions].*

-Interviewee

Meeting this need would not only inform Medicare policy discussions, but would provide insights relevant to the whole health care system. Respondents most frequently mentioned three types of data needs:

## Better Data on Quality of Care

This data gap is a two-part problem: a need to identify the right things to measure as well as the actual data needed to generate these measures. Information on quality is especially important as policymakers seek to expand Medicare pay-for-performance efforts, understand the impact of provider consolidation and integration, and assess how to incentivize and compensate providers within ACOs and other integrated delivery systems.

*We already have huge datasets for Medicare...but...other than mortality, we're really missing how all that spending is working for beneficiaries.*

-Interviewee

## More Data about Physician Practice

Interviewees noted that there is virtually no systematic, generalizable information about how physicians practice at a time when many doctors are organizing themselves in new ways and Medicare is experimenting with alternative models for paying physicians. Respondents cited a need to better understand the costs incurred by physician practices and their use of personnel and other resources to deliver care.<sup>1</sup>



## Any Medicare Advantage Encounter Data

Getting access to Medicare Advantage “encounter” data, which tracks actual services provided and resources expended in delivering care in these “capitated” plans (much the way claims data provides insights into resource use in a fee-for-service plan), has proven technically difficult and, because of the competitive structure of the Medicare Advantage program, politically challenging. However, interviewees noted that these data could offer a window into the inner workings of Medicare Advantage plans and a tool for assessing the strengths and weaknesses of these plans relative to traditional fee-for-service Medicare. They could also help CMS better risk adjust plan payments and provide valuable policy insights into the differences between Medicare Advantage and traditional Medicare in terms of enrollees, range of services, and performance.

## Other Data Needs

Other needs cited by interviewees include data to:

- help policymakers understand the impact of technological innovation on Medicare costs;
- accurately measure beneficiaries’ wealth, beyond income; and
- understand the Medigap market better.

## 3. The Way We Do Research Is Changing.

We also asked our interviewees about several aspects of the health services research enterprise and process and its relevance to the Medicare program. In addition to commenting on recent developments in the way research is conducted, respondents offered several suggestions for how health services research could be more useful to policymakers.

## New Electronic Data

While acknowledging the long-term potential of new electronic data from registries, electronic health records, and other sources, our interviewees were skeptical that these resources would inform Medicare policy in the near future. They believe privacy concerns and the decentralized, non-standardized nature of these data pose significant barriers.

*I can only imagine that the electronic health records will double and triple [the challenges faced when using existing data sources for research] because there'll be far more privacy issues you have to deal with. So availability will be tough. -Interviewee*

### **Rapid-Cycle Research**

Respondents offered diverse, conflicting perspectives about the potential value of the rapid-cycle research approach being used by the federal Center for Medicare and Medicaid Innovation. In the case of rapid-cycle innovation, some respondents cited the value of this approach in allowing ineffective ideas to “fail fast” and to spread successful innovations quickly. Others expressed the belief that only data from rigorously designed studies employing traditional health services research methodologies can produce generalizable results.

*[Studies indicate], we take 17 years to learn how to take best practices or better practices and get the world to adopt them. These are the kinds of things that very successful high-tech companies do routinely much faster than Medicare. -Interviewee*

*[Through rapid-cycle research], they do not intend to evaluate. They intend to implement ideas based on inadequate information. ACOs are the perfect example...So it's literally impossible to actually evaluate whatever this intervention is because the intervention is no longer well-defined and of course if you're going to evaluate something, you have to start thinking with data collection, and we're past that. -Interviewee*

### **Comparative Effectiveness Research**

Interviewees did not see comparative effectiveness research or patient-centered outcomes research as currently part of Medicare policy formation. Looking to the future, respondents alluded to the potential value of comparative effectiveness research in guiding the management of pharmaceuticals reimbursed under Medicare. Some respondents mentioned the Patient Centered Outcomes Research Institute's (PCORI) prohibition against considering costs as a significant limitation.<sup>2</sup>

*Comparative effectiveness should include cost-effectiveness. I know, obviously, all the political sides to that, but if we don't put that cost factor in there when we look at comparative effectiveness, we're missing the boat. -Interviewee*

Respondents offered several suggestions for researchers to consider when designing their studies in order to enhance their value to policymakers. They recommended:

- avoiding research questions with obvious answers or that re-churn existing knowledge;
- utilizing more qualitative research techniques such as interviewing key informants or preparing case studies; and
- drawing in evidence from non-peer reviewed, “grey” sources like trade publications, analyses of the health care industry prepared for investors, and news stories.

*If it is reinforcing our understanding and we already know it, then I see no reason to just keep pounding on the same thing. I just don't think it's useful. There are tons of articles like that with very beguiling titles that, in the end, don't tell you a thing. -Interviewee*

## 4. Understanding the Politics of Evidence and Medicare Policy Is Important.

Science sees itself as nonpartisan, but policy decisions rarely are. Researchers must understand that politics and ideology affect whether and how evidence is used. In some cases, reputations of funders or viewpoints of authors can render work difficult to inject into policy deliberations. In other cases, however, stakeholders can help analysts and decision-makers clarify a policy problem or potential solution. Policy analysts indicated information from stakeholders may have value, though full recognition of the source and its biases is critical.

*I was at a discussion the other day where a researcher said, “Well, states should just see that this is going to save them money and just do it. What’s the barrier?” Politics. I think maybe researchers should take more political science classes. -Interviewee*

Researchers also need to take political feasibility into account, both in framing research questions and in describing next steps or recommendations that flow from study findings. Interviewees stressed that a solution that is not politically feasible is of little or no use to policymakers seeking solutions they can apply now.

## 5. Timely Research and Personal Relationships Are Key to Informing Medicare Policy.

Interviewees offered advice for researchers who want to work with policymakers, especially concerning when and how they disseminate their study results to the policy community. While many of these suggestions are not new, their prominence across the interviews suggests there remains significant room for improvement in the ways researchers produce and communicate study findings to inform policy.

*[Research] has to be very relevant and very accessible. If you can nail both of those, you’re good. -Interviewee*

Respondents repeatedly noted that study findings need to be available to policymakers at the time decisions are made in order to be useful. While acknowledging that this suggestion can make it difficult to align academic research results to currently relevant policy questions, respondents advised researchers to give their best estimates and insights in response to a policymaker’s question, even if the current evidence is the ‘best available’ rather than unassailably the ‘best.’

*They have to get used to using real-time, somewhat relatively incomplete data because we don’t have the luxury of waiting for a lot of run-out in a claims data set... policymakers don’t want to wait three years or four years to have information around what’s working and what isn’t working. -Interviewee*

Interviewees also emphasized the importance of communicating in policymakers’ own language by avoiding jargon and describing research findings and their importance in everyday terms. Finally, they reiterated that successful translation and dissemination of research for policy is not a one-time event. Cultivating ongoing relationships with policymakers and policy analysts increases the value and impact of health services research for Medicare policy.

## Conclusion

The results from the AcademyHealth Listening Project's inaugural report underscore that the health policy community can be a rich source of information for health services researchers, whether the topic is Medicare or another area of health policy. Not only can policymakers help identify the most policy relevant questions for researchers to address and the data needed to do it, but they also offer important insights into how to communicate research findings and help the policy community use them most effectively.



The interviews are also valuable for what they do not include. In describing their research needs, respondents did not mention a number of issues that have received recent attention on Capitol Hill, such as the potential reform of Medicare's sustainable growth rate (SGR) and Medicare's current fee-for-service payment of physicians. A possible explanation is that these issues are waiting on political decisions, rather than the availability of additional research.

Looking ahead, AcademyHealth will use this first Listening Project report as a catalyst for discussion among the producers, funders and users of health services research about opportunities and challenges in moving research into policy and practice. Some of this discussion will occur at AcademyHealth's 2014 Annual Research Meeting, giving members of the health services research community the opportunity to reflect, expand, and even push back on the report's key findings. Future Listening Project reports will focus on other areas of health policy and health care delivery where new or better research is needed. Through this work, we seek to enhance the ability of AcademyHealth members and the field more broadly to effectively inform an ever-evolving health care system.

# 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 research (HSR) and spur the production and use of timely, relevant evidence to improve health and health care.



The Listening Project is also a signature activity of AcademyHealth's Translation and Dissemination Institute, a constellation of initiatives to help move knowledge into action. Launched in 2013, the Institute addresses the challenges of getting the best HSR to the right audiences, at the right time, and in a form useful to decision-makers. In addition to the Listening Project, the Institute undertakes activities that promote the translation and dissemination of HSR. It also serves as an incubator for new and innovative approaches to moving research into policy and practice, which includes 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 (EPCs) in the United States<sup>3</sup>. The core of the project is a series of interviews with research users conducted in two rounds each year. One round focuses on the HSR needs of those in the health policymaking community. Key informants include government agency analysts and political appointees, think tank staff and other non-governmental experts, and advocates for diverse health policy perspectives. The second round of interviews focuses on the research needs of health care delivery system decision-makers. Key informants include both managerial and clinical leaders from organizations that provide health care. Each year, the two rounds of interviews focus on different, timely uses of HSR, usually around a specific theme.

During 2013, the project's inaugural year, the round of interviews with the policymaking community focused on Medicare. The second round of interviews is focusing on the HSR needs of delivery systems that serve relatively large percentages of vulnerable populations – safety net providers. Interviews in subsequent years will focus on other topics or will update previous years' findings.

## Methods

AcademyHealth conducted semi-structured, key informant interviews with 24 Medicare policy analysts and experts between April and June of 2013.

### Sample Population

We developed a list of potential interviewees from rosters of individuals who participated in AcademyHealth projects and meetings in the last two years and had expertise relevant to the Medicare program. Because of the broad reach of AcademyHealth programs, the resulting list represents diverse perspectives and knowledge of the Medicare program. In creating the list, we focused on intermediaries who “support better connections between the policy needs of [research] users and findings from researchers.”<sup>4</sup> In particular, we targeted two groups: (1) analytic staff in congressional, executive and independent

federal agencies tasked with supporting the development or implementation of Medicare policy; (2) other Medicare experts currently employed by think tanks who previously served in government agencies with Medicare responsibilities. We used a snowball sampling strategy to achieve relative balance among agencies and, where relevant, political perspectives represented. All individuals we approached agreed to participate in the interviews or referred us to colleagues they believed were better qualified to respond. The final participant group included 18 current and five former federal employees. One interviewee had never worked for the federal government.



Two of the interviewees no longer in government service were former political appointees; one worked for Democratic elected officials, and one worked for Republican officials. All of the interviewees who currently or formerly worked for the federal government were nonpartisan career employees. Although their professional training differed, almost all respondents had analytic training at the Masters or doctoral level. Some also had prior experience as traditional health services researchers. As confirmed over the course of the interviews and discussed in the report that follows, interviewees' current or former jobs included reading and using peer-reviewed, published HSR studies.

### **Instrument and Interviews**

With input from members of the Translation and Dissemination Institute's Advisory Committee and other core AcademyHealth leadership and staff, we designed a semi-structured interview guide reproduced in Appendix A. One week before each interview, we provided the interviewee with a list of questions that focused on three broad areas: (1) interviewees' expected data and research needs over the next three to five years; (2) the ways in which interviewees accessed and used analytic evidence, including HSR, to inform their Medicare-related work; and (3) interviewees' perspectives on how HSR could be more useful to Medicare policy<sup>5</sup>.

We conducted four interviews by telephone. All others took place in-person. They were a mix of individual and small group interviews of up to five people. Two AcademyHealth staff participated in each interview. One staff member posed the questions, while the other took notes. With the consent of the interviewees, we audio recorded 22 of the 24 interviews. For the other two interviews, we relied on detailed notes for our analysis.

### **Qualitative Analysis**

AcademyHealth staff developed an a priori codebook and used qualitative data analysis software NVivo 10 to code notes or verbatim transcripts of each interview for complex concepts as well as stated Medicare 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 or set of notes. Throughout the process, inconsistencies between the reviewers' coding were deliberated, emergent codes were added based on discussions between the two coders, and the code list was refined iteratively. Appendix B reproduces the final code list.

The report that follows draws heavily on the use of verbatim quotes to illustrate each finding. To ensure candor in the interviews, we do not identify interviewees by name, nor, at the request of several participants, do we attribute comments to interviewees' specific agencies or branches of government. However, we try to indicate the frequency with which particular points or themes arose over the course of the interviews.

## Listening Project Interviewees' Stated Research Needs

- *Accountable Care Organizations*
- *Provider Market Structure*
- *End-of-Life Care*
- *Medicare Costs*
- *Medicare Advantage*
- *Payment*
- *Beneficiaries' Access to Care*
- *Beneficiary Knowledge and Decision-Making*
- *Pharmaceuticals*
- *Waste, Fraud and Abuse*

## Results

Our analysis revealed comments and themes that fall into five categories: (1) comments about Medicare policymakers' specific research needs, (2) comments about Medicare-related data needs, (3) comments on the research process itself, (4) comments about the politics of evidence and Medicare policy, and (5) advice to researchers about how to work effectively with policy analysts and policymakers. We summarize our findings in five sections that reflect this division.

Many of the interviewees' comments and suggestions about the translation and dissemination of Medicare research found in sections III, IV, and V below are not specific to Medicare and are consistent with the substantial literature from the United States and abroad about how to effectively move research into the policy arena<sup>6</sup>.

### I. Research Needed for Medicare Policy

The primary purpose of this inaugural round of the Listening Project was to help researchers direct their efforts toward topics that are relevant and timely to Medicare policy. Respondents identified 10 areas where they believe new or better research is needed to inform Medicare policy.

**Accountable Care Organizations (ACOs).** Respondents raised a number of research needs related to the functioning and performance of Medicare ACOs<sup>7</sup>. A key question with implications beyond the Medicare program is whether Medicare ACOs actually improve beneficiaries' health.

*Being able to track whether, in fact, health outcomes are better...would be helpful to us in thinking about whether Medicare ACOs are actually producing better results for Medicare patients and for assessing [these outcomes] in commercial [non-Medicare ACOs] as well.*

-Interviewee

Our interviewees also raised the question of whether Medicare ACOs save money, and if so, how, suggesting that ACOs are "black boxes" in need of illumination. They noted that while Medicare has established how dollars flow into participating ACOs, we know little about how these organizations deploy those dollars, how they organizationally structure themselves, the financial and other incentives participating providers face, the extent to which providers buy in to different types of ACO arrangements, and the specific mechanisms that drive any actual changes in beneficiary or provider behavior

*Who gets the dollars and who makes the internal decisions about the use of the dollars? I think we really need to be studying inside many of these pilots and experiments – what works, who does it, and how they do it.*

-Interviewee

Respondents also suggested that understanding the internal provider remuneration schemes adopted by successful ACOs could help inform efforts to design new payment systems that reward value beyond the Medicare ACO program.

*How do you do a bundled payment system that's aimed at reducing payments in the wrong places and encouraging them [in] the right places when you have to say to the actors in the system, "Okay, our goal is to take money away from you"?*

-Interviewee

Finally, respondents noted the need to understand whether ACOs could result in unintended consequences. For example, ACOs could increase Medicare spending by increasing concentration in the provider marketplace. Respondents also cited the example of hospital-based Medicare ACOs that reduce the need for acute hospitalizations over the longer term by providing preventive and other care that improves beneficiaries' health. Such reductions in hospitalization would reduce revenue flowing to participating hospitals, creating the possibility that the hospitals do not recoup their initial investments to create the ACO.

**Provider Market Structure.** Respondents raised research needs related to provider competition, integration, and consolidation, and the implications for Medicare costs and quality. In addition to the need to study the potential unintended consequences of ACOs mentioned above, respondents mentioned a need to understand how the trend in hospitals hiring physicians or purchasing their practices outright is affecting beneficiaries' access to care, health outcomes, service quality, and costs. As an example of such research questions, one interviewee speculated about the cost implications for Medicare when a physician practice can bill at a hospital outpatient rate once a hospital has acquired it.

**Medicare Costs.** The cost of the Medicare program and the care it pays for emerged as a high priority research topic in a variety of ways. Some interviewees focused on program costs in general, citing a need to understand whether the recent slowdown in Medicare cost growth is a temporary phenomenon or the beginning of a lasting change.

*There's some question as to whether it really is all just due to the recession or whether it's partly due to changes in provider behaviors that are finally starting to take hold.*

-Interviewee

Other respondents focused on the need for research to inform policy approaches to controlling costs, including viable strategies to manage particularly expensive Medicare beneficiaries such as dual eligibles and those with multiple chronic conditions.

*People always cite the statistics about the small percentage of people with multiple chronic conditions who take up most of the Medicare dollars. We[ve learned] that over and over...From a policy standpoint, the next [question] is what do we do about them? That's where I find a real vacuum...we don't need more ways to [describe the problem]. We need to figure out what we do about it.*

-Interviewee

Respondents also noted that more research on effective care coordination practices could help inform this issue. One person pointed to Medicare Advantage encounter data<sup>8</sup> (discussed in more detail in Section II of our results) as a potentially useful tool in determining whether beneficiaries with coordinated care plans use services differently. Another research approach suggested by interviewees for developing cost control strategies was to

conduct detailed cost comparisons between Medicare and the private sector. One interviewee provided this example:

*Are there places that are really high cost for Medicare that are also high cost for the private sector? If they're [both] high cost, is the reason the same or is it that Medicare is doing a much better job [than the private sector] at controlling prices because it can, but it has no leverage on utilization, [whereas the situation is] the reverse on the private side?* -Interviewee

In a similar suggestion, some respondents suggested analyzing high-performing health care providers as a way to identify strategies that could help control Medicare costs. Just as they saw a need to study the internal workings of ACOs, interviewees noted that “we don’t really know enough about what’s going on inside” high-performing hospitals, physician groups, and other provider organizations to understand their common characteristics and the mechanisms that make them more efficient than their counterparts. Respondents suggested this work could include examining how medical staffs experience major organizational change and their role in implementing strategies to constrain costs and improve efficiency.

*What is the impact of...this transformative period in medicine, what is that experience like at the medical staff level?...Are they part of the inertia that sort of prevents us from getting more traction in some of our models?* -Interviewee

**End-of-life Care.** While acknowledging the sensitivity of the issue, respondents pointed to the need for additional research on end-of-life care, a major component of Medicare costs. Some suggested that many of the challenges in end-of-life care are representative of the problems facing the health care system more generally.

*I think that end-of-life [care] is just as problematic as other components of health care because care at the end-of-life is not coordinated...The reason we pay so much attention to end-of-life is because it's costly, but I see it as part of the spectrum.* -Interviewee

Others described a need for studies focused specifically on the Medicare hospice benefit. They pointed to research suggesting Medicare beneficiaries may underutilize the hospice benefit because it was designed for diseases like cancer where there is a relatively good understanding of when a patient is ready to enter hospice. For beneficiaries with other conditions, however, that moment is less well-defined. Interviewees suggested that research to better define the most appropriate moment for patients to consider the option of hospice could help assure optimal use of the benefit.

Some interviewees suggested that we also need a better understanding of who uses the hospice benefit and for how long, given the number of very short and very long hospice stays and data pointing to racial and ethnic minorities and other subgroups using the hospice benefit less frequently than other beneficiaries.

**Medicare Advantage.** Interviewees’ most frequent comments about Medicare Advantage (MA) expressed the hope that researchers would have access to encounter data to better illuminate if and how MA plans coordinate care and whether they are more efficient than

traditional fee-for-service Medicare. Another strain of comments focused on the need to understand the characteristics of beneficiaries who enroll in MA plans and why the percentage of beneficiaries who do so has grown significantly in recent years. In articulating this latter question, one respondent hypothesized that as current cohorts age into Medicare, they are already accustomed to getting their health care through a private plan.

*Maybe it's really just going from a plan they already have to a plan that has a similar name run by the same company. They're already used to how it works... Why is that? I don't think I've seen an article answering the question: why [does MA account for] 27 percent [of Medicare beneficiaries] today and why was it a lot less 10 years ago? I'd like to know.* -Interviewee

Interviewees also pointed to evidence that MA plans attract healthier than average Medicare beneficiaries, noting policymakers' limited ability currently to adjust MA payments to reflect enrollees' actual risk of needing services. While encouraging research in this area, they acknowledged that developing better risk adjusters is difficult.

*Risk adjustment is...one of those things like mom and apple pie. Nobody's ever against risk adjustment, but everybody always complains about the specific risk adjuster you come up with...I know there are a lot of people working in this area, but I think it's just a really, really hard problem...* -Interviewee

**Payment.** In identifying research topics related to Medicare payment, interviewees described a need for research to better illuminate the actual costs incurred by providers in delivering services. One respondent expressed this need using physician services as an example.

*Most Medicare payment systems are built on really imperfect information...Medicare doesn't collect [information on the cost of running a physician practice], so to the extent that others can find a way of using industry or trade data in a reliable, believable way... they would help all of us.* -Interviewee

Respondents also focused on the particular challenges posed by Medicare benefits, highlighting recent interest<sup>9</sup> in incorporating population-level health interventions into primary care.

*We think it's really important to do, but we have no idea how to do it, how to price it...or who to pay sometimes...And how do we align incentives so that the thing doesn't spiral out of control cost-wise, but people actually bother providing the services?* -Interviewee

Other respondents pointed to a lack of understanding about the readiness of providers to participate in new payment systems.

*If you were going to change to a prospective bundle[d payment] that says, for example, for someone with stroke we're going to pay X amount of money one time to one entity and then that has to cover the care for that beneficiary across multiple settings,...is the market ready to take something like that on? That's a research project that I think no one is doing and needs to be done.* -Interviewee

**Beneficiaries' Access to Care.** Although Medicare beneficiaries have health insurance, interviewees suggested the need for research on access to care, particularly beneficiaries' ability to secure primary care. One interviewee pointed to a need to know whether the emergence of restrictive benefit designs, such as the use of preferred pharmacy networks, may be affecting access for beneficiaries enrolled in Medicare Advantage and Part D prescription drug plans.

**Beneficiary Knowledge and Decision-Making.** A number of respondents described the need for research on Medicare beneficiaries' health literacy – in particular, how well beneficiaries understand the program and their benefits, and the implications for enrollment decisions and choices about care. Some respondents called for evidence on effective strategies for helping beneficiaries become more active consumers of their care.

*The one big area we need to understand more about is the way beneficiaries understand and interact with the program and the health care system in general. We have some evidence that they, a lot of times, don't understand their benefits. They don't understand the health care marketplace or the way that they can use the services.*

-Interviewee

Interviewees also noted the diversity of the Medicare population, suggesting that research examine how different subpopulations of beneficiaries behave. For example, one respondent pointed to the possibility that low-income beneficiaries might respond differently than other beneficiaries to proposed Medicare innovations like tiered networks in which beneficiaries pay higher cost-sharing for some providers than others.



**Pharmaceuticals.** Respondents noted two recent trends in the use of pharmaceuticals that have generated a need for new policy-relevant research. The first trend is the growing number of new biologicals and other drugs that treat conditions affecting relatively small numbers of patients (sometimes referred to as “specialty drugs”). Because such drugs tend to be expensive, they could pose a significant cost burden to Medicare over time. With the emergence of personalized medicine and the eventual approval of new biologicals currently in the research pipeline, respondents expect this challenge to grow. Beyond research to help identify the most appropriate uses of these drugs, respondents suggested the need for studies to help design policies, processes, and incentives to manage their actual use in clinically appropriate ways. For example, one respondent suggested research to measure the impacts of recent trends by payers to create tiers of cost-sharing and access rules specifically for specialty drugs.

The second trend is the growth in polypharmacy, or the use of multiple medications by a patient, which can include unnecessary prescription drug use. Respondents noted that, to-date, most research and policy have focused on efforts to assure Medicare beneficiaries take prescribed medications – i.e. financial access to pharmaceuticals and adherence to the prescribed frequency and duration of treatment. These interviewees believe too little is known about health complications resulting from polypharmacy and their cost implications for Medicare.

*A lot of research I've seen would say...adhering to medication or having a drug covered increases its use and tends to lower the health spending generally, but .... we're not convinced that that's true for all cases, particularly if you are looking at people who are on 10-15 medications.... People seem to think that the access is the issue, rather than [the possibility that] people may be taking too many drugs.*

-Interviewee

## Listening Project Interviewees' Stated Data Needs

- *Quality of Care Data*
- *Medicare Advantage Encounter Data*
- *Physician Practice Data*
- *Data on Technical Innovation and Costs*

Beyond these two trends, respondents identified several specific questions related to Medicare coverage of drugs. These include a desire to understand more about why initial Medicare Part D costs were significantly lower than projected, how drug spending and utilization trends in Medicare compare with those among non-Medicare insured populations, and the impact of having little cost-sharing for low-income beneficiaries on the use of higher versus lower cost drugs.

**Waste, Fraud, and Abuse.** Respondents noted that while federal officials are putting more resources into identifying fraud and abuse within the Medicare program, the disparate data on this topic have not been able to answer key policy questions, especially about the effectiveness of alternative approaches to reducing the problem. One interviewee lamented that Medicare does not know how its efforts to eliminate waste, fraud and abuse compare with those in the private sector, but acknowledged the potential difficulty in studying the issue given the reluctance of private insurers to admit there is a problem or discuss their efforts to combat it.

## II. Data Needed for Medicare Policy

In addition to identifying specific research needs, respondents expressed general frustrations with the data limitations facing both health services researchers and policy analysts – namely, the unavailability of the timely, high-quality data needed to produce studies to inform current policy debates.

*I'm not so much frustrated with the topics that are chosen by academic researchers. I'm most frustrated with their lack of data. They just don't have the data available to answer the questions that we're interested in, the way we would like for them to answer [those questions].*

-Interviewee

While many respondents acknowledged that data availability is often outside the control of individual researchers, they do not view this as a pass for using ill-fitting data in research studies. Multiple respondents described a tendency among some researchers to conduct analyses with the data that is easy and available, rather than the data that's most policy relevant.

*One of the frustrating things is authors...try to analyze public policy, but they have the data set that they have and that's what they're going to work with. And they make some really convenient assumptions so they can use that data set...They go through all the machinations to get to the very end and come to a bottom line. Stylistically they've done it, but some of their assumptions are just so far out of the realm of either what's politically feasible or... under discussion.*

-Interviewee

Interviewees also identified four types of data gaps that they believe limit Medicare policymaking.

**Data to Measure Quality of Care.** One data gap was mentioned in almost every interview – insufficient information about the quality of care delivered. Interviewees identified several ways in which quality data are important for Medicare. In particular, they noted the need for better quality data in order to:

- operationalize Medicare pay-for-performance efforts including bundled payment, readmissions penalties, and quality-related bonuses;
- understand the impact of provider consolidation and integration, including ACOs, on the quality of care patients receive;
- risk adjust; and
- attribute patient health outcomes and services provided to individual providers in order to compensate and incentivize them appropriately within ACOs and other integrated delivery systems.

In contrast to the other gaps mentioned above, which reflect only a lack of data, interviewees noted that the lack of quality information can be a two-part problem.

*In the quality area, is the issue that we just don't have ... measures that are correlated with outcomes of interest, or we now know how to define what we're looking for, but the data just haven't been there?* -Interviewee

Some respondents focused on a need to develop better measures that capture the dimensions of health care quality that policymakers can use to develop policy and manage the Medicare program. One interviewee described this problem in terms of the relationship between quality and costs.

*I think the evidence is mixed over whether we're measuring the right kind of things. Are they the things that really translate into [strategies for controlling] costs? Or are they simply indications of quality that don't translate into savings of any kind? ... We're taking it on faith and some research with mixed results that the quality measures we're looking at are directly related to changes in spending and better care. In my mind, the jury is still out.* -Interviewee

While acknowledging institutional efforts like the Agency for Healthcare Research and Quality (AHRQ) National Quality Strategy and those of the National Quality Forum, interviewees noted the role health services research plays in developing new quality measures that correlate with actual patient experiences in the health care system and the outcomes of services they receive.

*The process measures that people are being paid on [in current Medicare pay-for-performance efforts] don't really seem to connect with any kind of outcomes. We're really not happy with the direction things are moving. I mean, we need much better research to come up with the quality measures that measure things that really affect people's lives and [can be used as the basis for paying provider] bonuses.* -Interviewee

*The [National] Quality Strategy, which was part of the ACA, makes eminently good sense in terms of marshaling and maximizing resources, but it would be helpful if the research community paid some attention to the....priorities [the National Quality Strategy] identified so that some of these gaps are filled.* -Interviewee

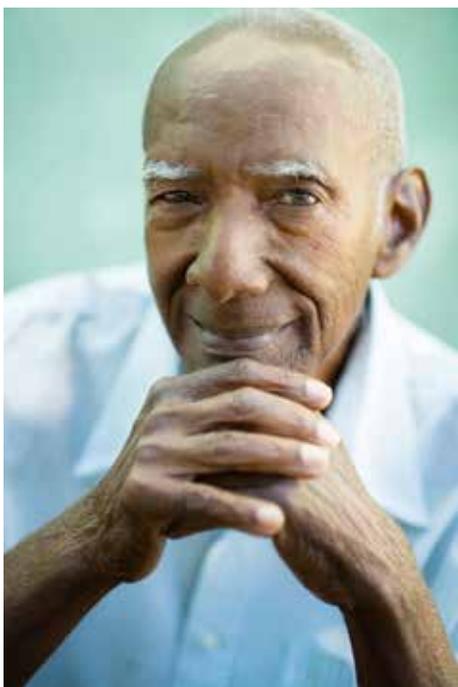
Other respondents focused less on the need to create new measures and more on the lack of actual data needed to operationalize the quality measures already developed.

*We always talk about quality and how what's missing are actual outcomes – health outcomes. We have a lot of process measures in Medicare, but to actually see whether something is making people healthier, some sort of clinical information would be helpful. I don't know how you would get that. We have huge datasets for Medicare, but... we're really missing how all that spending is working for beneficiaries.*

-Interviewee

Interviewees also noted that quality data need to be timely to be useful, and a few expressed the hope that clinical information from electronic health records (EHRs) could eventually fill some of the gaps in quality data.

**Medicare Advantage Encounter Data.** Respondents frequently noted the long-time lack of encounter data (which we also mention in the section on MA research needs above). While some interviewees pointed to indications from the Center for Medicare and Medicaid Services (CMS) that the agency would soon make encounter data available, others expressed skepticism, pointing out that health plans and CMS have promised this resource for many years. A few respondents also questioned how detailed the encounter data would be, or how comparable to fee-for-service claims, given that MA plans regard such information as key to their proprietary business strategies. In addition to the role encounter data could play in developing new risk adjusters, as mentioned earlier, respondents underscored the value of such data in understanding if and how MA is more efficient than traditional fee-for-service Medicare and in helping policymakers predict some of potential impacts of “premium support” proposals that would cap the federal government’s financial contribution toward beneficiaries’ Medicare and increase reliance on private health plans.



**Physician Practice Data.** Several respondents pointed to the lack of representative, reliable and detailed data about outpatient physician practice over time<sup>10</sup>. The absence of such data comes at a time of great flux in physician practice due to the implementation of electronic health records, the ACA, and delivery system innovations. For Medicare, data about physicians is particularly relevant given the federal program’s dominant role as a payer of physician services and as the setting for many experiments with new payment models and ACOs. Respondents pointed to the importance of understanding both hospital and physician practice as the two sectors become more integrated and attempt to better coordinate patient care.

**Data on Technological Innovation and Costs.** Respondents pointed to the lack of data that would provide a clearer understanding of the impact of technological innovation on health care spending. Although economists point to technology as a key driver of health care costs, they have lacked the data to measure this relationship directly<sup>11</sup>. The respondents noted that this piece of missing information is particularly important in understanding and addressing long-term health care spending trends, including those within Medicare. One respondent reported some success in getting useful information on the relationship between technology and costs from Wall Street financial analysts, but she noted that it was of limited value because these analysts “think in a very different way” about costs than do health services researchers and health policy analysts.

**Other Data.** Interviewees briefly mentioned two other data gaps. One respondent described a need for more accurate data on Medicare beneficiaries’ wealth, noting that

policymakers commonly use income as a proxy despite evidence that income is not a good predictor of beneficiaries' assets. Another respondent suggested that better data about the Medigap marketplace and the beneficiaries who purchase particular Medigap policies could be valuable to policymakers.

### III. Comments About the Medicare Research Process

We asked interviewees for their perspectives on a range of issues related to the generation of Medicare-relevant evidence and the research process, from the emergence of rapid-cycle evaluation and patient-centered outcomes research (PCOR) to the availability of new forms of electronic clinical data. Their responses suggest that while policymakers and policy analysts are generally aware of these new approaches and data, they are somewhat unclear as to the specific research currently underway, with conflicting opinions about its potential value. In addition to reflecting on these issues, respondents offered advice on how researchers might improve the usefulness of their work for Medicare policy.

#### Perspectives on Rapid-Cycle Evaluation of Medicare Innovations Are Mixed

The interviews revealed both strong support and significant concerns about the approach to improving Medicare embodied within the Centers for Medicare and Medicaid Innovation (CMMI). Some interviewees expressed enthusiastic support for CMMI and the “rapid-cycle” evaluations it undertakes as key to the establishment of a “learning health care system.”

*I think it's incredibly important to do that kind of research. I lived for decades with [CMS's traditional approaches to conducting research]. I mean, they did five to seven years of studies and came out with reports that said we need to do more studies. That's what we have to get away from...we need to invent and discover ways to do rapid-cycle research, particularly how to go viral with innovation, with best practices against the background of [research] that says we take 17 years to learn how to take best practices or better practices and get the world to adopt them. These are the kinds of things that very successful high-tech companies do routinely much faster than Medicare.*

-Interviewee

This same respondent went on to discuss the methodological validity of the “rapid-cycle” approach.

*There's rigor to things like the Toyota production system [which incorporates an evidence-based approach to on-going quality improvement]. It's an engineering and scientific rigor...Toyota would never try to improve its process by doing randomized controlled trials. It's a much more focused engineering approach and you fail fast. There's argument for failing fast, trying lots of things and failing fast, but also learning from where things are successful. It's a much more agile kind of research enterprise than you normally have.*

-Interviewee

Others indicated deep skepticism about the value of information produced through this approach, expressing the opinion that traditional research methods are the best way to draw valid conclusions about what works.

*{Through rapid-cycle research}, they do not intend to evaluate. They intend to implement ideas based on inadequate information. ACOs are the perfect example...So it's literally impossible to actually evaluate whatever this intervention is because the intervention is no longer well-defined and of course if you're going to evaluate something, you have to start thinking with data collection, and we're past that.*

-Interviewee

And still other interviewees endorsed the goal of generating findings more quickly, but they indicated concern because they were not familiar with the particular methods CMMI was adopting.

*I don't know [if CMMI's approach will produce useful information] because I haven't seen any results yet. I don't know. I mean there's promise there, but I don't have a good knowledge of what the evaluation of these very promising ideas will [look like].*

-Interviewee

One of the supporters acknowledged that rapid-cycle research could fail but suggested that the problem would not be with the method itself, but rather with its execution.

### **The Medicare Policy Community is Uncertain about the Implications of Patient-Centered Outcomes Research (PCOR)**

We asked respondents about their thoughts on the role of comparative effectiveness research (CER) and patient-centered outcomes research (PCOR) for Medicare. A number of respondents indicated that they did not have a good sense of what the Patient-Centered Outcomes Research Institute (PCORI) was funding, and hence, could not evaluate its potential to inform Medicare policy.

Among those who did have thoughts on this topic, the overwhelming sentiment was that CER/PCOR is less relevant to Medicare policy than it could be. For some, the concern was PCORI's funding priorities to-date.

*We're really interested in what's going to come out in comparative effectiveness research...we're not that encouraged by what we see for PCORI funding. I think they've broadened the topics so much that the kinds of things we thought would be coming out—comparing two treatments—won't come out.*

-Interviewee

For others, the problem is the tendency to exclude Medicare beneficiaries in studies early in a particular health care technology or service's lifecycle (i.e. before it diffuses widely among the Medicare population).

*Go back to Jim Lubitz's work that's 20 years old now.<sup>12</sup> When you look at how technology diffused in the Medicare population, frequently, he was finding that the technology that 75 to 85-year-olds were using [was introduced] 20 years earlier among 45-year-olds. Then it disseminated. People got much better at using [the technology and then introduced it widely among] older age groups. It's not true for every procedure, but that kind of long timeframe suggests that comparative effectiveness research could have a huge impact if you [included Medicare beneficiaries before a technology] disseminates widely into Medicare.*

-Interviewee

Other interviewees pointed to factors that are largely outside the ability of researchers to address, in particular, the restriction that research funded by PCORI does not consider costs<sup>13</sup>. At the same time, these interviewees acknowledged the political difficulty associated with potentially denying coverage of services that PCOR/CER suggests do not provide value.

*Comparative effectiveness should include cost effectiveness. I know, obviously, all the political sides to that, but if we don't put that cost factor in there when we look at comparative effectiveness, we're missing the boat.* -Interviewee

Interviewees also pointed to the issue of off-label, unproven uses of technology – particularly for cancer patients – as another area where PCOR/CER could be more relevant to Medicare by making better use of “Coverage with Evidence Development” (CED). Respondents noted that the Food and Drug Administration (FDA) often approves new cancer drugs for very specific uses on the basis of research studies involving small numbers of carefully selected patients. CED is a policy introduced by CMS in the 2000s, in which Medicare would pay for an off-label or experimental service only if a beneficiary was enrolled in research studies intended to establish whether the service is effective. While suggesting that CED offers the opportunity to overcome economic barriers to research and expand our understanding of how well a health care service works, respondents also noted it creates a political difficulty if the evidence gathered narrows the covered use of a health care technology or service.

*[The CMS Administrator] probably suspected CED wasn't going to work... but it's the best idea so far in the Medicare context. It's the politics. It's hard to say “no” [when making decisions about what to cover in Medicare].* -Interviewee

#### **Data From New Electronic Sources Are Not Yet Part of Medicare Policy Discussions**

The implementation of the *Health Information Technology for Economic and Clinical Health (HITECH) Act*, EHRs, the growth of electronic registries, and recent efforts to make federal health data widely available have focused attention on the role these new data streams may play in health services research and health policy in the coming years<sup>14</sup>.

We asked respondents if they have anticipated the role these emerging data sources, especially those that provide clinical data about beneficiaries, could play in informing Medicare policy. With a few exceptions, interviewees indicated that these resources (or their potential as research tools) are not yet a part of Medicare policy discussions<sup>15</sup>. They saw Medicare claims and representative, national surveys as the mainstay of data resources for policy analysts and researchers. Some respondents also mentioned the value of increasingly being able to link survey data and established electronic disease registries like the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) program with Medicare claims.

Most respondents did acknowledge the long-term potential of research that uses EHR and other electronic data to inform Medicare policy, especially new approaches to payment. At the same time, however, they identified several challenges that will need to be overcome in order to achieve this potential. Overcoming privacy restrictions was the barrier most frequently mentioned by interviewees.

*I can only imagine that the electronic health records will double and triple [the challenges faced when using existing data sources for research] because there'll be far more privacy issues you have to deal with. So availability will be tough.* -Interviewee

Interviewees saw other potential challenges arising from the decentralized nature of EHR systems and registries. In the case of registries, respondents pointed to the fact that most of these emerging databases are proprietary and sponsored by professional medical societies, speculating that they would limit access to information that may not be in the interest of the physicians they represent. If they did provide access, respondents noted that costs could be significant. Others pointed to the fact that interoperability could be a problem for researchers – both technological interoperability and the likely differences in what data different systems collect and how providers choose to use the systems.

A few respondents were more positive, noting that there are new electronic data resources currently available that are underutilized by researchers. One interviewee noted the growing availability of standardized data on Medicare spending on the CMS website, broken down by geographic locale, provider type, and other ways, speculating that this trend could lead to new questions for researchers to study.

*They're moving to put this data out there, and that could create a real revolution. Journalists will start looking at it. Academics are going to have to keep up with that. When journalists see some hospice in some little town having twice the billings of any other place in the country, they'll start asking questions.*

-Interviewee

Another interviewee pointed to the availability of EHR data from the Veterans Health Administration (VA) and advocated greater use of these data to inform Medicare policy.

*For Medicare – we should underline this - VA is an enormously important model because most of the veterans are over 65, and not only [does the VA] have the electronic health records, they have a large research staff connected to most leading academic centers. They have the Million Veterans genetic program to add bio bank stuff to all their EHRs....They also have a very large chunk of their population that looks like the dual eligibles, people with multiple chronic conditions including mental illness or substance abuse. It's a wonderful test bed for advancing all of these issues related to Medicare, and it's a very underused resource.*

-Interviewee

### **Opportunities for Improving the Relevance of HSR for Medicare Policy**

In addition to comments on the specific approaches and data sources discussed above, the interviews captured general suggestions on how the research process might be improved. In particular, respondents identified considerations for researchers at the study design phase that may enhance the usefulness of subsequent findings. Multiple interviewees noted that these suggestions were not specific to Medicare-related research only.

*Choose a Policy Relevant Topic.* Respondents noted that researchers and the work they produce often seem out-of-touch with the needs and priorities of policy audiences. As evidence of this disconnect, one individual recalled his experience as a reviewer for a peer-reviewed HSR journal.

*Often I am surprised to find submitted papers that are very poorly informed about what has actually transpired in the policy world. They have their abstract little construct and their nice little models for their situations. I remember [reviewing] one paper where I wrote back and said, "This really has nothing to do with reality because Congress already did this, which you haven't addressed at all."*

-Interviewee

Other respondents expressed frustration with studies that contribute what they consider few new or meaningful insights to the current literature. One individual noted the tendency of researchers to answer obvious questions or re-churn existing knowledge, when what's most helpful to policymakers is research that advances the collective understanding of a population or issue.

*If it is reinforcing our understanding and we already know it, then I see no reason to just keep pounding on the same thing. I just don't think it's useful. There are tons of articles like that with very beguiling titles that, in the end, don't tell you a thing.* -Interviewee

In an important caveat, one respondent described the usefulness of research that updates old studies to current conditions and circumstances. He noted, for example, that it would be helpful to have recent versions of classic studies such as the RAND health insurance experiment.

In order to achieve policy relevance, respondents described the need for different “altitudes of research” to inform Medicare policy, ranging from studies that address conceptual, big-picture questions to those examining a specific policy, intervention, or technical issue. One person noted the usefulness of studies that produce specific numbers that analysts can use in assessing a given policy option.

*But it's also immensely important, in terms of evaluating...regulatory policy changes to really get down into the details. A lot of times in the literature we see these broad strokes of global evaluation, but I think we've lost a lot of the more mundane but still very useful kind of analysis.* -Interviewee

Similarly, a respondent emphasized the importance of focusing on the particular data points that drive or could drive decision-making on an issue. Citing discussions about where to place the low-volume hospital payment adjustment, one respondent described the difficulty in finding peer-reviewed studies that treated hospitals as real entities.

*I read about production functions. I read about all the problems that you have when you try to estimate a hospital cost function. But when a [Congressional] staffer asked me, “What are the pros and cons or the flaws with this kind of analysis?” there wasn't anything that was popping up [in the literature].* -Interviewee

*Do Not Underestimate the Value of Qualitative Research.* A broad cross section of respondents emphasized the value of information from qualitative research to inform policy. They described key informant interviews, document review, and similar techniques as ways to better understand quantitative results, to get a sense of what is happening in the marketplace, and to provide a window into how specific healthcare provider organizations and the individuals within them operate.

*[When trying to replicate successful Medicare pilots] more broadly, the likelihood of achieving the same results you've achieved in one place changes depending upon what the marketplace looks like...Qualitative research around market characteristics and where things are more likely to be successful is something that would be really useful.* -Interviewee

*Consider Information From Non-Peer Reviewed Sources.* Interviewees indicated that non-academic literature plays a growing and important role in the work of Medicare policy analysts, and they believe it should also be a resource for health services researchers, particularly in understanding the context or policy implications of their research. Such “grey” literature includes trade publications, topical reports from various sources, news accounts, and industry websites, among other types of non-peer reviewed information.

*In terms of just keeping current with what’s going on or anticipating what may be going on, I think you need to have a mix of everything...reading association websites and just going through their policy positions because that’s what [policymakers] are hearing and you’ve got to know where they’re coming from.*

-Interviewee

Interviewees also suggested the grey literature can have value beyond just anticipating policymaker needs. Although stakeholder reports are usually intended to bolster an advocacy position, respondents noted that they can help one understand those stakeholders’ positions and the evidence upon which they are based.

*We have stakeholders that are coming here on a more than daily basis. They give us lots of reports that they’ve contracted for and we look at them all...we take them all with a grain of salt, but the more we look, the more we have, the more likely we are to get a feel [for the stakeholders’ perspective.]*

-Interviewee

#### **IV. The Politics of Evidence and Medicare Policymaking**

The interviews underscore the importance of politics and ideology in shaping the perception and use of evidence in Medicare policymaking. Comments from respondents suggest that the political or ideological perspective underlying a piece of information affects whether and how it is used in the policy process. Grey literature – which in some forms can blur the lines between research and stakeholder self-promotion – is increasingly gaining the attention of policymakers and presenting new challenges for the analysts charged with separating evidence from opinion. Importantly, the interviews also suggest that health services researchers must consider the political feasibility of the policy options and ideas they explore if they wish for their research to be useful.

##### **Politics and Ideology Affect How Evidence Is Perceived and Used**

We asked interviewees to describe the ways in which partisanship and ideology influence the way Medicare policy audiences perceive and use HSR and other types of evidence. Some respondents described the role of politics in limiting the federal research agenda, noting that some topics are so politically charged that they are virtually off-limits to researchers who work in government. End-of-life care was repeatedly cited as one such topic. Interviewees who expressed the belief that there should be more attention to end-of-life care described the topic as too imbued with emotion to be addressed easily in a political environment.

*It's really tricky, this whole thing about end-of-life care. It's an incredibly important discussion to have, but it quickly deteriorates into, "You're rationing and you're trying not to give care to my grandmother," and that's not at all what it's about. It's a body of work that the government has a hard time doing because immediately, as soon as we start doing it, the political debate ensues.*

-Interviewee

*That whole research area [end-of-life care] really needs some work. It is so politicized, I don't think the government can fund it, but someone needs to fund it.*

-Interviewee

Respondents also pointed to political or ideological undercurrents in stakeholder reports and noted the skill of interest groups in getting their self-funded research in front of policymakers. For their part, policy analysts are spending more of their time trying to assess the value of stakeholder reports, as well as the other forms of grey literature described earlier in this report.

*It looks like it's an academic study and it looks like it could have been peer-reviewed, and in fact, parts of it might actually turn up in a peer-reviewed journal later, but then you have to spend a lot of time trying to figure out who paid for it and whose argument it supports.*

-Interviewee

*I think one thing that I have to be careful of is that there will be a piece that will appear in New England Journal or JAMA or something like that and then there will be an article written about it that will put the spin on it, and then you have to go back and figure out, did the original article actually have that spin.*

-Interviewee

Finally, interviewees noted that traditional research studies, even those appearing in the peer-reviewed literature, can also reflect a particular political perspective or unacknowledged set of assumptions. According to one individual, many research funders have a worldview that influences the types of projects they support. This worldview may ultimately distort research findings, or whether and how those findings are received in the policy and political arena.

#### **Medicare Researchers Need to Consider Political Feasibility**

Despite the importance of politics in shaping evidence use, respondents observed that health services researchers frequently ignore the political realities that are likely to influence the usefulness of their work. Multiple individuals recounted reading studies with findings that pointed to policy options that were virtually impossible in the current political climate.

*I was at a discussion the other day where a researcher said, "Well, states should just see that this is going to save them money and just do it. What's the barrier?" Politics. I think maybe researchers should take more political science classes.*

-Interviewee

Respondents emphasized the importance of considering political feasibility, both when framing research questions and describing next steps or recommendations that flow from study findings.

*Even when you're framing a research question, are you framing a policy option? First of all, are you framing something that is actionable with a policy option? Suppose you found that X is correlated to Y – is there a way to change X that is politically feasible? It doesn't mean you should never look at that particular X, but maybe you should also look at X2 and X3 because those you could more conceivably make adjustments to in policy. I think people should have more appreciation for the dynamics of what's politically feasible.*

-Interviewee

*There are a lot of good ideas on how the health care system can be reformed, but I think the biggest question is, how do you get there in our current [political] environment?*

-Interviewee

## V. Working with Policymakers

Respondents' proximity to both the Medicare policy and research communities makes them uniquely positioned to offer practical advice to researchers interested in more effectively working with Medicare policymakers. Comments from respondents highlighted the barriers, pitfalls, and missed opportunities that frequently keep health services researchers from producing useful information that is available at the time policymakers need it and in a format they understand. Importantly, respondents also offered advice about how researchers might improve the timeliness of their work, establish effective working relationships with policymakers, and communicate the importance of their research in accessible, meaningful ways. As mentioned in the introduction to the Results section, these suggestions are consistent with the very large, existing literature about how to effectively make research a part of health policymaking.

### Research Needs to be Timely, Not Perfect

As respondents observed, a common frustration with health services research is the poor timeliness of study findings. They noted that research that could assist in decision-making is often not available when policymakers need it, and by the time study findings are available, they are no longer relevant.

*The standard sort of complaint is that they did a nice analysis, but it's five years out of date, it doesn't reflect current conditions, and it isn't exactly what we had in mind.*

-Interviewee

Respondents cited several factors that contribute to this phenomenon. One factor is the slowness of the research production process, which one individual noted as he described the usefulness of a non-peer reviewed information source – market analyst reports prepared for financial investors.

*I think sometimes those market analyst reports are great because their data is so much more current. We've had this discussion before. In traditional academic "lock-step," you get the data, do the research, submit it to peer review.... et cetera. That takes a lot of time. So often you're looking at a couple years at least of lag time between data [collection] and [published] results.*

-Interviewee

Some respondents contrasted the government-based health care research enterprise with innovation in other fields, particularly information technology. One respondent noted that industries embracing a more flexible research environment are better able to push the bounds of current knowledge and turn results around quickly<sup>15</sup>.

*I'm not sure that disruptive innovations can really flourish when we have a giant bureaucracy that says, "It has to be this way. These are our rules."*

-Interviewee

Citing another factor influencing the timeliness of study findings, respondents noted that incentives for academic promotion and tenure tend to reinforce traditional means of disseminating research findings, sometimes at the expense of alternative, potentially faster approaches.

*The career track for research is not rapid learning research. The system is a reward to other things rather than the speed of research results. I think our problem is that getting results fast enough has not been a priority in the research culture.*

-Interviewee

Additionally, respondents described a tendency among researchers to pursue the perfect study at the expense of producing timely findings. One person noted that while methodological rigor is critically important, the belief that there is a single "right" way to do things – for example, by way of a randomized controlled trial – can limit researchers from exploring other approaches that may produce valuable information more quickly.

As respondents observed, producing timely research to inform policy often requires working with data that is messy or incomplete – circumstances that make many researchers uncomfortable. Respondents encouraged researchers to learn to work within these constraints to produce findings that are both robust and timely.

*They have to get used to using real-time, somewhat incomplete data because we don't have the luxury of waiting for a lot of run-out in a claims data set. The second thing is to get used to the idea of doing really sophisticated regression-based analyses on a quarterly basis so that we're not just relying on quarterly snapshots of descriptive information to draw conclusions. Policymakers don't want to wait three years or four years to have information about what's working and what isn't working.*

-Interviewee

### **Cultivating Relationships with Medicare Policymakers Is Important**

Interviewees strongly encouraged researchers to be proactive in establishing and maintaining relationships with policymakers and the analysts who advise them. This may entail personally sharing the results of a research study, offering to serve as a reference in the future, or resending previous research findings at the time they are relevant to a policy debate.

*If you want to be relevant, you've got to make it possible for people to know you've got something useful.*

-Interviewee

*Really pay attention to the policy debate...more than just the broad brush strokes, paying attention to things that are coming up in hearings or from mark-up...getting a better understanding of what kinds of detailed information that [Congressional or agency] staff, who are the ones really writing the policy, need instead of just taking a shot in the dark. -Interviewee*

Interviewees also emphasized the importance of being accessible, even when questions come at the last minute or seem inconvenient.

*When somebody calls and asks you a question, don't blow them off. It may seem stupid, but it really matters. -Interviewee*

Respondents strongly endorsed fellowships and other short-term positions in state or federal government as a means for researchers to better understand how policy decisions are made and what types of information are most useful. Similarly, attending policy conferences exposes researchers to the issues people pay attention to, as well as how questions and policy options are framed.

#### **Researchers Need to Communicate Research Findings in Accessible Ways**

Although researchers are commonly encouraged to communicate research in ways that busy policymakers and analysts can quickly access and understand, our interviewees indicated that lack of accessibility and clarity remains a significant problem. They identified a number of communication strategies that could help researchers better articulate the meaning of their work and the implications for Medicare policy. A common theme was the importance of speaking the same language as policymakers – namely, by avoiding jargon and learning to describe research findings and their importance in every day terms.

*Things are almost at cross purposes because if you're an academic researcher and you're in an academic setting, you're trying to get published, you're trying to get tenure, you're trying to appeal to your peers. You speak that language, that highly-technical language, and that is not the same language that policymakers speak. -Interviewee*

Interviewees suggested that researchers produce different types of publications for different audiences. Multiple respondents suggested that for a given study, researchers produce two types of publications: 1) research articles for journal publication and 2) shorter, more speculative pieces that describe in plain language, and perhaps with well-designed charts or tables, how the study was carried out, the credibility of the results, and what can and cannot be concluded from study findings.

*If you're really trying to [reach both audiences], maybe you write things for academic journals and use whatever [terminology] academics use, but if you want to be relevant to a policy world, you have to translate that almost into a different language...it's not the same publication. -Interviewee*

Several interviewees noted the importance of clearly communicating study limitations and helping policy audiences understand their implications.

*When you think about translating research, you need to help people – the lay reader, certainly. What are the legitimate takeaway messages? What can you construe or conclude from this work, and what can you not conclude? How can you generalize from this study? Usually in a research study there is a statement that says, “We can’t generalize to any other population.” Boy, does that ever get lost.*

-Interviewee

Importantly, respondents also cautioned against becoming so caught up in methodological constraints that the potential contribution of a study is lost entirely when communicating with policymakers. One person noted that in the policy world, a researcher’s best estimate can be very helpful, yet it is difficult to encourage researchers to think in these terms.

## Conclusions and Next Steps



The results from AcademyHealth’s Listening Project underscore that the policymaking community can be a rich source of ideas for health services researchers seeking to make their research more policy relevant. Following the original intent of the project, the interviews elicited a wealth of information from policy analysts about their Medicare research needs. Not surprisingly, there are many holes in our understanding of the Medicare program and its impact on beneficiaries and providers. These gaps represent important opportunities for the producers and funders of HSR to help improve the health care system.

The interviews also show that policy analysts and other experts have important insights beyond their knowledge of specific research gaps. Their comments include concrete suggestions for researchers seeking to make their work more useful to policy audiences, from the selection of research questions to the effective communication of study findings. The interviews also suggest that cultivating relationships with policymakers and policy analysts is an ongoing process that requires time, patience, and a willingness to adapt to the more “messy” environments in which policy decisions are made.

The interviews are also valuable for what they do not include. For example, topics that respondents did not mention include the potential reform of Medicare’s sustainable growth rate (SGR), Medicare’s current fee-for-service payment of physicians, or a handful of other issues that have received recent attention on Capitol Hill. A possible explanation is that these issues are waiting on political decisions, rather than the availability of additional research.

The contribution of this report will ultimately depend on the reception and reaction it receives from the health services research community. Drawing on AcademyHealth’s reputation as a trusted convener and information broker, we will share this first Listening Project report at our 2014 Annual Research Meeting, using it as a jumping off point for a productive discussion among the producers, funders and users of HSR about the opportunities and challenges facing the field moving forward, particularly in the area of research translation and dissemination. We hope this conversation will provide an opportunity for researchers, analysts and others to reflect, expand, and even push back on the report’s key findings. Beyond this report, AcademyHealth will continue its Listening

Project efforts by engaging policy analysts and experts who focus on other areas of health policy, as well as the leadership of health care delivery systems to discern their HSR needs. Through this work, we seek to enhance the ability of AcademyHealth members and the field more broadly to effectively inform an ever-evolving health care system.

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### Endnotes

1. No participants mentioned the National Ambulatory Medical Care Survey (NAMCS), a survey of physicians and their patients’ ambulatory visits conducted by the National Center for Health Statistics, or the extent to which this data resource does or does not meet their need for information about physician practice. For more about NAMCS, see <http://www.cdc.nchs/ahcd.htm>.
2. PCORI has determined that comparative clinical effectiveness research, as defined in the Affordable Care Act (PL 111-148), does not include cost, and thus they do not fund such research. In addition, CMS is prohibited by law from using PCORI research in determining whether particular services are covered by Medicare.
3. For more details see: Law S, Flood C, Gagnon D. on behalf of the Listening for Direction III partners. Listening for Direction III: National Consultation on Health Services and Policy Issues, 2007-2010, Final Report. 2008.; Lomas J, Fulop N, Gagnon D, Allen P. On being a good listener: setting priorities for applied health services research. *Milbank Quarterly*. 2003;81(3):363-88.; O’Haire C, McPheeters M, Nakamoto E, LaBrant L, Most C, Lee K, et al. Engaging stakeholders to identify and prioritize future research needs. 2011.; Methods Future Research Needs Report No. 4 (Prepared by the Oregon and Vanderbilt Evidence-based Practice Centers under Contract No. 290-2007-10057-I.) AHRQ Publication No. 11-EHC044-EF. Rockville, MD: Agency for Healthcare Research and Quality.
4. Gold M. Pathways to the use of health services research in policy. *Health services research*. 2009;44(4):1111-36.
5. 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).
6. Recent contributions to this literature produced in the United States include: Fox DM. History matters for understanding knowledge exchange. *Milbank Quarterly*. 2010;88(4):484-91.; Fox DM. Systematic reviews and health policy: the influence of a project on perinatal care since 1988. *Milbank Quarterly*. 2011;89(3):425-49.; Jewell CJ, Bero LA. “Developing Good Taste in Evidence”: Facilitators of and Hindrances to Evidence-Informed Health Policymaking in State Government. *Milbank Quarterly*. 2008;86(2):177-208. Recent examples from the international literature include: Lavis JN, Boyko JA, Oxman AD, Lewin S, Fretheim A. SUPPORT Tools for evidence-informed health Policymaking (STP) 14: Organising and using policy dialogues to support evidence-informed policymaking. *Health Research Policy and Systems*. 2009;7(Suppl 1):S14.; Gluckman P. Towards better use of evidence in policy formation: a discussion paper. Auckland, New Zealand: Office of the Prime Minister’s Science Advisory Committee. 2011.; Lavis JN. How can we support the use of systematic reviews in policymaking? *PLoS medicine*. 2009;6(11):e1000141.; Bennett G, Jessani N. The Knowledge Translation Toolkit: Bridging the

7. Medicare ACOs include those formed as part of the Medicare Shared Savings Program, the Pioneer ACO Model, and the Advance Payment ACO Model. For more information see: <http://www.cms.gov/Medicare/Medicare-Fee-for-Service-Payment/ACO/index.html?redirect=/ACO>.
8. Because the federal government pays Medicare Advantage plans a set amount for each enrollee, there are no claims data that delineate actual services received and include some other clinical data about each enrollee. Encounter data would provide information about enrollees' actual encounters with their providers.
9. For example see: Institute of Medicine Committee on Integrating Primary Care and Public Health. Primary Care and Public Health: Exploring Integration to Improve Population Health. Washington, DC: National Academy Press, 2012. Accessed at: [http://www.nap.edu/catalog.php?record\\_id=13381](http://www.nap.edu/catalog.php?record_id=13381).
10. No participants mentioned the National Ambulatory Medical Care Survey (NAMCS), a survey of physicians and their patients' ambulatory visits conducted by the National Center for Health Statistics, or the extent to which this data resource does or does not meet their need for information about physician practice. For more about NAMCS, see <http://www.cdc.nchs/ahcd.htm>.
11. Studies to-date have usually arrived at this conclusion by eliminating other causes of cost growth. For example see: Cutler DM, McClellan M. Is technological change in medicine worth it? *Health affairs*. 2001;20(5):11-29.; Zuckerman S, McFeeters J, Fund C. Recent growth in health expenditures: Commonwealth Fund; 2006..
12. Although not 20 years old, for an example of Lubitz's research that supports the interviewee's point about the diffusion of medical services into older cohorts of Medicare beneficiaries over time, see Lubitz J, Greenberg LG, Gorina Y, Wartzman L, Gibson D. Three decades of health care use by the elderly, 1965–1998. *Health Affairs*. 2001;20(2):19-32.
13. PCORI has determined that comparative clinical effectiveness research, as defined in the Affordable Care Act (PL 111-148), does not include cost, and thus they do not fund such research. In addition, CMS is prohibited by law from using PCORI research in determining whether particular services are covered by Medicare.
14. For more on these issues see [www.edm-forum.org](http://www.edm-forum.org), the website for the AHRQ-funded Electronic Data Methods Forum.
15. HITECH does play a role in Medicare policy by creating bonus payments and penalties to Medicare and Medicaid providers to incentivize the adoption of EHRs.
16. See section III of our results for respondents' comments on the rapid-cycle research approach being used by CMMI.

## Appendix A

### Instrument Used for Semi-Structured Interviews

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1. Tell us how your work relates/related to the health care system and/or health care policy.
2. Which communities or stakeholders do/did you represent or interact with most often?
3. To what extent is/was collecting, reviewing and assessing research part of your work? How often do/did you engage in these types of activities?
4. What are the most significant issues related to Medicare costs and value that you expect to face/you expect Medicare policymakers to face three years from now? Five years from now?
5. Is there specific information related to Medicare costs and value not obtainable by policymakers (for either current or future anticipated needs)? Do you have suggestions for how to fill those gaps?
6. Does this missing information represent actual gaps in the literature or just lack of access or unfamiliarity with what already exists?
7. Are there key sources you rely on for research on the health care system?
8. Who/What do you consider trusted sources of technical information? Are there common sources you consider untrustworthy in some way? Why?
9. Do politics or ideology play a role in what evidence is used in the policy making process? In how evidence is used?
10. What do you think is the most useful format for receiving information about the results of a research study? (i.e. journal article, brief, research synthesis, etc.)
11. What can the HSR community do to promote the use of research-based evidence among policymakers?
12. What advice would you give to researchers and funders seeking to enhance the policy relevance of the research they undertake or support?
13. What didn't we ask that we should have?

## Appendix B

### Final Codebook Used to Analyze Interviews

Parent Code	Child Code	Definition
Access		Issues or research questions related to beneficiary access to care including physician willingness to take Medicare patients.
Advice		Advice to academic health services researchers seeking to improve the policy relevance of their research.
Beneficiary Behavior		Issues or research questions about general beneficiary behavior. Does not include explicit mention of how beneficiaries behave in response to cost-sharing or other benefit designs features.
Benefit Design		
	Cost-sharing	Issues or research questions related to the structure of Medicare FFS cost-sharing including deductibles, co-pays, co-insurance, out-of-pocket beneficiary spending, and proposals to restructure cost-sharing. Does not include Medicaid payment of cost-sharing or low-income subsidies (LIS) comments.
	Coverage	Issues or research questions related to Medicare FFS coverage of particular services, drugs, or devices or the process for determining such coverage.
	Supplemental insurance	Issues or research questions related to supplemental insurance for Medicare FFS including employer-sponsored insurance for working and retired employees, and Medigap. Does not include Medicare Advantage (MA), Medicaid, or low-income subsidies (LIS) comments.

## Appendix B, cont.

### Final Codebook Used to Analyze Interviews

Parent Code	Child Code	Definition
Care coordination/PCMH		Issues or research questions related to the coordination of care for Medicare beneficiaries including patient-centered medical homes (PCMH). Does not include ACOs.
CER, PCOR or CEA		Comments about comparative effectiveness research, patient-centered outcomes research, or cost-effectiveness analysis.
CMMI		Comments about CMMI, research and evaluation of CMMI innovations, or rapid-cycle evaluation as a concept.
Data and Measurement		
	Data availability	Comments about researchers' access to data, including its cost.
	EHR data	Comments about the role of data from electronic health records (EHR) in Medicare research or policy analysis.
	Encounter data	Comments about need for or uses of encounter data in Medicare research or policy analysis.
	Lab data	Comments about the need for or uses of data from clinical laboratories in Medicare research or policy analysis.
	Measurement	Comments about the measurement of quality, beneficiary wealth, or other concepts for research or management purposes.
Disparities		Issues or research questions related to health disparities among Medicare beneficiaries.

## Appendix B, cont.

### Final Codebook Used to Analyze Interviews

Parent Code	Child Code	Definition
Duals		Issues or research questions related to dual eligibility for Medicare and Medicaid including low-income subsidies (LIS)
End-of-life care		Issues or research questions related to care at the end-of-life including services provided, their costs and the Medicare hospice benefit.
Evidence Use		General comments about the use of evidence in policymaking and policy analysis (Medicare or otherwise).
Frustrations		Comments about frustrations, concerns, limitations of academic health services research for policy analysis or policy-making.
General cost and value		General comments about Medicare costs not covered by codes that refer to specific Medicare services or types of care.
Innovations		Comments, issues, or research questions related to Medicare innovation or CMMI. Does not include comments about CMMI evaluations including rapid cycle evaluation as a concept.
Market/Provider Organization		
	ACOs	Issues or research questions related to accountable care organizations (ACOs) as a concept as well as the Shared Savings, Pioneer, and other Medicare ACO programs/demos and their evaluation. Does not include general comments about CMMI research and evaluations.

## Appendix B, cont.

### Final Codebook Used to Analyze Interviews

Parent Code	Child Code	Definition
	Concentration/integration	Issues or research questions related to provider market structure including hospital consolidation, physician group consolidation, hospital purchasing of physician groups, hospital/physician integration (as a concept/trend, not ACOs), and market concentration.
	Provider internal management	Issues or research questions about how provider organizations' internal management practices.
Medicare Advantage (MA)		
	MA benefit design	Issues or research questions related to the design of MA plans including premiums, cost-sharing, supplemental benefits, MA drug benefit design.
	MA general	General and miscellaneous comments about MA.
	MA plan payments	Issues or research questions related to payments to plans except risk adjustment of payments. Includes geographic variation, plan bids, plan participation.
	Risk Adjustment	Issues or research questions related to the risk adjustment of MA plan payments. Does not include comments about the use encounter data in research and policy analysis.
Miscellaneous		Comments worth noting that do not fit in any other category.
Payment		

## Appendix B, cont.

### Final Codebook Used to Analyze Interviews

Parent Code	Child Code	Definition
	Bundling	Issues or research questions related to bundling as a concept as well as bundling demonstrations and their evaluation. Does not include general comments about CMMI evaluations or rapid cycle evaluation.
	P4P/Value purchasing	Issues or research questions related to pay-for-performance (P4P) as a concept as well as specific P4P programs including PQRI, physician value payment modifier, Medicare non-payment for readmissions. Does not include Shared Savings Program or other ACO demos.
	Payment General	General comments about Medicare payment not specific to one of the other codes.
	Prospective payment systems	Issues or research questions related to any current prospective payment system not addressed by other codes including payment issues for hospital inpatient and outpatient services, post-acute care, and physician services. Does not include Part D or Part B drugs.
Pharmacy		
	Part D	Issues or research questions related to Part D benefit design, payment, program spending, stand-alone Part D plans, coverage/use of brand versus generics, and pharmacy networks.

## Appendix B, cont.

### Final Codebook Used to Analyze Interviews

Parent Code	Child Code	Definition
	Pharmaceuticals/Pharmaceutical management	Issues or research questions related to poly-pharmacy, drugs in development, general role of pharmaceuticals in health care, management of drug therapy, pharmaceuticals and health outcomes, and issues related to Part B-covered drugs and drug administration.
Politics/Ideology		Comments about the role of politics and ideology in Medicare policy making and policy analysis.
Post-acute care		Issues or research questions related to post-acute care other than payment-related issues.
Program integrity		Issues or research questions related to program integrity, waste, fraud, or abuse.
Qualitative research		Comments about the role of qualitative research as it relates to Medicare.
Quotes		Text from interview we may want to reproduce as quotes in the report.