Introducing a Protocol To Obtain Patient Comments Using the CAHPS® Clinician & Group Survey

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Dale Shaller
Good day, everyone, and welcome to our Webcast on Introducing a Protocol to Obtain Patient Comments Using the CAHPS Clinician & Group Survey. My name is Dale Shaller, and I’ll be the moderator for today's Webcast.

Our Webcast today is one in a series on CAHPS, which stands for Consumer Assessment of Healthcare Providers and Systems produced by the CAHPS User Network.

We know that many of you are familiar with CAHPS, so I’ll just say a few words of background about the CAHPS program. CAHPS is funded by the Agency for Healthcare Research and Quality, or AHRQ, and the CAHPS program develops standardized surveys for assessing patient’s experiences with their care and produces a number of products and services to support their use, such as the National CAHPS Database.

CAHPS surveys have been developed for use in multiple health care settings. As shown here, the CAHPS family of surveys includes HCAHPS for hospitals as well as CAHPS for dialysis centers, and nursing homes, and hospice.

The suite of ambulatory care surveys has expanded to include not only the Health Plan Survey, which is where it all began in 1995, but now CAHPS surveys for surgical care, behavioral health, home health, and most relevant to our Webcast today, for medical groups, practice sites, and individual clinicians, CAHPS Clinician & Group Survey or CG-CAHPS.
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Shaller (opening), Slide 4
The focus of our Webcast today is to introduce a new beta version of a supplemental item set for CG-CAHPS, which we refer to as a CAHPS Patient Narrative Elicitation Protocol, or the Elicitation Protocol for short.

We'll review the development and testing process for the new protocol, offer recommendations for implementation, highlight the experience of one early adopter, and then, invite your participation in further testing of the open-ended questions.

Shaller (opening), Slide 5
Well, let's begin by first describing what the CAHPS Patient Narrative Elicitation Protocol is. The Elicitation Protocol is a structured series of five open-ended questions that prompt survey respondents to tell a clear and comprehensive story about their experience with a provider that they've seen and also his or her office staff.

It's intended to complement the closed-ended survey questions that are contained in the standard CG-CAHPS Survey and provide value-added information helpful to both clinicians and patients.

Shaller (opening), Slide 6
We'll be discussing the motivation for developing this new set of open-ended questions throughout the Webcast, but we want to provide just a little bit of context before we get started.

I think many of you know that growing numbers of Americans are increasingly seeking and finding online reviews of health care providers. A Pew Research Center study in 2012 found that nearly 60% of all adults in the U.S. say that they've looked online for health information within the past year. About 20% of internet users are looking for information specifically about doctors or other providers, and they're finding it primarily in the now over 70 online provider rating sites that have emerged in the last decade.

While, in some ways, this surge in consumer interest in sites with patient comments is pretty heartening, it also poses some serious concerns such as the fact that comments on these sites are usually very small in number for any given doctor and are virtually never drawn from a representative sample of patients so that they can easily be skewed in either a positive or a negative direction. Although, most studies indicate that posted comments are pretty much overwhelmingly positive.

And while comments are powerful and they're increasingly attracting a large audience, they represent only a small partial picture of overall physician quality. We also think we can learn a lot more from patients by asking them questions in a more systematic way. So, it's with these concerns in mind that the CAHPS Reports Team set out to develop a more rigorous, scientifically grounded method for collecting patient comments: The CAHPS Patient Narrative Elicitation Protocol.

Shaller (opening), Slide 7
And to describe the development and implementation of the protocol, we'll be hearing today from two members of the CAHPS Reports Team, starting with Mark Schlesinger, who's a professor of Healthy Policy at the Yale School of Public Health. Mark will be followed by Lise Rybowski, President of The Severyn Group. And we'll also hear from Barbra Rabson, who's President and CEO of the Massachusetts Health Quality Partners about their experience using the Elicitation Protocol and their statewide CG-CAHPS Survey project in Massachusetts. And again, I'm Dale Shaller, also a member of the CAHPS team.
Shaller (opening), Slide 8

Before we begin, just a few of the standard housekeeping details. For example, if you need any help at any time during the Webcast, just use the “Q&A” icon, which is at the bottom of your screen. You can also join us, if you’re not already, by phone at any time by dialing the number you see, 855-899-1542, and entering the conference ID number, which is 51724843.

Sometimes people will have trouble with their computer freezing during the presentations and if that happens to you, just hit your F5 button on your keyboard to refresh your screen. And what may be happening is just the lag that sometimes happens in the advancing of slides because of your internet connection speed. And you can also just try logging out and logging back in to the Webcast to solve that problem.

Shaller (opening), Slide 9

We have a large number of people on the Webcast today, which is great. But we’ll be taking questions submitted online only. And to ask a question, again, you click the “Q&A” icon to get that box to appear. And all you have to do is type in your question and then select the Submit button.

Please do feel free to send questions in at any time during our presentation, because we love to hear from you. That makes the Webcast a lot more interactive. And we will address as many as possible during the Q&A session that we have sprinkled throughout the Webcast.

Shaller (opening), Slide 10

The slides from today, this always comes up. I just want to mention that the slides for today are available now for downloading, but if you click on the icon at the bottom of your screen, it says “Download Slides”. That’ll give you a PDF version that you can download and save as you wish.

I also want to point out that in about two weeks, anyone who’s actually registered for this Webcast will receive an email regarding the availability of a replay.

Shaller (opening), Slide 11

We also have some additional resources available for you to get to under the “Resources” icon. And you’ll find, for example, a document which is a guidance document, that we’ll be reviewing today, on how to implement the CAHPS Patient Narrative Elicitation Protocol and several other resources such as URLs, sites to -- further information about the Elicitation Protocol.

Shaller (opening), Slide 12

So now, before we begin with our first presentation by Mark, we wanted to conduct a quick online poll to ask all of you which of the following five options, and there’re five, you’ll have to scroll down to see the fifth one, best describes your current use of open-ended questions? And you can go ahead now and use your cursor to hit the radio button to select your answer. Make sure you hit the Submit button, which is at the bottom of the question list.

And as you do that, I’m going to read through the options. The first one is I use open-ended questions as part of a CAHPS Clinician & Group Survey. The second is, I use open-ended questions as part of a different CAHPS survey, such as HCAHPS. The third one is, I use open-ended questions as part of an in-house or proprietary vendor survey. Or, I use open-ended questions administered on their own, example via a comment card or a stand-alone survey. And then, the final question is, I do not use open-ended questions to collect patient feedback.
So, give you a couple more seconds before we go on to the results. And I will see what we have come up with.

All right. So, what we're looking at here is, wow, over 16% of our registrants actually use open-ended questions today as part of a CG-CAHPS Survey. About 13% use as part of a different CAHPS survey like HCAHPS. A full almost quarter use an open-ended question or questions as part of an in-house or proprietary vendor survey. Some use open-ended questions on their own through comment cards or such. And then, finally, we knew some people who are attending today aren't even in a position to survey.

So, about a third of us are not using open-ended questions at all. So, I think that's a very interesting set of results that indicates consistent with all the evidence that we've seen. A lot of interest in using open-ended questions as a way to gather patient feedback that complements or can expand on the information that can be obtained from closed-ended surveys.

So, that was a very helpful start. And I think it's a great way for me to hand over to Mark, who's going to now describe the development and testing of the CAHPS Elicitation Protocol. So, Mark, over to you.

**Mark Schlesinger**

*Schlesinger, Slide 13*

Thank you, Dale. I am operating blind. So, the all-powerful Bria will actually do the advancement of the slides. So, Bria, next slide, please.

*Schlesinger, Slide 14*

So, thank you all for being a part of this. We developed this Elicitation Protocol with four aspirations in mind. First, to develop a way of collecting qualitative data that was complete in that it fully captured all the aspects of a patient's experience with their doctor.

Second, that it be balanced. That is, it had the same mix of positive and negative experiences as they actually experience in their interactions with the clinician. Third, that it be meaningful so that a clinician or another consumer reading about their experiences could understand not only what happens, but as best they could retell it, why it happened.

And fourth, that it be representative. That people who feel less empowered, who feel less literate, who are not used to having anyone actually ask them about their health care experiences would nonetheless feel comfortable recounting them as part of the elicitation. Next slide please, Bria.

*Schlesinger, Slide 15*

So, we developed the operationalization of this under a set of expectations for how we wanted to field this eventually. We were looking for a short and not time-consuming protocol. So, our goal was one that would be five to seven questions in length. We ended up with five. And that would take no more than five to ten minutes to answer. We ended up with one that averages about five to six minutes, on average.

To test the protocol, we collected hundreds and hundreds of narratives from patients about their interactions with clinicians. The final Elicitation Protocol I will describe for you today involved testing with 330 patients. For whom, about 54 of them, we collected what we call gold standard interviews, where several weeks later, we went back and did hour to 90-minute long interviews about their interactions with their doctor. And that's the standard against which we are comparing the performance of these very short five-minute elicitations.

We refined the protocol for those elicitations through two different rounds of testing and refinement. What I'm going to describe for you today are just the results of the second round.
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Schlesinger, Slide 16
The details are more fully described in a publication -- Bria, next slide please -- that came out last year in the Journal of Health Services Research. For details, you can all go get that. I’m going to give you just an overview today. Next slide, please.

Schlesinger, Slide 17
So, what you should now see is the five-question Elicitation Protocol. I will not read it to you, but as you read it, what you will see is that there is a narrative flow to the questions. We start with the question of what people anticipate, or expect, or would like to see when they go to a doctor. How well their experiences matched up with those expectations. Whether they had particular events that were positive or negative. And more broadly, what the relationship they had with their clinician was like.

Now, you’ll notice that some of this text is highlighted in green. These were the parts of the protocol that we changed as we refined the protocol between round one and round two. And each of those sections plays a very important role.

So, we added the question on what people look for, because it turned out that was a very good warm-up question for people who’re not used to telling their stories about health care. And it’s helped them put their own story in order in their own heads.

We added the details about “please explain what happened, how it happened, and how it felt to you”, because that encouraged people to go to a level of detail that was very useful, and then, making sense of the story they were telling to us.

And then finally, in Question 5, we had this somewhat oddly worded question for those of you who are survey designers, where we ask how the patient and the provider relate to and interact with each other. That was very explicitly to get people thinking out of the concrete and thinking more about the relationships that they had. We got a lot of good data on that, particularly about provider communications, provider empathy, and the like.

What’s really important to recognize is that these additional nuances to the questions were especially important in getting good elicitations from people who had less education, for people had less familiarity with the health care system. In short, the people for whom they would’ve had harder times telling their stories otherwise. Next slide, please.

Schlesinger, Slide 18
Now, the range of responses we got were varied. And so, what we’re going to do is show you two brief examples just to give you a feel for that range. So, the first of the elicitations, which you can see before you on the screen here involved a respondent who was at the lowest tenth percentile, if you rank order the quality of the elicitations. This is not the very bottom, but it’s near the bottom. It’s at the lowest tenth.

And as you can see, the person answered the questions, but they were not all that responsive. They didn't give that much detail. And it's a little hard to discern other than the fact that they were pretty happy with their doctor, that -- exactly what went on with their care.

Schlesinger, Slide 19
By contrast, next slide, please, Bria, the next elicitation is from the 90th percentile. So again, it’s not the best. It’s not the most fulsome. But it’s up there at the high end of elicitation. And here, you can see an immense amount of detail. Immense amount of detail both about the content of their interactions, what they liked and
disliked about them, and a lot of concrete information about things that could be made better, or if they were already good, could be replicated by other clinicians or other staff. And we’re going to come back to that actionability point in just a moment. Next slide, please.

Schlesinger, Slide 20
Now, we can quantify how well we did on those four norms that we set out originally, completeness, balance, meaningfulness, and representativeness. And so, that's what we do on the next four slides.

This first slide, Quantitative Results 1, conveys the results on completeness. So, what we did was divide up patients’ experience into ten different domains. And those are listed at the bottom of the graph on the right-hand side. You'll see there're things that CAHPS composites already measure, and a number of areas that CAHPS does not directly measure.

Overall, we got about a 60% hit rate, meaning that if something was talked about in that hour-long to 90-minute long interview, it also showed up in the elicitation. Since the interviews were 60 to 90 minutes, and the elicitations are only 5 minutes, 60 percent’s a pretty good score.

Now, you'll notice that the bars are clustered. There's a blue bar, a green bar, and a gold bar. The blue is the performance on average for all the elicitation modes we tested. The green bar is the phone sample. The gold bar is the Web-based sample.

And you'll see that pretty much, by the time we got to the second version of the elicitation, the one that you have presented to you today, we had pretty much equal performance in most dimensions between the phone and the Web-based elicitation. There's one slight exception to that I'll tell you about in just a bit.

Notice as you look across the ten domains at the right, there are some domains like the domain of staff interaction where virtually everything that was talked about in the interview also got talked about in elicitation. And many other domains, communication, coordination, perceived confidence, caring, where the elicitation does a really good job capturing what was in the gold standard interviews.

And then, there’s a few domains where we didn’t do quite as well like thoroughness, like shared decision making. The silver lining there, the good news is that those domains were domains where patients just didn’t have all that much to say. And so, the Elicitation Protocol performs best in the domains that matter most to patients, as expressed by what they said. We'll show you that more in a little bit. Next slide please, Bria.

Schlesinger, Slide 21
So, the second criteria, if you remember, is balance. That the positive and negative mix that's described in the elicitation matched that of the interview. This was such an important area we measured in a bunch of different ways. And you'll see there's four different clusters on this graph to reflect the four different measures we used.

Notice that at the 1.0 level, where that blue line is across the screen, that is the perfect balance. That is the exact same mix of positive and negative between the elicitation and the matching interview. If the bar is over that blue line, it means the elicitation was more positive. If it's under that blue line, it means the elicitation is more negative than the interview.

And as you can see, pretty much across the board, we came very close to hitting exactly the right balance. The one exception, which you see at the far right, is for what people had to say about the staff. There, the elicitation
was a little more positive than the interview, but not by much. Just by about 10% to 20%. So, on average, balance is really good. Next slide please, Bria.

Schlesinger, Slide 22
Quantified Results Number 3, what we call narrative coherence or meaningfulness, if you were listening or reading the narrative, could you get why things happened the way they happened? Now, we measured this with a construct of like six different dimensions.

That's what we call coherence. It's over on the left-hand side of the graph. It scored about as well as completeness. Again, we got about 60% of the coherence overall in the elicitation that we did in the interview.

Notice here, there's a little gap between phone, when people could talk about their experiences in green, and the Web elicitation. That gap is largely in terms of the amount of detail they related. Notice that when you look at what we call texture, that's where the big gap is between phone and Web. In terms of the completeness of the story and all the other dimensions, the two modes of elicitation look quite similar.

Schlesinger, Slide 23
Finally, next slide, please, Bria, Quantified Results 4, representativeness. Notice here the color scheme has changed, because we're graphing something different. Not phone versus Web, but the average performance on the elicitation in blue compared to the performance for three subgroups we were worried about not actually being as responsive to the elicitation. The gold bar, people with high school education or less, the red bar, people who were seriously ill. We were worried they would just have so much to say they wouldn't be able to organize it in a coherent response. And the gray bar, people 65 and over, who we thought might have less experience being kind of more vocal consumers.

As you can see across the board for every single measure, all three of these groups we thought we were going to be at risk actually performed as well or better than average in terms of the elicitation. Next slide, please.

Schlesinger, Slide 24
So, the other thing we did, all this data I've given you before was tested using an online internet panel. We also wanted to see how well this performed out in the field. And so, we worked with partners in California and Massachusetts, Barbra, who you'll hear more from later, will describe more the experience in Massachusetts.

For this field testing, we did not have the intensive interviews as a measure. And so, the main thing we were focusing on is whether when people got on, how often they would give open-ended responses. You can see that range from 18% to 25%. And whether they would basically get tired with the number of interviews that they had, with the number of questions they were answering.

So, we looked at the response rate between Question 1 and Question 5. And in fact, the response rate was exactly the same. So, people who started the Elicitation Protocol completed the Elicitation Protocol. Next slide, please.

Schlesinger, Slide 25
Now, the punch line of all of this is the extent to which these open-ended questions give us information that is useful above and beyond the closed-ended CAHPS data. And so, there are three categories in which this might have value.
One is, because there's concrete illustrations of things that CAHPS is already measuring with its closed-ended questions and composites. Second, areas where we are measuring things with composites, but the open-ended questions give us different aspects of those areas that aren't captured by the composites. And third, information that actually goes beyond where we have the closed-ended measures. Now, next slide, please, Bria.

Schlesinger, Slide 26
Overall, if you look at the frequency of people's responses across the ten different categories, you can see them organized as they're presented in this slide. There's a pretty simple balance across healthy people, people with chronic illness, and people seriously ill. Although, not surprisingly, people who are more seriously ill and chronically ill tended to pay more attention to coordination of care issues than people who are relatively healthy. Next slide, please.

Schlesinger, Slide 27
Here we are going to provide you with, very quickly, a few concrete illustrations of each of the three different aspects of care. So, for concrete examples from the staff, we have a positive and negative response, which you can read here, where you can learn not just why someone rated the staff high or low, but what either had gone right or not gone so right. Next slide, please.

Schlesinger, Slide 28
In the second dimension, coordination of care, we have now in the CG-CAHPS 3.0, a new coordination of care composite, but it's one that focuses largely on information exchange, and what you heard from the comments of patients is that that mattered to them. But what also mattered to them was how their primary care clinician helped them with referrals and helped coordinate care among other providers. And here, you see a couple examples of that. Next slide, please.

Schlesinger, Slide 29
And then, there were a bunch of domains where we do not have CAHPS closed-ended measures or composites, but which came through very vividly with important examples of information from the open-ended questions. We illustrate two here.

One had to do with the extent to which providers were involved in helping people with billing and coverage issues. And again, you can see some discussion of both things that went right and things that didn't go so right. Next slide, please.

Schlesinger, Slide 30
And then, perhaps more commonly, and in some ways, more powerfully, a whole set of responses around the domains related to empathy and emotional connectedness between the clinician and the patient. We don't have good ways of measuring that with closed-ended questions, but they matter a lot to people. And how they matter and how that was manifest in their relationship with their doctor comes through very vividly in the open-ended information. That provides valuable feedback potentially to clinicians to understand how their patients are seeing and interacting with them from the patient perspective.

All right. That's the overview. We can open things up for questions.
Great. Thanks, Mark. That was a great overview of the development testing process. And we do have several questions that have come in. I'm going to start with one that asks if the study that you've reviewed included patient interactions with any specialists or just primary care providers.

Excellent question. We asked them for the interaction with the clinician who was most important to them. That was often primary care providers, but for people who had had more serious illness, and we deliberately sampled for people with serious illness and chronic illness. That was often a specialist, where the specialist was kind of playing the role of the primary care provider for them. We also got some responses from people whose most important provider was their dentist. So, we got a range of coverage in that. It was weighted toward the primary care providers.

Okay, great. Another question related to implementation asks if the 12 months reference period will be used with the protocol or the 6-month retrospective reference period. You've mentioned the 3.0 version, which is the 6-month reference period. How would you answer that question?

That's a good question. Obviously, we're in transition, because some people are still using 2.0. Some people are transitioning to 3.0. Our recommendation is that the open-end question be designed to match the time sequence of the closed-ended questions so the two can be connected together. We did observe in the open-ended data that people don't exactly draw a bright line at either 6 months or 12 months. It spills over a little bit. So, it's kind of a fuzzy boundary a little bit there.

All right. Another question relates to what patient population was the tested population? Was it commercial? HMO? PPO? Medicaid? Medicare?

Good question. We don't know much about their literal insurance coverage. We do know about their demographics, including their age. So, about a third of the sample would've been in the Medicare population. We don't know if it's Medicare private insurance, that is Part C plans, or general Medicare.

In the younger population, we just don't know. We have a number of people who are lower income. So, probably, they were in Medicaid. Probably in Medicaid Managed Care, because that's mostly what Medicaid is these days. But we know demographics. We don't literally know what insurance plan they're -- it was a wide variety of insurance coverages.

All right. There are a number of other questions, Mark. So, let me just try to get you to answer as quickly as possible. So, one relates to the importance or lack of importance of shared decision making as revealed in the experiment. Can you see if this is different for people with serious illness or perhaps approaching the end of life?
Mark Schlesinger
It's a good question. We didn't have that many people at the end of life. It's important to recognize though that shared decision making as it's typically constructed is a particular aspect of the broader category of physician/patient communication.

And there were lots of important expectations about how people wanted to discuss things with their clinicians that weren't exactly shared decision making. So, they didn't go in that category. The boundary there between those categories is a little -- again, a little fuzzy.

Dale Shaller
All right. Now, I'm going to ask one more. We'll try to come back to other questions that are still in the queue if time allows. But this question relates to the qualitative coding, asking about how were the questions classified as positive versus negative? Was it all manual analysis through human review or was there any automation used in the actual coding of responses?

Mark Schlesinger
Another excellent question. All our data was carefully double coded with human coders with external review, but there are good natural language processing programs out there, which are particularly good at what is referred to as sentiment analysis. That is, applying a positive versus negative score to responses.

Because we were doing what was microcoding. We were looking at the positive and negative of very particular aspects of their comments. We were looking for not simply overall how positive and negative, but how positive and negative they were about each different facet of their experience. That's why we did the human coding for this.

Dale Shaller
Rybowski, Slide 32
All right. Great answers to great questions. And there are more. We'll try to get to as many as possible. But let me turn now to our next presenter, who is Lise Rybowski, to talk about some of our suggested guidance on implementation of the Elicitation Protocol. Lise?

Lise Rybowski
Rybowski, Slide 33
Thanks, Dale. So now, you've heard about the questions, and I'm going to share some information about how the guidance that we provide to implement the Elicitation Protocol. So, there are two ways to field the items. You can do it with -- you can field these items with the Clinician & Group Survey or a version of it, and you can field them on their own without closed-ended questions. And we just saw that some of you have been doing that.

We do recommend fielding the items with the Clinician & Group Survey, largely because of the sampling frame. And as Dale and Mark have both been saying, with the survey, you have a randomized representative sample of recent patients.

Also, as you just heard from everything Mark was telling you, part of the value of the protocol is the insight it provides into the responses to the closed-ended questions. We are definitely seeing that you get a lot of insight when you hear the words of patients who're answering the survey to understand what's actually driving their responses.
But we recognize that there is some interest, and you can field the protocol on its own or with another type of survey. And when you do that on its own, that’s a way that you could get ongoing feedback in between administrations of the survey. And it’s also a way to get feedback from subgroups of patients whose experience you may be interested in.

**Rybowski, Slide 34**

So, first I’m going to talk about using the protocol as part of the Clinician & Group Survey. And so, there were a couple things I’m going to cover. We’re going to talk about where you place the items in the survey, sampling, the data collection modes, and then, finally, what you can do to manage the information that you get with the comments.

I’m going to review these issues now, but I also want to point to where you can find this guidance. It is available on the AHRQ CAHPS site in a document called “About the CAHPS Patient Narrative Elicitation Protocol.” And you can also find that document in the “Resources” tab on this Webcast.

**Rybowski, Slide 35**

So, as far as incorporating the items into the survey, many of you are familiar with CAHPS surveys. So, you know that CAHPS surveys are designed with what we call core items or core survey, which is consistent across all versions of the survey.

Any user of a CAHPS survey can then add other questions, which we refer to as supplemental items. The CAHPS program has developed a large number of supplement items or you can add your own to customize the survey to meet whatever your information needs are.

So, the Elicitation Protocol, those questions Mark showed you, functions like a set of supplemental items. And we recommend that you place them before the “About You” section of the survey. And for those of you who aren’t as familiar with CAHPS survey, the “About You” section is the section at the end that asks respondents for their demographic characteristics.

We also suggest adding a subhead and the text you see on this slide. This text has two purposes that are highlighted in green for you. One is to signal that this part of the survey is a little different, and that it’s asking for descriptions. That is, it’s giving the respondent opportunity to describe their experiences in their own words.

Second, we want to remind people not to use these comments to request advice, care, or services. You can’t really stop people from doing that. We know they do it. But we want -- this is at least a reminder that that’s not the purpose here. So, we do recognize that this is a concern for users. And I will come back to this issue in a moment.

**Rybowski, Slide 36**

As far as the sampling methodology is concerned, the good news is that there’s nothing about the sampling methodology of a CAHPS survey that changes because you’ve added the open-ended questions. We’re largely making this point that we want you to follow the guidance for the CAHPS Clinician-Group Survey, because we want to emphasize the benefits of using the CAHPS protocol for the purpose of patient narrative.

As you heard from Dale in his introduction, we all know that the patient comments that we see online, they’re volunteered. We don’t know who’s providing them. We don’t know whether the commenter’s even a patient.
And also, for anyone who's looked, you've probably noticed that there are rarely enough comments to have an assurance that those commenters are representatives of the provider's patient population. And in fact, we know from studies by Pew and others that only a very small percentage of consumers come online to volunteer comments about their experience.

So, by using the CAHPS sampling methodology, you know that you're drawing from a population that meets the requirements for the survey so, it's representative of the patient population and they are recent visitors. You're also getting comments from more patients of a given provider not just those who independently are choosing to go online to share their experience.

Rybowski, Slide 37
I want to talk now about data collection. So, those of you familiar with CAHPS surveys are probably aware that the recommended data collection modes for CAHPS surveys are mail, telephone, and Web, which is sometimes referred to as email, where both mail and Web administrations are followed by telephone. And we make that recommendation because we want to ensure that the respondents are representative and comparable across administrations of the survey.

For the Elicitation Protocol, we're recommending the use of telephone and Web followed by telephone and that's how the protocol was tested. In our testing, we found that responding to these items, that time ranged and I think you might've seen that in Mark's slide, but on average, it took about five to six minutes. Some people took longer so, one implication is we would encourage you not to limit the time people have to respond online or on the phone.

Similarly, the comments varied in length from about 20 words to more than 300 words for those who, I guess, had a lot to say. So, this has implications for a Web survey in that you'd want to give respondents ample space to respond.

Rybowski, Slide 38
Another consideration during the administration process is the use of invitation and reminder letters and emails. So, it's a standard recommendation in the CAHPS guidelines to use a series of letters or emails. And these letters serve multiple purposes. They inform the respondent of the survey and its purpose, they let them know how the survey's going to be used, who's sending it, and they encourage participation in the survey itself.

So, we recommend some changes, because in this case, when you're adding open-ended questions, this gets more complicated, because people are describing their own experiences, and those individual comments will likely be shared with providers.

So, you can't offer the same level of confidentiality that you can offer with closed-ended questions where we're aggregating the results. So, you want to acknowledge that and reassure respondents that you'll be screening the comments to remove identifiable information.

We also recommend letting respondents know how their comments will be used. So, if you're going to share the comments with providers, let them know that. If you're going to post them online, let them know that.

Because we provide sample language for letters and emails, if you've ever looked at that language, you'll see there is -- we do have text about keeping responses private. So, we do have suggestions for deleting and revising that text so that you're not promising a level of privacy that isn't accurate, because the comments will be shared.
And similarly, you want to make sure that you don't have a statement saying that no one involved in care will see individual answers, because that's the point. We also would recommend adding a statement indicating that you're taking steps to ensure the responses don't contain information that could reveal the patient's identity, particularly names and phone numbers.

*Rybowski, Slide 39*

So, how do you do that? You really have to work with your vendor to identify and remove identifiable information and I say that with the caveat that there really are limits to how much you can do if people share details about their care that make them recognizable. There is a natural tension here between people who are sharing their experiences and, perhaps, providing enough information that someone could identify them.

Another concern is that respondents may use comments to request help of some kind, and this gets back to the point I made earlier. In some cases, they may not realize that nobody's going to be reading their comments right away.

So, we know that some organizations have put systems in place to flag comments that require a response from providers and forward those comments to the relevant provider and we are looking into how this gets done and how well it works.

*Rybowski, Slide 40*

Now, if you're using the protocol by itself, we do recommend using the CAHPS sampling methodology for all the reasons I was just discussing with the one side note is that if you're targeting a subgroup of patients, you may want to survey all of those patients and not a sample.

But as with the survey, we'd recommend use of Web and telephone as data collection modes. If you use a different approach, it's important to remember that the CAHPS guidelines are designed to preserve anonymity. So, if you're doing something different, you really need to consider how you're going to protect the respondent from being identified through your data collection process.

And of course, as I just noted, the CAHPS methodology includes the use of invitation and reminder letters or emails. And so, we recommend doing something similar, if you can, to inform respondents about the questions, how the information will be used, and of course, to encourage responses.

As for using the responses, how you use them really depends on how you collect the information. If you're not starting with a representative sample, we don't recommend posting the responses, because respondents won't mirror the patient population.

Some organizations that collect comments deal with this issue by publishing -- holding off on publishing until they have a certain number of responses. There are no set rules for this right now, but this is something we're looking into. You can share the information with providers, of course, but you do need to let them know that the population isn't representative. It is still useful for QI.

Finally, if you're using this protocol, we do ask that you acknowledge the Agency for Healthcare Research and Quality and CAHPS as the source, especially if you're publishing the results of your research.

*Rybowski, Slide 41*

So, you can tell from this presentation that we do still have a lot of outstanding questions about survey administration and use of responses, which is why we're calling this a beta version. And as you'll hear more
from Dale, we are really eager to find people and work with some of you to help test the protocol -- continue to test the protocol and answer some of these questions.

So, for example, we’d like to give you an estimated response rate so, that’s an area we will be doing more work in. In the pilot that Mark told you about, you saw a response rate that hovered around 20%. And the pilot required an extra active step by respondents before they got to those open-ended questions.

In other uses of open-ended questions though, we’re hearing much higher rates. Even as high as 80%. So, we need a better understanding of that range and what practices lead to higher rates. A third point, which is really “the elephant in the room,” is how do you analyze and summarize responses from individuals? This is very different than the closed-ended questions of the CAHPS survey.

So, we know that a lot of survey vendors, and researchers, and others are doing work in this area, and we look forward to working with all of you so we can provide more useful guidance on this point.

And finally, we plan to continue investigating strategies for sharing feedback with both providers and health care consumers. As some of you are aware, the CAHPS team has been conducting experiments with reporting comments alongside standardized measures of quality, and we’re going to continue to share our findings. We’ve published some of them already and we are continuing to share that research. And we are eager to continue work in this area, particularly to better understand how to meet the needs of providers for this information.

Rybowski, Slide 42
So, you’ve heard about the questions and what we can tell you so far about using them and that leads us to our second polling question. Which of the following best describes your interest in using the CAHPS Elicitation Protocol? So, some of you may be very enthusiastic, so “yes, I really want to be an early adopter.” Second, “I’m intrigued and will discuss it with colleagues.” Third, “I’d consider it after others have tested it,” and fourth, “I’m not interested.”

If you could all reply, that would be great. And then, we will look at the responses. So, oh, we’ve got a lot of people saying that they’re “intrigued and will discuss it with colleagues,” almost 70% of you. That’s wonderful. Glad to see it. Some who want to be an early adopter, and as Dale’s going to tell you, we would like to hear from you. About 15% would consider it after more testing, which is a reasonable response. And some of you are not interested, which I understand, particularly those of you who aren’t even doing surveys.

All right, Dale. I’m going to hand this back to you.

Dale Shaller
Rybowski, Slide 43
Great. Thanks, Lise. We do want to move forward as quickly as possible to Barbra’s segment, but I do want to knock off a couple of questions that have come in. We’ve got a long list.

Some have to do with the optional nature of implementation. And I think we just really want to underscore that this is a supplemental item set that we’re describing that can be used the way we’ve structured it with the CAHPS Clinician & Group Survey. It’s not required.
And so, in terms of implementation, that's entirely up to you, because it is an optional set of questions. We encourage people to use the questions, to field them, and then, to, as we'll talk about later, let us know about it so that we can monitor your progress and hopefully even engage in some testing with you.

So, we are now going to move on to our last segment, which is Barbra Rabson. And Barbra, I'll turn it over to you right now so you can talk about your experience with the statewide implementation of the protocol in Massachusetts.

**Barbra Rabson**

*Rabson, Slide 44*

Okay. Thank you, Dale. And hello, everyone. I appreciate the opportunity to share our experience with collecting patient comments, and this came out of a meeting- MHQP's interest in this- we convened a national meeting in 2014 about advancing ambulatory care patient experience measurement and reporting.

And one of the priorities that came out of the meeting was that we need to do a better job in capturing patient narratives. And one of our patients, who was at the meeting, said, “If you pay attention to what patients are saying, you will uncover gold,” which is something that we feel that is true, and we've had some very good luck so far doing that.

*Rabson, Slide 45*

So, MHQP is a regional health improvement collaborative. We just celebrated our 21st anniversary. We have two decades of bringing together patients, providers, health plans to drive improvement and patient experience, clinical quality, and appropriate resource use.

*Rabson, Slide 46*

We have been a national leader for over a decade in capturing the patient voice through statewide survey work, and we work with providers to integrate the patient voice into care improvements and we also publish the data so that consumers can make better informed choices.

And as you can see, we field a very large survey annually. We send out over a quarter of a million surveys to Massachusetts patients. These are commercial patients. And we report back to over 500 practice sites about the information we collect and then, we publicly report on our Web site. We’re also published with Consumer Reports our data in Massachusetts.

*Rabson, Slide 47*

So, in terms of-- Mark mentioned the pilot that was done in Massachusetts and California. This was actually MHQP and CHPI, CHPI being the California Healthcare Performance Information System.

And we conducted a pilot study. Following this national meeting I mentioned, the idea that we need to improve existing data collection methods to improve value and reduce cost in capturing this data, we piloted a number of things in this study. One was looking at a shorter form and whether they could provide comparable answers and rank providers similarly. This was actually before 3.0 came out.

We also looked at email approaches and how -- if they gave sufficient response rates and ranked providers in comparable ways. And for this call, which is -- the pertinent issue is “Will open-ended narrative questions elicit meaningful and actual information?”.
And again, as Mark mentioned, we tested actually two different protocols. One, the five-question protocol that Mark mentioned. And then, we tested a three-question protocol, because we were a little uncertain whether patients would respond to a five-question protocol, that maybe it would be too long.

*Rabson, Slide 48*
But it did compare favorably to the three-question protocol and so, that's what we ended up using this year or this past year in 2016 when MHQP incorporated the opportunity to provide patient comments in our 2016 statewide survey. For those patients that responded electronically.

And you can see here that we had, our adult survey, we had about 1,400 patients responding, which was about, just about 20% of the responders that provided comments. And 18% of those came from people who we actually emailed the survey to.

We also have an option where we send out a paper survey, but in the cover letter, we say you can respond online. And we give a URL, a Web link. And close to 22% responded to that. And in the letter, we say that we urge you to respond online because if you do respond online, you can offer your patient comments. Whereas if you respond by mail, that's not an option.

We did find that for the adult surveys, women left more comments than men. The numbers you can see.

*Rabson, Slide 49*
And then, if you look at our pediatric survey, slightly fewer, we had 1,155 patients provide comments. Slightly lower response rate in terms of leaving the comments. And again, the breakdown between email and this Web link where the Web link being slightly higher. As I said, that could be because we said -- we offered the ability to give comments as an enticement to respond by Web.

*Rabson, Slide 50*
I'm going to share a few of the comments that we collected and we sorted these by likely to recommend or less likely to recommend. As the prior speaker said, there's a challenge that we have to figure out the best way to feed this information back to providers in a really useful way.

So, this was the first sort. And so, these are a few comments from positive patients. Dr. X is so personable and very caring. I have never been happier with the care he provides or suggestions he makes to keep me healthy. The office is fantastic. I strongly recommend everyone looking for a doctor. This is a pretty typical positive comment. Really nice to get. Doesn't tell you that much information. I think actually often you can get more information from the negative comments in terms of opportunities to improve or useful information about what's going on.

Although this last comment, here -- my most recent physical was great. I arrived on time. They took me right in. The nurse did the EKG before seeing the doctor. He came in after. He was well prepared. Went through a checkup, thorough checkup. Blood test was ordered and got through in 30 minutes. Didn't feel rushed. I have a high level of trust. This is a really obviously helpful comment supporting the care provided is really excellent.

*Rabson, Slide 51*
Then here's some comments for patients that were not as likely to recommend. Patient's concerns were shot down. I was not treated well. Treated me like I was stupid. These are really important things for an office to hear if they want to improve their care and their patient experience.
So, again, this really illustrates how valuable or how rich the patient voice is. And back to the original quote, if you pay attention to what the patient is saying, you will uncover gold, in terms of really understanding what is going on in your office and how things work for your patients.

Rabson, Slide 52
I mentioned some challenges. Clearly, I can’t stress enough that we will only be able to make progress in collecting patient narratives if we move to electronic modes of collection. And this is a significant challenge for us, because there’s such a lack of systematic collection and maintenance of valid email addresses for us to use in survey collection.

And also, there’s ongoing concerns about the protection of patient’s emails and actually cellphone numbers that sometimes they’re collected. The office has them, but they weren’t specifically collected in order to conduct a patient experience survey.

And so, while we’ve been fortunate in Massachusetts that a number of groups have been very active collecting emails, both on the part of physician organizations and health plans, there are quite a number of organizations who don’t have these emails that they can share for sending out to patients. That’s sort of the step one is that we really need to improve the data collection of emails that we have of information to be used for these surveying purposes.

I mentioned developing a systematic way to analyze a patient free text feedback. That's something that Lise has talked about. We're learning here. I mentioned that we sorted out with comments that tied to willingness to recommend -- not willing to recommend, which is a helpful start, but there's other work to be done to provide this back to -- to report it back to providers in a user-friendly way.

And then, also, helping providers integrate these patient narratives effectively into quality improvement efforts, because this data collection is new. It’s something that we all need to learn how to better incorporate it into our workflow.

Rabson, Slide 53
And so, in terms of next steps, we’re going to continue to collect patient narratives in 2017 and continue to push for increased electronic surveying in the survey that we do. We are amending the language a little bit that encourages participation. We feel that as we said that we’re looking for higher response rate. And we felt maybe some of the language was -- discouraged a little bit of response. So, we'll be experimenting with that.

And so, we’ll improve our methods for processing and reporting back to clinicians. And finally, we’re looking into future methods for reporting the patient experience comments to consumers along with other survey results. On our Web site, we reported the -- at the practice site level on our Web site, and then, incorporating physician-specific comments is something that we’re going to figure out what’s the best way to do that.

So, thank you, and look forward to questions.

Dale Shaller:
Shaller (closing), Slide 54
Great. Thanks Barbra. Okay. We have just a few minutes left. And there are a lot of questions. We’re going to try to get to as many as possible. Several relate to the issue of implementation by email or online administration versus mail. Going to direct that to Lise in terms of what do we know about the ability to collect this information by mail versus the way it was tested by online administration or phone administration?
Lise Rybowski
Right, so the testing that we did in the pilot test was all done with -- over the telephone or over the Web. We did not do testing on paper. It's not that it couldn't be done, but it's far more complicated and costly. And so, for the purposes of -- for our purposes, for testing, we did not do it that way. It is conceivable that it could be done, and I think there are vendors out there that do it. Mark, do you want to add anything to that?

Mark Schlesinger
No, I think there's not much reason to think that the depth or quality of the responses would vary between paper responses and Web-based responses, but because we didn't test, we can't say for sure.

Dale Shaller
Okay. A number of questions relate to the suitability of these five questions for use with health plans, or hospitals, or other settings of care. Mark, do you want to address those sets of questions?

Mark Schlesinger
Yes. It's obviously a complicated question. At the health plan level, health plan surveys incorporate questions about the medical staff within which the open-ended protocol would be perfectly reasonable if appended to part of the questions about the clinicians in a health plan.

If you start moving to different settings, it poses different complications about how you appropriately ask about people's care when there's big turnover of clinicians and there's not obviously one clinician to single out.

Our aspiration is to develop comparable protocols that apply in inpatient and equally complex settings. I'm not at all convinced that this one's appropriate for those settings. We are doing a little work with some colleagues looking at applying an open-ended protocol to safety questions in inpatient care. But that's in the very early stages of its development.

Dale Shaller
Okay. Here's another question, Mark, I think for you. It relates to the wording of the questions. A, were they tested? Well, obviously, with patients or the public? And secondly, some of them appear to be double- or even triple-barreled. Is that an issue for this kind of elicitation?

Mark Schlesinger
Excellent question. All the questions were both pilot tested, and cognitively tested, and we got feedback from everyone who participated in the -- or at least solicited feedback from everyone who participated in the elicitation experiment.

The questions sound really complex, if you're used to designing surveys for closed-ended questions, including the double- and triple-barrel nature of them. They all work as open-ended questions. It's remarkable how different people process open-ended questions rather than closed ones.

And we explored this in great detail. Not only do they work, but they're very natural. So, that last question, which sounds like it ought to be a really awkward question for people, literally no one had problems. It just sounded natural to them. They didn't balk at all. They responded easily to that.
Dale Shaller

Shaller (closing), Slide 55
Okay. We have hit the hour and I do apologize for not being able to get to all of the questions. We’re going to move to wrap things up to respect everyone’s time. I do want to emphasize again, this is an optional set of questions that can be added to either the 2.0 or 3.0 version of CG-CAHPS. It is not required. There’re a couple of questions that came in about CMS applications for either HCAHPS or ACO PQRS. Those are all questions for CMS, but we know that they’ve expressed interest in getting this kind of information, but in no way is it a current part of the requirement.

I do want to again refer you to the guidance document that Lise has mentioned, which is available on the CAHPS site. The URL is embedded in this slide. Very importantly, this has come up a couple of times. We want to encourage you to let us know if you’re interested in using the protocol or if you’d like to participate in further testing with members of the CAHPS team. If so, just send us an email with Elicitation Protocol in the subject line and let us know how we can get in touch with you.

Shaller (closing), Slide 56
And finally, please complete the very short evaluation that appears at the end of the Webcast. Your feedback is very important to us. You can get in touch with us any time through email at this address, or by our telephone line indicated here, or visit our Web site.

I just want to thank our speakers again. Mark, Lise, Barbra for your contributions and to all of you for attending today’s Webcast. Thanks again and have a great rest of your day.