



## A Call to Action: Addressing Research Gaps to Provide Better Healthcare Value for Consumers

As policymakers, academics and other stakeholders focus on ways to extract better value from our healthcare system, it is critical that we recognize where our knowledge is insufficient to incentivize change at the pace and with the certainty that consumers need.

This report describes some of the specific gaps in our knowledge base that prevent us from getting to a system that delivers the right healthcare, at the right time, at the right price. Despite the myriad activity by payers and efforts of researchers, there are many areas where the evidence for or against interventions is inconclusive, key data are missing and an overarching research framework is absent. What's more, one of the most greatly contested areas is the very definition of value in healthcare.

### SUMMARY

This report describes some of the specific gaps in our knowledge base that prevent us from getting to a system that delivers the right healthcare, at the right time, at the right price. To learn where these gaps exist, we interviewed 14 researchers working in health services research and closely related fields.

Gaps in the evidence can be hard to see yet have a profound effect on the slate of strategies being considered by policymakers and other stakeholders and the types of research that get funded. We call upon researchers, funders and other stakeholders to establish and execute on a national agenda to fill gaps in critically needed evidence with respect to practices and policies that increase healthcare value.

To learn where these gaps exist, we interviewed 14 researchers working in health services research and closely related fields. While the researchers universally agreed that we do not have enough evidence to get to healthcare value, there was a diversity of opinions about where these gaps lie. Several respondents, though by no means a consensus, assigned high priority to defining what we mean by “value,” identifying which healthcare services are valuable and which are not, and determining how to overcome resistance from providers that provide low-value care.

This report details the discussion around these research gaps and needs. The report also captures lively discussion about other types of barriers that keep us from getting to better healthcare value.

The researchers universally agreed that we need to be smarter about the types of research we fund and conduct. The lack of complete consensus around the highest priority items reinforces the need for some foundational work to establish an overarching infrastructure for this type of research and further clarify our goals.

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### Introduction

Steep year-over-year increases in health spending and uneven quality, outcomes and patient experience have plagued our country for many years. Fortunately, many stakeholders are beginning to coalesce around tackling the issue of low-value health care, with more and more

attention being paid to a wide range of possible remedies.<sup>1</sup>

What is missing from our approach is a systematic understanding of where evidence is lacking and a framework for prioritizing how we fill those gaps.

To begin to address this shortcoming, we held informal interviews with 14 prominent researchers in the field of health services research and related fields and asked them questions such as:<sup>2</sup>

- Do we have sufficient evidence to address our healthcare value problem?
- If not, what are the most important evidence gaps to address?
- Besides targeted funding, what other types of resources are needed to address these gaps?

Our goal is to jump start an important conversation that must be part of our overarching approach to addressing the healthcare value problem: recognizing, categorizing and prioritizing evidence gaps that need to be filled.

## What is an Evidence Gap?

A research or evidence gap is defined as a topic for which missing or insufficient information limits the ability to reach a conclusion for a question. A research *need* is defined as a gap that limits the ability of decision makers (policymakers, consumers, practitioners) to make informed decisions on matters of importance.<sup>3</sup>

It's worth noting that many of our interviews with researchers started with a need to describe the key challenges that face the healthcare system today. This important exercise will undoubtedly be part of the future conversations as well. But as our summary below illustrates, a system problem is not always related to a lack of evidence.

## Gaps are Hard to Pin Down

Despite the collective wisdom of our interview group, many of our respondents struggled with basic question at the core of this report. It is notoriously difficult to ask people to step outside of what they know and to think about what they don't know. This thought exercise requires the adoption of a framework larger than what they know—only then can one begin to “see” what's missing. In order to find and articulate

evidence gaps, researchers needed to see the “big picture” by viewing their own work in the context of the larger health policy framework.

Since this report is the first to take a broad look at healthcare value research gaps, we captured the totality of responses without trying to restrict our interviewees to certain topics.<sup>4</sup> We freely acknowledge that the responses we received were likely biased by respondents' current and future research interests and by the fact that, as one respondent noted: “We don't know what we don't know.”

By casting a wide net, we can begin to identify the range of research gaps. Our hope is that researchers and funders will use this knowledge to prioritize their agendas toward activities that produces a system in which patients get the right care, at the right time, at the right price.

## What is Value in Healthcare?

We did not provide participants with a definition of healthcare value for the simple reason that healthcare value nomenclature could itself be an evidence gap.

Respondents agreed that different stakeholders have different opinions about what exactly constitutes value in healthcare, not to mention the strategies we should pursue to reach it. Almost all viewed this as a fundamental problem.

Respondents had a variety of opinions about whether a universal definition of healthcare value—a taxonomy—could improve our ability work across stakeholders and whether this constituted a research gap.

For a few respondents, lack of consensus about what is meant by value was the most significant issue of all.

- *We have no definition of value, and certainly none that speak directly to consumers.*
- *With no definition of value, how can we know what evidence we need if we don't know what we're measuring.*

Value means different things to different people. The short hand is price combined with quality. Price is hard enough but quality is multi-dimensional. We need to pick the concepts, not the words. We're not far off. Need to agree on what it really means.

But not all researchers agreed that a concise definition

would be particularly useful. A few participants argued that it was completely unnecessary since the primary drivers of value such as cost and quality are broadly understood, if not clearly defined.

- *...pervasive, but not super important. People often don't use terms very rigorously.*

Most agreed this is an important problem, but respondents differed with respect to how best to solve it.

One felt the issue was inherent to the variety of actors in the healthcare system and that it was not necessary to reconcile different definitions as long as there was consensus when groups were working together.

- *Value is difficult to accomplish in a consensus way - has to do with different disciplines. Value to an economist always has cost embedded in it -bang for the buck. Physicians think about value without having money in the equation. We need both perspectives. Don't try to reconcile. But within a discipline, we can darn well agree on how to measure it.*

Several didn't think this qualified as a research gap. It is more of an activity gap—in other words there were non-research ways to address it.<sup>5</sup>

- *It is a problem. Not a research gap. It is best resolved by getting a wide range of stakeholders and thought leaders into a room to come up with a nomenclature.*

But for a few, this was a gap that research could address.

- *No one has rigorously studied what stakeholders mean by value.*
- *Research useful to find out if there is or isn't consensus within a stakeholder group. And is the remaining variation manageable?*
- *Value is hard. You can do work that helps illuminate the different aspects of value. For example, how satisfaction relates to clinical outcomes. Pick a specific measure and do work to resolve issues.*

Despite a lack consensus on what healthcare value means and a diversity of view on next steps, there was

broad agreement that our country needs to lower costs, increase quality, and improve patient experience.

## Lack of Evidence to Address Healthcare Value

The only area of complete consensus was that our knowledge gaps are great enough to prevent us from having a system that delivers the right care, at the right time, at the right price.

This consensus went far beyond the basic tenet of researchers that there's always more to learn. Rather, the researchers we interviewed felt that there were large, fundamental gaps in our knowledge base that are preventing us from moving forward with certainty with respect to results we can expect from the interventions that might get us to better healthcare value.

Beyond this, interviewees had a diversity of opinions about where these specific gaps existed, which were most important and what contributed to the gaps. Further, they also said that knowledge gaps are not the only barrier to getting better healthcare value for consumers—as discussed in a later section.

## Evidence Gaps Run the Gamut

Many participants identified gaps in what we know about the various reforms and current strategies that aim to improve healthcare value,<sup>6</sup> starting with the simple observation that for many of these strategies the evidence is mixed. Without knowing which interventions are most effective, it is difficult to chart definitive policy prescriptions moving forward.

- *We don't really know which interventions lead to best possible outcomes.*

Respondents' comments revealed quite a few differences with respect to the reason for ambiguity around strategies:

- *Much going on to promote value. We need to simply evaluate what we're doing.*
- *We need more granular evidence as to why successful interventions succeed. What are the marginal contributions of individual elements in practice transformation?*

- *We need to uncover why we get different results—sometimes a weak signal; sometimes methodological.*
- *Payment models are just a part of the solution. We don't have good information about how to get systems to do population health planning and population health approaches.*

How to approach the issue of incentives (broadly defined) was mentioned often:

- *We know incentives matter. We don't know what else matters as much or more. And how those differ between clinician and patient.*
- *Incentives matter, but how do we leverage this info? Financial incentives may be over emphasized and providers may respond better to other incentives, like aids that help them do the "right thing."*
- *We need to learn more about the use of nudges—behavioral economics—and apply to healthcare.<sup>7</sup>*

The emphasis our respondents gave this topic suggests that getting to more definitive information about the interventions that work is a high priority and also very "doable." However, more than one respondent noted that the inconsistent rigor and quality of studies often hampered their usefulness.<sup>8</sup>

- *The way to do this is to do higher-quality studies. We are using inadequate methods, not control groups. And there's a rush to study something new quickly before it's had a chance to realize its potential.*

## Foundational Evidence is an Acute Need

While getting better studies on the interventions that work was an important focus for these discussions, participants identified several other critical needs that underlie efforts to get to better healthcare value.

### Availability of Data

A critical gap is the limited availability of raw data. Rich data sources are the foundation of good research and informed policy.

While not strictly a research gap, many respondents

cited missing or inaccessible data as one of the most important barriers to research that can address healthcare value. As one respondent put it: "If you have data, you can find funding and you are able to publish."

- *Limited data is the biggest problem that we have.*
- *Amazing to learn how little data health services researchers, health economists and clinical researchers have to do their jobs. Our problem is not lack of interest, funding, or importance, it's data.*

These data gaps were many and diverse. The most common complaint was a lack of privately insured claims data. The majority of Americans have private health insurance, but researchers and policymakers rarely have access to this treasure trove of information. Respondents noted:

- *Private claims data is rarely accessible to researchers.*
- *Claims data for the under 65 and the post-65 Medicare Advantage population. How can CDC monitor healthcare without these data?*
- *Nearly impossible to get good claims or encounter data that identifies providers and place of residence.*
- *Pricing data is a big gap—we simply don't know what hospitals and others are paid for their services.*
- *Commercial claims data is proprietary. If you want to analyze payment rates in the commercial sector, the data is fragmented and too expensive.*

Many respondents used Medicare as a yardstick. While far from complete, the Centers for Medicare and Medicaid Services (CMS) releases a significant amount of de-identified claims data. In contrast, this type of data is rarely available for the non-Medicare population. While some states have developed all-payer claims databases in order to bolster their own data sources, such data sources are still relatively few and far between.

- *The federal government has made progress liberating data but Medicaid data is so far behind Medicare data. It's way behind where it needs to be. Not just "free" the data but*

*invest, improve and get it out.*

Several respondents made references to the fact that private companies treat claims and health data as proprietary assets. One respondent argued that since taxpayers indirectly support the market for private insurance,<sup>9</sup> researchers should be able to study claims data on behalf of the common good—otherwise we don't know if we are getting good value for our tax dollars.

But the data needs go beyond claims data:

- *Claims data have inherent limitations. Can't indicate diagnostic errors (believed to occur 10-15% of time).<sup>10</sup> This means we have a huge bias in the performance measurement world.*
- *Data on medical harm—the system doesn't include diagnostic harms and only measures harms in hospitals. Numbers come from reviews of medical records.*
- *Improved electronic health records [EHRs] could fill in some gaps. De-identified EHR data would be even more important, especially if linked to claims and provider characteristics. But using templates in EHRs for purposes of data aggregation forces mistakes—lose granularity.<sup>11</sup>*
- *There's little value in measuring care at large levels. It's not actionable and not useful for identifying the cause of problems. The National Center for Health Statistics has very good datasets but very difficult to access, In contrast, Medicare makes equally sensitive data more available.*
- *Data from other sectors, for example, data from juvenile justice system. Younger people with mental health issues disproportionately end up in the justice system.*
- *Longitudinal data is lacking. We don't follow individuals over time.*
- *EHR data could help us know what works. Would help with comparative-effectiveness gaps. But incompatible EHRs are a real problem.*
- *Registry data look at differences in behavior and effectiveness of different approaches. Medical harm is a gap that could be addressed using registry data.*

- *Need to align diverse datasets in a new ways. For example, traffic patterns. If we could follow up on a 911 call we could learn where to locate particular services.*

There was widespread agreement that much of this data exists, it is simply inaccessible. But some critical data—like longitudinal data—aren't even being collected.

One respondent provided this useful caution: “Data gaps should not be a separate category in the absence of a research question.”

### Comparative Effectiveness Research

Comparative effectiveness research (CER) is meant to determine how well alternative medical treatments work. Surprisingly, the Institute of Medicine estimates that more than half of the treatments delivered today are without clear evidence of effectiveness.<sup>12</sup>

This type of research forms the basis for interventions that might change provider or consumer behavior. In essence, it defines our desired endpoint. Despite its importance, many respondents identified the lack of robust comparative effectiveness research as a critical evidence gap.

- *Comparative effectiveness research is a critical gap that needs to be filled.*
- *It's a tragedy that we can't do cost-effective research.*
- *The lack of comparative effectiveness research takes large areas of medical delivery away from our ability to influence. We need a better base of effectiveness data.*

A closely related topic is being able to label services and treatments as low-value or high-value. More than one respondent lamented that we know too little about what is high value or low value. One respondent believed we are better on knowing—and stating—*what to do* compared to knowing *what not to do*. Another gap this respondent identified is the value of surgical treatments.

And yet several respondents offered words of caution:

- *Don't go overboard—CMS no longer has the will or resources to do good coverage policy because it keeps getting rolled by Congress.*

- *Comparative effectiveness is a second order problem. First we must know the value end-point we're looking for.*

### Better Patient and Provider Communication

Many respondents discussed the absence of data on how to communicate information about high- and low-value treatments to patients and providers as a critical, foundational research gap.

- *How do we communicate the issue of over-utilization?*
- *We don't design quality measures that consumers will use.*
- *We have a major communication challenge—how to talk to people (all stakeholders) about quality.*
- *What is the best way to engage consumers? And how to take consumer diversity into account?*
- *How people actually make decisions in the healthcare marketplace. Not simple. Using right brain psychology, for example, people assume high price means high quality.*
- *The doctor-patient interaction is critical to getting good outcomes.*
- *No strategies to overcome barriers to discussing value in patient/provider conversations.*

### Other Foundational Research Gaps

While they merited far less discussion, two other foundational gaps were mentioned:

- *We don't know how to do risk adjustment correctly. The more promising outcomes measures need to be careful of patient risk status. We have a responsibility to do a good job at risk adjustment.*
- *How do we balance the need to innovate with the need to make things affordable?*

## Quality Measurement Touches Almost Everything

Researchers identified quality measures as a key component of value that needs additional research.

They noted that quality is inherently subjective and will inevitably be defined differently by stakeholders. Furthermore, many noted the multidimensional (sometimes referred to as multifactorial) aspect of quality: cost, convenience, comfort, and other factors determine the perception of quality. Therefore, quality, like value, can be hard to define with simple metrics. The difficulty in bridging various conceptions of quality may be a fundamental impediment to providing it. In their own words:

- *Quality is subjective. The goal of a medical intervention is different for different people. A physician's idea of quality can be different from the patient's. We need to look at various measures like satisfaction and happiness. We can do a lot better than we're doing now to measure and put numbers on this.*
- *We don't know the relationship between what we measure and getting better outcomes. Many of our measures are to ensure we don't skimp on care, as opposed to get better outcomes.*
- *The pathway from measure to outcome can work in a number of different ways. We will need multiple systems because we will have multiple goals/needs (providers vs consumer, health plan vs cancer care).*
- *Not one size fits all, plus constrained by available data. Further, different audiences need different things. Consumers want a summary but providers need detail.*

Many participants focused on the need for research that would contribute to patient-informed measures, as well as measures that would actually be used by patients.

- *What are the best ways to engage consumers?*
- *We need research on the best consumer measures that actually align with better quality.*
- *It would be great to have a better understanding of consumer resistance to quality information.*
- *We don't know what consumers want the healthcare system to do for them. While we've gotten better at assessing*

*clinical quality of services, we're missing the "big picture." For example: paying for appropriate diagnosis or [signaling] sympathy for their problem. We need a broad view.*

But other stakeholders were also included in the list of quality-related research gaps:

- *What happens if we feed quality data in a systematic way to primary care providers—for referrals, not their own behavior? We don't know what will happen.*

Some respondents envisioned a path forward that included:

- *We know some providers produce better outcomes. Study those providers to gain a better understanding how they do it.*
- *Better systems for measuring quality. A system has motivation for why you're measuring quality, recognizes that there is noise in measurement and allow signals to serve as proxies for other measures.*

## Disconnected Financing

Many respondents mentioned the importance of social determinants of health—issues such as housing and income—that fall outside the realm of medical care and yet have a tremendous impact on health. Financing streams for programs that influence social determinants are often separate from those that finance medical care. For instance, Medicaid and the U.S. Department of Housing and Urban Development may serve the same individual and yet fail to coordinate in any meaningful way.

Respondents felt that financing silos are another factor inhibiting our ability to realize better outcomes. One respondent cited this as our largest research gap and almost all respondents felt that it was a real problem, in some cases a huge problem.

- *The biggest gap is looking at non-medical factors and how health services can better connect with services that address housing and education. We spend more on medical to achieve health outcomes than on social services. How do we align our financing system?*

- *We need entities that are accountable for this. How do you imbue a culture of population health and move resources to a more effective uses?*
- *We need creative financing that allows new forms of capital to come in.*
- *We don't measure the social benefit of a health intervention. For example, if an asthma program enables kids to stay in school what are the longer-term impacts? Increased chance they go to college? How we measure this is pretty primitive.*
- *Research can help us better understand the magnitude of the problem.*
- *We need to expand the notion of what health is to allow more flexibility in the system—better evaluations of projects like the duals demonstrations.*
- *Funding silos are a big problem. Example: If food stamps don't provide enough food to someone then, for example, diabetics can end up hospitalized because of low blood sugar.<sup>13</sup> There are unintended consequences of limited social spending.*

A related research gap identified by one respondent is the geographic connection between medical and social services. The respondent described an ongoing study in Arlington County, Virginia to understand the use of EMS equipment—where are they used, travel times, the locations of 911 calls. Are pharmacists available where they are needed? What is travel time to get these services?

But not all respondents agreed that our financing disconnect was an evidence gap. For several, it was a problem of political will.

- *The larger barrier is politics related to the distribution of funds. It is a problem that deserves attention but may not be an evidence gap.*
- *We arbitrarily determine some things as healthcare and others not. Don't know how research would change that.*
- *Funding silos are driven by statutory authority. We need to change dysfunctional governments at all levels.*

One respondent speculated that better evidence on the

payback from social service interventions could overcome a lack of political will.

Another aspect of the financing disconnect is whether we're trying to achieve short-term versus long-term goals.

- *The potential exists in the near term. But it's more of a problem in the longer term. We don't have the stability in people's insurance coverage to capture future savings.*
- *It is a real problem. If more than one year we can't use global capitation or community-based ACOs. We need an entity responsible for the actual health of the population. Other countries do it this way. For example, the Australia's Ministry of Health is at risk for health spending over time.*

One respondent suggested focusing on opportunities that don't have this time dimension: "We should focus efforts on short term, because we're not close on long term."

The other challenge that was surfaced is that success in getting people healthier might not save money. While researchers debate the best way to measure this, finding long-term savings to pay for early interventions is not assured.

## Other Missing Elements, Though Not Evidence Gaps

Respondents were asked—besides research funding—what else is needed to close research gaps? One respondent succinctly answered: "Funding and data are enough. If it's publishable, we're good."

But several respondents described other gaps that are important but do not constitute a lack of evidence.

### Stronger Evidence Standards Needed

Many respondents pointed to the need for additional rigor and better quality studies to reduce our knowledge gaps:

- *Reports that aren't well done are taken as evidence.*
- *We have a lot of cooked evidence—making it up and claiming it is evidence. This also applies to the mis-use of evidence.<sup>14</sup>*
- *We need to be able to score evidence.*

- *Meta analysis is very important because many are natural experiments and not rigorous enough.*
- *We might be looking at the wrong data. I debate on the usefulness of claims data; it doesn't give us the clinical side and even EMRs may miss this information. We need other data to figure out what constitutes low- and high-value care.*
- *Research has to be very clear about the study design. Otherwise you run the risk of comparing apples and oranges. Need a control group.*

One respondent went further:

- *Our single biggest problem is a research infrastructure gap. The biggest killer in America today isn't stroke or heart disease, it's why can't we do evidence-based policy. Funders bounce around. Why? We don't have a conceptual model for what the problem is that enables us to tackle problems systematically.*

Pragmatically, some felt that myriad efforts are worth piloting even with imperfect evidence, so long as they do not inflict damage on consumers. One respondent encouraged trying many interventions—enough to get a pattern of information. He noted that trial and error are the best we can do the early stages, but we also don't have well-designed research and analysis to evaluate the results.

The challenges to improving this type of research were also raised:

- *The basic flaw of normal regression to the mean undermines many of these studies. High-cost patients don't stay high cost in year two even if you do nothing.*
- *Requirements of random controlled trial are costly and can slow down the acquisition of knowledge. We have a structural problem. How do you finance the collection of adequate information, then do the larger scale research?*

## Activity Gaps

Our discussions with researchers provided an important nuance about the activities that must accompany the

closure of research gaps in order to turn research into action. We call these the “activity gaps.”

- *Unfair to ask research to provide an exact recipe. The cook matters.*
- *People are looking for simplistic answers to very broad questions. Can't be done.*

Almost all respondents mentioned political will as an impediment to getting to better healthcare value. Several researchers argued that this conversation must also acknowledge that there are gaps in policymakers' ability to pass evidence-based policies. Many policymakers know the right things to do to reduce cost and increase quality but are unwilling or unable to implement these policies.

- *How much more do we need to know about poorly aligned incentives? What is the marginal information in doing more of this work? More important: with this knowledge, how do we create change?*
- *Sometimes we can't deal with the tradeoffs.*
- *Translating research into practice is a big need.*
- *If Medicare doesn't come down hard on prices, private insurers don't have wiggle room.*

Other activities that were identified include:

- *We need some strategic direction—CMMI just tries everything to see if it sticks. Need a balanced group of smart people to provide direction.<sup>15</sup>*
- *We need more cross-fertilization across disciplines/stakeholders. The RWJF meeting on culture of health was inspirational. More of this would be beneficial.<sup>16</sup>*
- *Partnerships among stakeholders; large payer willing to participate.*
- *Engage with insurers. Need managed care companies in the game.*
- *Physicians willing to try new approaches. But there is physician resistance.*

- *Willingness of people to have their programs evaluated.*
- *Changing laws to get rid of barriers to value-oriented purchasing.*
- *Distinguish between gaps in literature vs attention.*

### Are We Missing Strategies to Address Some Issues?

We speculated that a type of research gap might consist of areas where our tool set is simply too small. Examples might include addressing provider shortages or devising strategies that still work when a provider or other entity has considerable market power.

Mostly, this did not ring true with our respondents:

- *We've known for a long time how to address the issue of doctor shortages in rural areas, such as changes to scope of practice laws and telehealth.*
- *Provider market power. We have tools for when providers are highly concentrated, such as narrow networks and tiered networks.*
- *There are strategies to deal with monopoly power.*
- *There's a strategy for everything.*

But for a few these loomed as real problems:

- *There isn't a price high enough to get providers to practice in certain places.*
- *We need research into regulatory options when there's no competition.*

### Which Gaps Are Highest Priority?

Respondents were asked to single out the most glaring gaps in our first open-ended interview question, and again at the end. They were asked: “If you had all the funding you needed, what healthcare value research would you conduct over the next two years?”<sup>17</sup>

Reflecting the real world complexities of addressing this policy problem and the diversity of personal views, our exercise did NOT result in a consensus list of the most important gaps.

However, a few broad themes were mentioned by respondents. As one respondent put it: “Identifying which healthcare services are valuable and what we mean by value. Then, how do we overcome resistance from those that provide low-value care?”

Many of the respondents mentioned an aspect of this basic trio: 1.) How do we define value, 2.) What services are low and high value and 3.) How do we overcome resistance to change?

- *Defining what we mean by value.*
  - *Comparative effectiveness research so that dollars spent on healthcare are not squandered.*
  - *The ability to measure performance accurately.*
  - *Focus on overuse. How to measure and communicate the implications of overuse of low-value services. We don't know if overuse is being driven by patients or providers.*
  - *How to do value-based decision making well with input from the patient and provider.*
  - *How to engage patients to help them become partners in their care. How to get people to shop with much better consumer-facing quality measures. If providers know that patients might shop around, it might lead to better value.*
  - *Aligning quality measures with physician perceptions of quality.*
  - *What to tell a physician about how to deliver [economists' view of] value from small primary care to big systems.*
  - *We need to address physician burn-out rate and help them be successful in new value-based payment systems.*
  - *Focus on removing disincentives. Make physicians less responsive to financial incentives and instead on intrinsic motivation.<sup>18</sup> If you can get just as much value from existing payment models, why invent new ones?*
  - *More granular evidence as to why successful interventions work. Marginal contributions of individual elements of practice transformation.*
- Many of the other topics identified as highest priority also touched on new themes:
- *We don't know what works at the community level.*
  - *Measuring how non-medical interventions influence healthcare in the long term.*
  - *How to provide higher quality care to vulnerable populations. While coverage is important, better-quality care is the mechanism to better health. We've emphasized the financing but not the care.*
  - *How to integrate behavioral and acute in primary care practices.*
  - *How to provide patients with a better understanding of their health insurance choices.*
  - *We don't know how to do value-based insurance design.*
  - *Need to know more about the imprint of medical training on future practice patterns.*
  - *Women's reproductive health. We have insufficient focus on early determinants of perinatal outcomes, high prematurity rates and high rates of unintended pregnancy.*
  - *Newborn health. We need to tackle high neonatal and infant mortality due to low birth-weight and inadequate access to women's healthcare. Care of newborns in the NICU is the most expensive hospital episode in the non-Medicare population and we have no information on quality of these units or the under/over use of services.*
  - *Medicare advantage. We spend a lot of money on these plans, and while there is data available these plans are understudied.*
  - *Provider pricing. We lack a good understanding of the prices charged by hospitals, physicians and other providers. Why are these prices as high as they are and what can be done to get to lower prices?*
  - *Market power. Develop feasible public policies to take on the issue of market power.*

## Conclusion

All participants in this project agreed that there are gaps in our knowledge base that pose a significant barrier to getting to better healthcare value. In light of the consumer harm from overpaying for healthcare, lack of transparency and other problems,<sup>19</sup> it is unconscionable that we do not have an overarching structure for recognizing, categorizing, prioritizing and addressing the gaps in our evidence.

We call upon funders—foundations, government entities and others—and researchers to continue this conversation around research gaps. As prior collaborations have shown, it is critical that consumer advocates be part of that conversation to include patient and consumer perspectives. We issue this call to action in order to provide consumers with better value for their healthcare dollar, because healthcare is one of the most important purchases we make.

The diversity of opinions expressed suggests that it will not be simple to impose an overarching framework or infrastructure to address evidence gaps. An early conversation may need to explore the feasibility of an improved research infrastructure, along with clearer rules for the type of evidence needed, as suggested by several respondents.

To put it succinctly: We don't know everything AND we don't have consensus.

Respondents emphasized that filling these research gaps will be insufficient in and of itself. Getting to better healthcare value for consumers will also require achieving consensus around what our goal is and mustering the political will to head towards that goal. What's more, we need increased attention to the ancillary activities that enable research (like data availability and defining research standards) and the activities that turn research into action.

- *There's a lot we know already but need to act upon it.*
- *We are horrible at scaling and replicating innovations. We know what it takes to improve. We just don't do what we need to improve. We don't need to know more, we need to do more.*

As policymakers, academics and other stakeholders continue to hone their focus on value in the healthcare system, it is critical that we acknowledge the evidence gaps that currently exist, while heeding the wise advice of our respondents to also address the other types of gaps (activity, research standards and other) that slow our progress towards better healthcare value.

## Notes

1. For an overview of these interventions, please see: [www.healthcarevaluehub.org/files/7714/2860/6607/Strategy\\_Infographic.pdf](http://www.healthcarevaluehub.org/files/7714/2860/6607/Strategy_Infographic.pdf)
2. A list of participants is included in Appendix A and a fuller description of our methodology in Appendix B.
3. Adapted from Robinson, Karen, et al., *Frameworks for Determining Research Gaps During Systemic Review: Evaluation*, Methods Research Reports, AHRQ Publication No. 11 (February 2013).
4. Our methodology is described in Appendix B.
5. Activity gaps are described more fully in a later section of this report.
6. There are myriad strategies that have been proposed to improve healthcare value, from provider payment reforms to transparency measures to new systems for delivering care like Accountable Care Organizations and Patient Centered Medical Homes. For an overview of strategies, please see: [www.healthcarevaluehub.org/files/7714/2860/6607/Strategy\\_Infographic.pdf](http://www.healthcarevaluehub.org/files/7714/2860/6607/Strategy_Infographic.pdf).
7. This respondent specifically mentioned the following study as an example: Castleman, Benjamin, and Lindsay Page, "Summer nudging: Can personalized text messages and peer mentor outreach increase college going among low-income high school graduates?" *Journal of Economic Behavior & Organization of Education*, Vol. 115, Issue C (2015).
8. In a following section, we describe respondents' ideas for additional rigor.
9. The tax treatment of Employer Sponsored Insurance subsidizes the provision of private coverage by

exempting this form of compensation from federal income taxation. This is the largest tax break in federal tax code, exceeding what we "spend" on mortgage deductions. In addition, private Medicare Advantage plans receive federal funding. Finally, most individuals purchasing private coverage through an exchange receive a federal tax subsidy.

10. We could not confirm this frequency. A somewhat lower frequency was reported here: Singh, Hardeep, Ashley Meyer and Eric J. Thomas, "The frequency of diagnostic errors in outpatient care: estimations from three large observational studies involving US adult populations," *BMJ*, Vol. 23, No. 9 (September 2014).
11. This respondent was referring to the absence of free text options in EMR, sometimes forcing inaccurate information into the record.
12. Institutes of Medicine, *Learning What Works: Infrastructure Required for Comparative Effectiveness Research: Workshop Summary* (2007).
13. Seligman, Hilary, et al., "Exhaustion of Food Budgets at Month's End and Hospital Admissions For Hypoglycemia," *Health Affairs*, Vol. 33, No. 1 (January 2014).
14. "Why Medicare Advantage Plans Pay Hospitals Traditional Medicare Prices," *Health Affairs*, Vol. 34, No. 8 (August 2015).
15. *The Center for Medicare and Medicaid Innovation: Activity on Many Fronts*, The Urban Institute and

Robert Wood Johnson Foundation (February 2012).

16. *Building a Culture of Health: A New Imperative for Business*, Robert Wood Johnson Foundation, Harvard Business School, and Harvard T.H. Chan School of Public Health, Boston, MA, (April 18-19, 2016).
17. Our methodology is described in Appendix B.
18. Rice, Thomas, and Robert Berenson, "Beyond Measurement and Reward: Methods of Motivating Quality Improvement and Accountability," *Health Services Research*, Vol. 50, No. S2 (November 2015).
19. Healthcare Value Hub, *Why are Health Care Costs an Urgent Problem?*, Easy Explainer No. 2 (May 2015).

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**ABOUT THIS SERIES**

The Healthcare Value Hub takes a careful look at the evidence and consults with experts in order to clarify for advocates, media and policymakers the important cost drivers and the promising policy solutions. Hub Research Briefs, Easy Explainers, infographics and other products are available at our website. Note: This publication was produced when the Healthcare Value Hub was affiliated with Consumer Reports. As of July 1, 2017, the Hub is part of Altarum Institute.

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## Appendix A: Respondents

While our report does not attribute quotes and views to any specific individual, those that participated in our project gave us permission to list them. We are grateful they shared their opinions and insights.



**Robert Berenson, M.D.**, is an Institute Fellow at the Urban Institute where he conducts research and provides policy analysis on healthcare delivery issues, particularly related to Medicare payment policy, pricing power in commercial insurance markets, and new forms of health delivery based on reinvigorated primary care practices. In 2012, he completed a three-year term on the Medicare Payment Advisory Commission and from 1998 to 2000 he was in charge of Medicare payment policy and private health plan contracting at CMS.



**Stuart Butler, Ph.D.**, is a Senior Fellow at the Brookings Institution. He is also currently an Adjunct Professor at Georgetown University's McCourt School of Public Policy and a Visiting Fellow at the Convergence Center for Policy Resolution. Prior to his current position, he spent 35 years at the Heritage Foundation. He is a member of the editorial board of Health Affairs and played a prominent role in the debate of healthcare reform.



**Michael Chernew, Ph.D.**, is the Leonard D. Schaeffer Professor of Health Care Policy and the Director of the Healthcare Markets and Regulation (HMR) Lab in the Department of Health Care Policy at Harvard Medical School. Dr. Chernew's research activities focus on several areas, most notably the causes and consequences of growth in health care expenditures, payment reform, and Value-Based Insurance Design (VBID).



**Adams Dudley, M.D., M.B.A.**, is a Professor of Medicine and Health Policy and Director of the Center for Healthcare Value at the Philip R. Lee Institute for Health Policy Studies at the University of California, San Francisco. His research focuses on improving the quality and value of care while reducing harm and waste. He is co-founder of the California Hospital Assessment and Reporting Task Force (CHART) and currently leads California's initiatives to establish price transparency and an all payer claims database.



**Austin Frakt, Ph.D.**, is a health economist and researcher; the creator, co-manager, and a primary author of The Incidental Economist; and a regular contributor to The New York Times' The Upshot. He has educational background in physics and engineering. After receiving his PhD in statistical and applied mathematics he spent four years at a research and consulting firm conducting policy evaluations for federal health agencies.



**Paul Ginsburg, Ph.D.**, is director of the Center for Health Policy at the Brookings Institution. He is also the Leonard D. Schaeffer Chair in Health Policy and Economics at the Sol Price School of Public Policy at the University of Southern California. A Harvard-trained economist and health policy expert, he served as a founding executive director of the Physician Payment Review Commission (now MedPAC), was a senior economist at RAND, a deputy director at the Congressional Budget Office, and a faculty member of Duke and Michigan State Universities.



Sherry Glied, Ph.D., is dean of the Robert F. Wagner Graduate School of Public Service at New York University. An economist by training, she was previously a Professor of Health Policy and Management at Columbia University's Mailman School of Public Health. From 2010 to 2012 she served as Assistant Secretary for Planning and Evaluation at the Department of Health and Human Services. Her principal areas of research are health policy reform and mental health care policy.



**David Goodman, M.D., M.S.**, is Professor of Pediatrics and of Health Policy at the Dartmouth Institute for Health Policy and Clinical Practice. He is also director and co-founder of the Wennberg International Collaborative, an international network dedicated to advancing research into the causes and consequences of unwarranted health care variations across regions and providers. He has served on numerous national advisory committees and published more than 120 research papers, editorials and national reports.



**Richard Kronick, Ph.D.**, is a professor at the University of California, San Diego. From August 2013 to March 2016 he served as director of the Agency for Healthcare Research and Quality. Previously he was Deputy Assistant Secretary for Planning and Evaluation in the Department of Health and Human Services. He served as Senior Health Care Policy Advisor in the Clinton Administration from 1993 to 1994. His articles have appeared in journals such as *the New England Journal of Medicine* and the *American Journal of Political Science*.



**Len Nichols, Ph.D.**, is Director of the Center for Health Policy Research and Ethics and a professor of Health Policy at George Mason University, in Fairfax, Virginia. He is the Principal Investigator on an evaluation of CareFirst's Patient-Centered Medical Home Program, and is also directing other projects on payment reform and disparities, efficiency, and population health.



**Anna D Sinaiko, Ph.D.**, is a Research Scientist in the Department of Health Policy and Management at the Harvard T.H. Chan School of Public Health. She has expertise in health economics and health policy, with a particular focus on consumer decision-making and how information and financial incentives alter consumer behavior in health care settings. Specific empirical projects include an examination of consumer response to tiered physician networks, of the impact of a web-based price transparency tool, and of choice of health insurance plans in Medicare and in private insurance.



**Peter Ubel, M.D.**, is Madge and Dennis T. McLawhorn University Professor of Business, Public Policy, and Medicine at the Duke University Fuqua School of Business. He is a physician and behavioral scientist whose research and writing explores the mixture of rational and irrational forces that affect our health, our happiness, and the way our society functions. His published books include *Pricing Life: Why it's time for healthcare rationing* and *Free Market Madness: How economics is at odds with human nature - and why it matters*.



**Alan Weil, J.D., M.S.**, is the Editor-in-Chief of Health Affairs, the nation's leading health policy journal. He is an elected member of the National Academy of Medicine and an appointed member of the Medicaid and CHIP Payment and Access Commission (MACPAC). He is a member of the Kaiser Commission on Medicaid and the Uninsured and a trustee of the Consumer Health Foundation in Washington, DC.



**Daniel Wolfson, M.S.**, is Executive Vice President and COO of the ABIM Foundation, a not-for-profit foundation focused on advancing medical professionalism and physician leadership to improve the health care system. Wolfson has been instrumental in leading the Choosing Wisely® campaign, a multi-year effort engaging more than 70 medical specialty societies to promote conversations between clinicians and patients about utilizing the most appropriate tests and treatments and avoiding care that may be unnecessary and could cause harm. Previously, he served for nearly two decades as the founding president and CEO of the Alliance of Community Health Plans.

## Appendix B: Methodology

While there have been some prior efforts to identify research gaps within the subject area of patient-centered outcomes research, we are not aware of any studies that take a broad look at the evidence gaps that exist across the issue of healthcare value.

Given that, we did not want to restrict or unnecessarily limit this initial conversation about healthcare value evidence gaps. We permitted the conversations to range broadly in order to see where the boundaries might lie. As we acknowledge in the body of this report, the responses we received were likely biased by respondents' current and future research interests and by the fact that, as one respondent noted: "We don't know what we don't know." In our view, we can get more structured about identifying research gaps as this community moves forward.

Researchers were selected based on their broad familiarity with our nation's efforts to address the issue of poor health care value. Each interview subject was asked who else was critical to interview. Our timeframe did not permit us to interview all of the highly qualified people that were suggested to us but we will reach out to all who were identified with a copy of the report and an invitation to be part of a national conversation.

Interviews lasted approximately 45 minutes and used an interview guide that included three sections:

- I. Open ended questions:
  - A. Do we have enough evidence to address the issue of poor health care value in our system?
  - B. If not, what are the biggest gaps in our evidence?
- II. Questions about specific areas that may be evidence gaps, with order varying with each interview. Subjects were asked if (a) this was a problem and (b) was it an evidence gap.
- III. Closing questions:
  - A. If you had as many resources as you needed, what do you choose to work on in the next two years with respect to health care value?
  - B. Aside from funding, what else is needed to address research gaps?
  - C. Who else is critical to interview?
  - D. Who needs to learn about these findings and what

are your ideas for getting the information in front of them?

- E. Is there anything we should have asked you but didn't?

Two Hub staff took notes during each interview. The quotes in this report are not transcribed from a recording but are a faithful summary of their statements from our notes, with one set of notes serving as a check on the other.

We are eager to add more researchers, as well as advocates and other stakeholders to this conversation. We asked Consumers Union colleagues and advocacy colleagues from outside the organization to review these findings and their initial reaction included these additional points or amplifications:

- Hospital harm data is very incomplete, and suffers from differing definitions that make it not comparable. And completely lacking is data on Rx harm (including in hospitals) although adverse drug events are known to be a large problem.
- With all the work on shared decision-making, is this really such a gap? Without giving doctors time to talk with patients, paying for that, encouraging other kinds of providers that may be better communicators (eg midwives) what is the point of knowing how to communicate?
- Another gap would be the issue of consumer perceptions/actions around privacy of their data. In the policy realm, it is very significant stumbling block—little confidence among some in de-identification of data.
- There are big gaps in what we know about how consumers think about value.
- Health equity—the extent, causes and solutions around disparities in treatment and outcomes is a huge area that deserves further research.

As described in the body of the report, next steps to close these research gaps could include multi-disciplinary stakeholder panels to prioritize gaps; transformation of research gaps into research needs or questions; refinement and re-ranking of priorities by stakeholders; and the addition of study design considerations. By capturing these reviewers' comments, we hope to signal the many places this conversation might take us.