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Who Cares What Patients Think?
Alliance for Health Reform and The Commonwealth Fund
December 4, 2006

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ED HOWARD: I'm Ed Howard with the Alliance for Health Reform. I want to welcome you on behalf of our chairman, Jay Rockefeller; our vice-chairman, Bill Frist; our soon to be co-chairman, Susan Collins; and the rest of our board to a briefing on a topic that is at once straightforward and an often overlooked factor in improving the quality of care in the United States, and that's the actual experience of patients in the health care system.

Largely with our partners in today's session, The Commonwealth Fund, the Alliance has held several sessions looking at how quality [inaudible], what steps that are taken that we know are good or not so good in affecting the outcome of care. What actually happens to patients in the hospital, in the doctor's office, is integral to assuring high quality care in programs like Medicare and Medicaid, as well as private insurance. And it may have an impact on outcomes as well.

As I noted, our partner is The Commonwealth Fund for today. The Commonwealth Fund is a private foundation, it stresses the need for a health care that performs at a high level, especially for the most vulnerable segments in our society. And here's something I learned only in reading Karen Davis's biographical sketch in preparation for today's briefing, and that is that Commonwealth is the fourth oldest foundation in the United States. We're happy to have Karen here representing the Fund and as one of our speakers on this topic that really brushes so closely to our personal connection to health care. And Karen, I don't know if you want to take a moment to say something on behalf of the Fund as opposed to your role as a contributing member of the panel at this point, but if you would. Let me then just do a little bit of logistical business if I can.

Right on top, on the left-hand side of your packets is a green question card you're going to be able to use when we get to that part of our program, and a blue evaluation form, which you might just take out right now, and sort of fill in as you go and as things occur to you. I'm particularly interested in your suggestions for how we can improve either this program or other programs that you'd like to see us do.

By the end of today – maybe I shouldn't promise until first thing in the morning – you'll be able to watch a webcast of this briefing on KaiserNetwork.org. You'll find electronic versions of the materials in your kits, both there and on our website, AllHealth.org. And within a few days, you'll have a transcript available for that briefing as well.

Now, we've got a very good lineup of speakers for you to learn from, and I intend to learn from them myself today, so let's get started. As I indicated, we're going to lead off with Commonwealth Fund's president, Karen Davis. More accomplishments than I could possibly cram into my introduction, so I'm going to refer you to that biographical sketch, which I learned from and you can too. She's a widely respected health economist, she's a distinguished health services researcher, she's headed The Commonwealth Fund for more than a decade now, and we're very pleased to have you with us, Karen.

KAREN DAVIS, Ph.D.: Thank you, Ed. Ed asked me if I had any response to the fact that we're old. We talk a lot about being an old foundation, founded in 1918, to make up for the fact that maybe we don't have as many resources as other foundations. But we have been working on the issue of patient-centered care for the last 20 years, in fact, helped start the patient-centered care movement in the mid-1980s by supporting the Picker/Commonwealth Program on Patient-Centered Care that developed some of the first instruments of patient-centered care for hospitals, particularly.

Today, I'd like to talk about what patient-centered care is, why it's important, how it can be improved, and what policies are required to promote it. To start with what it is, you have in your packets an article some colleagues and I published in the *Journal of General Internal Medicine* on the 20/20 Vision for patient-centered primary care. But overall, we view patient-centered care that patients want superb access to care, quality and safety. But patients also want to be engaged in their care and active partners in the care.

So a high-performing patient-centered care system would also use modern information systems that support the provision of high quality care as well as practice-based learning and quality improvement. Patient-centered care is care that is coordinated rather than fragmented, whether that's a primary care physician coordinating care with specialist referrals, or it's a hospital coordinating as a patient is discharged to home or to a nursing home care. Patient-centered care is integrated in comprehensive care. Dr. Barbara Starfield at Johns Hopkins University recently pointed out that a third of patients in primary care practices are referred on to specialists in the U.S. In other countries, the average is about 10-percent. The primary care physicians provide more of the care that patients need, and as a result the total cost of care is lower, and quality is often higher and outcomes are better.

In order to provide patient-centered care, it's important to listen to what patients experiences are, whether those are hospital patients or patients in primary care practice. We also think it's important to make information publicly available. So we're delighted, as Chuck Darby on the panel will talk about the Agency for Health Care Research and Quality's efforts to really develop a hospital patient-centered care instrument. And particularly, the 254 hospitals that voluntarily participated in 2005 in the data benchmarking project, which shows us that across hospitalized patients, the best hospitals are getting reports of about 90-percent to 100-percent of patients reporting that the hospital staff managed their pain well. They responded when they needed help, and they explained medications, particularly side effect of medications well.

But you see the great variation between the best hospital and those who were ranked in the tenth percentile. Why is it important to have patient-centered care? First of all, there is some evidence that high marks on patient-centered care is correlated with health outcomes. As an economist, I particularly think that listening to patients and generating consumer utility is important in and of itself. And in fact, all other goods and services must satisfy customers if they are to make their way in the marketplace.

But I think patient-centered care is also important for quality improvement. If you don't know that your patients are saying they're not having side effects explained, you don't know that you have a particular problem in your hospital, and may not be devoting efforts to deal with it. I also think measures of patient-centered care are an important complement to clinical quality measures, which we know can't embrace all of patients' care.

Just to give you one example of a study that has shown the relationship between patient-centered care, there are a few studies, particularly of hospital patients, that show that patients reporting better experiences within the hospital are more likely to get appropriate follow-up care. And in some cases, in fact, some studies have shown fewer complications and lower mortality for those patients.

Turning to some of the tools that can be used to improve patient-centered care. I was on an Institute of Medicine committee that in 2001 issued a report called “Fostering Rapid Advances in Health Care.” And we recommended that community health centers, particularly, clinics serving low-income communities, should be redesigned to make care very accessible and of high quality. This gives you an example of some work we supported in New York City through the Primary Care Development Corporation working with low income primary care clinics about how redesigning the patient's journey within the clinic can increase physician productivity, and certainly stop wasting patients' time.

These clinics have also redesigned their clinics to provide same day appointments which, again, improves productivity, staff satisfaction as well as patient satisfaction.

In our international work, we've been looking at how effective different countries are in managing chronic disease. And particularly, in our 2005 survey of Australia, Canada, Germany, New Zealand, the U.K. and the U.S., looked at how well these countries are controlling chronic conditions, an extent

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of which they provide patients with self-care plans, and also getting patients' responses to whether or not they felt like they were given clear instructions. I think the bottom line is that all countries have a long ways to go, with about half of patients saying either the physician did not give them clear instructions or did not make goals clear.

More recently, we released the 2006 Survey of Primary Care Physicians, and German primary care physicians were the most likely to say they give self-care plans to their patients. And again, you see they're one of the better of the countries on this indicator.

We've also been supporting some work of John Lawson at Dartmouth Medical College in an initiative called How's Your Health, which you can find on HowsYourHealth.org. Lawson is encouraging patients to fill out questionnaires on the internet and either provide it back to the community as a whole, or to their own individual physician. And he is also finding some evidence that if patients feel like their physician is giving them useful information about managing their chronic condition, if they feel more confident about their ability to manage that condition, then they are, in fact, more likely to report that their blood pressure is controlled or that they have screening for colorectal cancer, or that they are less likely to miss work as a result of physical or emotional problems.

This August, we released a survey of public views on the U.S. health care system. And contrary to a lot of stereotypes of the American patient that likes to go shopping for doctors, go to a lot of different places, in fact, what we found in our survey is that people are very frustrated with a fragmented health care system where one hand doesn't know what the other hand is doing, and that they are very eager to have a medical home one place or doctor responsible for providing their preventive and primary care, and coordinating that care.

They also want easy access to their own medical records. So not just general information on quality, although they expressed a lot of interest in that as well, but knowing specifically about their own medical records. And again, despite, for example, the New York Times story yesterday by Milt Freudenheim on patients being worried about the privacy of their record, at least on this survey, people are very eager to give permission to have all of the doctors involved in their care have access to their medical records, and that their care from different doctors be well coordinated.

That's somewhat difficult, given the current systems that are in place. The U.S. ranks very low on the proportion of physicians that have electronic medical records. This shows you a study from the European Union. More recent data that we have show that about a fourth of primary care physicians have electronic medical records in countries like the Netherlands, Denmark and others, of around 95-percent to 98-percent of physicians that have those tools and systems in place and good functionality with those systems.

What are the public policies that can be used to promote patient-centered care? First and foremost, it's making information available on patients' experiences with their care, whether that's from physicians or from hospitals. I'm delighted that you'll hear today from some of those experiments that have been done at the state level. I was on the Institute of Medicine committee that released in September its pay-for-performance report to Congress that called for Medicare moving toward pay-for-performance with rewards not only for clinical quality, but also for patient-centered care and efficiency.

I'm sure many of you know that in the private sector, many plans are stating to reward patient-centered care. For example, in the California Integrated Health Care Association Initiative, patient-centered care is 20-percent to 30-percent of the bonus rewards for medical groups in those participating manager care plans. That's also true in the Rochester Independent Practice Association Plan. It's very important that Medicare begin to build patient-centered care into the Medicare demonstrations, whether those are on public reporting or on pay-for-performance as well.

Another strategy for promoting patient-centered care is, in fact, using community health centers to become models of patient-centered care with design to make accessible and high quality in management of chronic conditions.

Another strategy that can be used to promote patient-centered care is having, for example, Medicare beneficiaries designate a medical home. Again, the Institute of Medicine report on pay-for-performance recommended that Medicare encourage all beneficiaries to designate a medical home, and to establish defined standards of serving as a medical home and compensating practices that service medical homes. You may resolve the sustainable growth rate once and for all this week, for all I know, but I think the SGR issue provides an opportunity to really improve payment for primary care by building in explicit allowances for those practices that serve this function.

And finally, a way of promoting patient-centered care is to make sure that the tools and systems are in place, including, first and foremost, information technology. Thank you very much, and thanks to my colleague.

ED HOWARD: Thank you, Karen. Next, we're going to hear from Charles Darby, who co-directs the CAPS project at the Agency for Health Care Research and Quality. That's CAPS, as in Consumer Assessment of Health Care Providers and Systems. Right, Chuck?

CHARLES DARBY, M.A.: That's correct, Ed. Thanks.

ED HOWARD: CAPS is a series of surveys that AHRQs made available to researchers and health plans and others. Chuck Darby has been doing sophisticated survey research work like CAPS for more than 30 years. We're pleased to have him here today to explain a little about the major effort to find out how patients are actually treated by our health care system. Chuck?

CHARLES DARBY, M.A.: We're sometimes referred to as CHAPS, which, of course, is a different brand name altogether. But we deal with it. The title of this session, which I thought was really great, was “Who Cares What Patients Think?” And we do. In fact, we design surveys to ask patients what they think about the quality of care which they receive. For a moment, let me draw a distinction between two broad types of quality.

One is technical quality, and that's what we use clinical measures to evaluate, and then there are things called interpersonal aspects of care. Donabedian is the researcher who made this distinction, and the CAPS surveys do focus on those interpersonal aspects of care. The interaction of the patient with the health care system and their provider in order to arrange care, and also to receive it.

Our surveys focus on what we call reports of that experience, and also ratings. Our earlier surveys focused on what we call patient satisfaction, and they tended to boil the

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measurement of patients' evaluation down into a single measure, were they satisfied or not? And this is similar to one of the wine ratings, that you might get a 98 or an 87. We try to get to the components of quality, and I'll talk a little bit more about their domains in a moment. But we try to get down to those individual components of quality so that we can give a richer set of information to consumers.

Early on, this type of measurement was justified on the basis of the degree to which it correlated with clinical measures. Did it affect clinical outcomes and other process measures? And we have come at this, and that's important, but also it's very important to see the patient's experience being reported out in and of its own self.

We also find in our qualitative work with consumers that this is the kind of information that they relate to. They understand it. They realize the clinical part of it is essential, but they don't understand a lot of the measures that are being used. We develop standard instruments and reports which we then put in the public domain. One critical part is, as a federal agency, we don't collect any of these data ourselves. We make the data available to others so that they can – or we make the instruments and other tools available to sponsors so they can collect the data and then report it out.

Let me for a moment, if you'll allow me to skip to this next slide. These are the domains that we're talking about.

And this is my cut edit. Others in the room that do this work might have a little different cut. But when I think of the remains [misspelled?] of patient-centered care, I think of these elements. Communication, which is probably the first and foremost of all these. How well does the doctor explain things in a way that you can understand? Does the doctor listen to you? Do they spend enough time with you?

Access. Can you get an appointment when you need it? Coordination of care. An item might be, does your doctor know everything that you think he or she should know about your medical history? Patient involvement. To what degree is the patient in their care as much as they would like to be?

Cultural competence. And this is an important one also. One of the items we have is whether an interpreter is available for a patient. Another one might be just does the practice understand the cultural differences of the patients that are there?

Next, health literacy. To what degree does the health care provider help the patient understand the information that they're being given about their treatment and their health? Health information technology. We're just starting now to develop some items that will get the patient's perspective on the use of the electronic medical record, personal health medical record, et cetera, to see what their view is in terms of what impact it has on the quality.

And finally, patient safety. Another critical element. In our hospital survey that Karen mentioned, we have an element that asks about whether side effects were explained, as she indicated in her slide. And if the patient understands and is told what medication they're being given. I'll go back to this slide for a moment.

These are the kinds of things that CAPS measures, are those things that the patient is the best, or maybe the only source of information. When you ask, "Did you understand the information that the doctor gave you? Did they explain it?" Only the patient can answer that.

We employ the best science, we have been blessed to have some of the best researchers in the field at Harvard, Rand, The American Institute's Research and Research Triangle and Westat, to help us with the work that we do. We aim to get broad stakeholder input. This has been a major hallmark of the work that we do. Every survey that we redesign, we get the input, first of all, of those who are going to be measured. Because they've got to understand this, and then those who are going to use the information, we'll meet their needs.

We focus on public reporting. Although there are a lot of other purposes I'll show you, we think our end goal is to do public reporting. We also, then, once the surveys are out there and the reports are out there, we provide technical assistance to those who are sponsoring the work. Adoption is

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our end goal. Ed said that I'd been doing this for 30 years, and a lot of those were research projects. And I know that there are volumes on somebody's shelf that have collected dust, and maybe they never opened. The CAPS project is more than a research project. It's a project to put tools in the hands of people so that they can measure quality and report it out.

I talked about adoption. We have the Health Plan Survey, that was our very first one that we developed, and it was issued in 1998. Two critical things happened, the so called tipping points. One is that the National Committee for Quality Assurance, NCQA, adopted our survey. They had their own survey, but they switched over to the CAPS survey.

Then the Centers for Medicare and Medicaid Services also adopted the survey. Medicaid programs are using it, many state Medicaid programs, the United States Office of Personnel Management. If you're a federal employee, you have CAPS data available to you that you can look at each of the health plans that are offered on Open Season. The Department of Defense also uses it for tri-care. So that at one point we have been able to say 138 million Americans are enrolled in health plans for which CAPS data are currently collected.

We have an evolving family of surveys. The facilities surveys include the hospital survey, two nursing home surveys, one of residents and a new one for family members which is currently being developed. A CAPS survey for in-center hemodialysis, and then ambulatory surveys. The health plan survey which has been in existence for a while, a new clinician group survey, and then one that's now currently under development for home health.

The HCAPS story is an interesting one. It took a long time and it was painful, but it all happened. And in a lot of ways, the reason it happened is because of collaboration in working with stakeholders. That was a critical, critical part of the work. There was a need for a standard survey. There are a lot of existing one out there, but no one was using it on a broad enough scale that you could make valid comparisons between hospitals.

So that, at this point now, some 3,000 hospitals have volunteered or enrolled to collect the data and report it to CMS so that in early 2008, CMS will begin publicly reporting those data to all consumers. It won't just be for Medicare beneficiaries, because the sample from the hospitals will be all the patients to come there, that are admitted to the hospital, and not just Medicare beneficiaries. This is a prime example of some federal partners working together to make something like this happen.

Finally, the use of the CAPS data for public reporting. As I have said, accountability, accreditation. NCQA uses it to accredit their health plans. The American Board of Medical Specialties is now considering the use of the CAPS clinician group survey for its maintenance of certification. There are pay-for-performance examples, and also for quality improvement. And quality improvement is the ultimate goal so that in the future, that's going to be one of our major focuses. We're about to start another five years of research in this project.

Reporting to consumers will also be a focus, and a major focus on the clinician group survey. You can imagine if this survey was administered for every doctor in the United States, the cost gets pretty high. So we will have to look at ways of reducing that cost. Getting the sample to be smaller, to have cheaper ways of collecting data on the internet. And the other side is to focus on the value. How do we improve the value of the data, and I'll talk about that in a minute. We work very closely with a lot of stakeholders, currently working with the ambulatory quality lines and the hospital quality lines.

The trusted agent concept. The idea to have a central database where CAPS data for a wide variety of surveys could be, once it's collected, put into this repository and then various sponsors and users of the data could draw back for their own purposes. This would be a trusted agent, meaning it would be trusted to not report this data out to anybody that they shouldn't, and to handle it in the right way. It could be used for many, many different purposes also.

This idea of a trusted agent was put out in the IOM report on improving performance measurement. And as I have worked in this field, I think there is a growing consensus around the kinds of things that we should be measuring related to patient-centered care, much more so than on the clinical side. A fairly parsimonious set of measures that could be administered and used on an ongoing basis.

Here's some contact information for myself and my colleague, Chris Crofton at AHRQ. We welcome your questions and comments at any time. Thank you.

ED HOWARD: Thanks very much, Chuck. And I should point out to people that a selection of documents representing both the instruments that Chuck was describing and some of the data summaries based on those instruments having been used are in your packets. And I think you'll find them both concrete and very useful as you try to think through this important issue.

Our final speaker is Melanie Karp. Melanie directs programs for the Massachusetts health Quality Partners. MHQP's a partnership of virtually all the key players in the Massachusetts Health Care System, which has begun a statewide project to measure actual patient experience. And I guess director of programs is the proper title? What did I say? Whatever I said, her name is Melinda. All I have to do is read it right on the card... A senior moment.

It's a good thing I have written down what I want to say about her besides her name, because she is, in fact, an experienced developer and user of quality improvement and performance measurement tools, and she's here to tell us how information about consumer experience can be put to use in the real world, because that's exactly what she and the Partnership are doing. Melinda, please.

MELINDA KARP, M.B.A.: In the brief time that I have with you today, I'm going to take you on a whirlwind, although I hope informative tour of who MHQP is and how and why patient experience, measurement, and reporting is so central to our strategic agenda in Massachusetts.

The headlines from October 1994 in *The Boston Globe* were what you see on the screen. *The Globe* did a spotlight series basically using Hickford [misspelled?] mortality data to, quote, measure the quality of hospitals in Massachusetts. As you might imagine, the hospital community was up in arms to have on the front page of *The Boston Globe* reports about their quality based only on mortality data.

It's fair to say that's not how they wanted quality about them to be measured. In fact, one of these 10 worst-performing hospitals was a hospital that had been spending the last several years engaged in a White patient-centered program to improve the way they manage end-of-life care, and specifically to make sure that their clinical staff

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communicated well with patients and families about end-of-life and Do Not Resuscitate orders. So it's not a big surprise that they ended up having higher mortality rates as they got better at respecting end-of-life wishes and Do Not Resuscitate orders.

Thanks to some visionary leadership among some of Massachusetts' hospital and health care leaders at the time, MHQP came to be shortly thereafter in 1995. Those leaders came together and said, "This isn't how we want quality to be measured in Massachusetts. And further, it's not enough for hospitals to measure hospitals and doctors to measure doctors. We need to establish a broad based collaborative where we can be accountable to each other and to the public, and have responsible and accurate reporting of the quality that's going on within our health care system."

As you can see from this slide, MHQP today is composed of a broad based set of stakeholders, really representing all of the health care interests in the state of Massachusetts. Our overall goal as an organization is to be the trusted leader in providing actionable health care performance data to all of these stakeholders to be used in a variety of ways, ultimately to improve the quality of care that the residents in Massachusetts receive.

In that vein, to become that trusted source, we have a 10- to 12-year history of comparative performance initiatives, really looking both at patient experience and at clinical

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quality. Our focus on patient experience really began with our flagship project as an organization. In 1998, we publicly released the first statewide hospital survey of patients' experiences with their care in the hospital.

Why did we go right into focusing on patient experience when there were lots of other domains of quality that we might have wanted to look at? MHQP had a set of researchers come to the table very early in our life as an organization, go through lots of literature, look at what was going on, both locally and nationally, and they came to the conclusion that one of the biggest gaps in information about quality had to do with the patient's experience.

Additionally – and Chuck has already talked about this, as Karen has, as well – patient experience is something that resonates with the consumer, with the patient, much more so than many of the clinical metrics that we look at. It also applies to everybody. Whether anybody who walks to the doctor's office, anybody who steps foot in the hospital, that data applies to them. And on the flip side, any hospital who has patients and any doctor who has patients, this data applies to them.

We've since continued our efforts on the patient experience agenda, moving from the hospital setting into the ambulatory care setting. The culmination of our work in that area was our first, again, in the nation public report of patients' experiences with their primary care practices in 2006. We started that work very shortly after we started engaging on the hospital side. That work was a bit further behind, in terms of development, and it just resulted in our public report this past March. As I said, a milestone for us has been this first public report at a statewide level. It was a survey that included 497 practices, which are most of the primary care practices in Massachusetts, representing almost all of the primary care physicians in the state. We included about 150,000 patients in this survey.

Interestingly, the survey was funded entirely in the private sector by MHQP member health plans. We fielded a 50-item instrument that covered eight domains, most of the domains that Chuck has talked about in terms of ARC's work. And in fact, the MHQP survey really has developed kind of in parallel, and in collaboration with the work that's happening with CAPS at a national level. The core CAPS clinician group CAPS items that you see in your packet mirror very closely the MHQP items, and we've been working very collaboratively with the CAPS team in the development of that survey instrument to create national standards.

The reports went to our physician community in November of 2005, and to the public in March of 2006. That time window, from November to March, is really important as part of MHQP's core collaborative process, in that we include those who are

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being measured in the development process. And we give them an opportunity to see their results, to comment on them to us, and if we need to, to make any corrections before we actually go to the public with their results.

So what did patients actually have to say to us about the care that they were receiving from their primary care physicians? Well, honestly, we got a mixed message. In terms of best performance, most of the practices in the state did extremely well on communication. As Chuck pointed out, the domain of communication are things like how well did the doctor explain things in a way that patients could understand, how well did the doctor, and how often did the doctor provide clear instructions. What to do if your symptoms got worse.

So what we saw was that doctors and practices largely did very well on that measure. The disconnect came when we looked at some of the other domains. Areas for improvement, as you see, were that more than a third of adult patients said that their personal doctor didn't always seem to know all of the important information about their medical history.

Patients reported that their primary care doctor was not always up to date and informed about care that they receive from specialists. Almost a quarter of adult patients, and even more of our parents of our pediatric patients said they did not get test results back from their doctor's office in some way, shape or form.

So the disconnect for us here, as we start to look at this was, gee, it seems like, for that 10- or 15-minute interaction that's going on behind the exam room door, in terms of communication, patients seem to be feeling pretty well about that. But in terms of the integration, the continuity, and the coordination of care, and the relationship building over time, we've actually got some places that we need to improve.

There are a number of reasons we could posit for why we saw what we saw, but in these three areas of improvement that I've highlighted for you, there's a trend here around transfer of knowledge and transfer of information. And that there seems to be a breakdown in terms of how information and knowledge about patients is getting transferred and translated to all of those taking care of the patient.

One of the most striking results that we saw was actually about team care. In today's era of primary care, where we fully acknowledge that primary care physicians are increasingly beleaguered and actually increasing dissatisfied with the way they're needing to practice medicine. And increasingly short on time. Given all of the chronic disease that they're expected to manage in their practices on a day-to-day basis, the notion of team-based care is more and more being integrated into how we provide primary care in the United States.

With the primary care physician there as well as a host of other team members, nurses, nurse practitioners, physician assistants also providing care to the patient. Well, what we saw with our results was that, that may be the system that we want and need to put in place, but from the patient perspective, it's not feeling great. And they're not having good experiences when they are seeing those other care providers that are part of the physician's team.

In this table, you can see that we asked several questions, both of the patient's experience with their primary care doctor and then their experience for that same question with other doctors and nurses in the practice. And the difference is striking. We've got a ways to go to help the patient both understand and integrate this concept of team care and to feel good about that kind of approach to their care.

I'm going to jump from the results that we found to actually how we translated these results to the consumer. Physicians got lots of detailed reports with lots of communication from us about those results. And then, to go to the consumer, to the patient, we translated the results on to our website. I'm going to give you a really quick snapshot here, and encourage you to go to our website and take a closer look through all of the results that we show.

And this slide is here just to illustrate for you that we really try to meet differing patients' needs in terms of the information that they had going into their search, or their look for some quality data. Patients could come into our site and search anywhere from just by ZIP code, if they were moving and needed to find a new doctor, a new practice, all the way down to searching by a particular doctor's name if they just wanted to see how their physician's practice was performing.

When they then drilled down to get results, this is the first screen that they would see. This was actually the result of a search a five mile radius from my ZIP code, and came up with these two pediatric practices. And that, you see, are the ratings in terms of stars for each of the domains of care across the top. And then the patient from there can drill down to look at the specific survey questions that represent how well doctors communicate. They can go down and look at the seven or eight survey questions and how that physician's practice performed cross each item. They can also go into the practice and look at all of the measures that we reported for that particular practice.

So how is MHQP data being used? As we've talked about, our data was reported to both physicians and to consumers. I can honestly say that we've gotten more traction in the physician community than we have in the consumer community, in terms of the data being used. Physicians are really paying attention to this data. They're using it internally for quality improvement purposes, and a number of practices and

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physician organizations are actually starting to tie it to internal physician compensation practices, in terms of bonus structures or core salary.

On the consumer side, as I said, we have not gotten as much traction as we have on the physician side, but we are starting to see lots of links to different sites in Massachusetts to the state website, to health plan websites, and directly from several provider organizations wanting their patients to be able to see the results from MHQP's work.

How is the data likely to be used in the future? I actually think, again, it maps very well to Chuck's slide about what we see on the national front, as most of you probably have heard about Massachusetts State Health Care Reform Law, in terms of providing universal access. Another component to that law is actually about transparency around quality and cost. And MHQP will be working very closely with the Quality and Cost Council in Massachusetts to make sure that the MHQP data actually gets integrated into those statewide reports that go out to consumers as part of that transparency initiative.

Chuck's already talked about physician certification. We would like to see that happen in Massachusetts as well. We're starting to hear from employers the importance of actually linking our reports directly to their sites. As they're the ones ultimately paying for health care, they'd like to see our reports directly linked to their sites.

And finally, health plans are starting to think about how best to incorporate these results into their product design, their pay-for-performance, much as we're already seeing in California, and recognition programs with the physician practices in their network.

So what are the key lessons so far? Most of these, we've actually already talked about in the last number of minutes. The one that I'd really like to focus on is physicians wanting to do the right thing, and needing the tools to improve. As MHQP moves forward with our strategic agenda around patient experience, this is a place that we want, and very much need, to focus. What I hear almost all the time when I go out to talk to the physician community about their results, is a fair amount of anxiety.

And physicians are competitive by nature, they want to do the right thing, and they need the tools to help them improve. And they don't feel like they have all of the tools and the resources they need to help them improve in these dimensions of care. So we'll be spending some time working with them to facilitate them getting those tools.

Ongoing challenges. Creating a sustainable financing model for continued measurement and reporting. As I said, MHQP's member health plans have funded our survey efforts to this point in 2007 to the tune of $1 million. They've been really clear that they cannot continue to sustain that effort on their own. That, in fact, it's not enough to have all of our stakeholders at the table collaborating on development and implementation, but we need to have more collaboration in terms of payment. And we need to bring the public payers into the loop, Medicare and Medicaid, and get them engaged in our statewide efforts, as well as the physician community.

Finally, there's lots and lots of energy around this. And one of our continuing challenges will be to be able to meet everybody's differing informational need, be it the physicians, the health plans, and the consumers. And we've actually already talked about all of MHQP's next steps in the course of discussion. And I am way over my time, so thank you for your indulgence, and I'll stop there.

ED HOWARD: Thank you, Melinda. I'm sure that at some subconscious level, I couldn't process the fact that there were two Melindas involved in this briefing. Melinda Abrams of The Commonwealth Fund was very instrumental in putting it together. We had a wonderful time on some of the conference calls, when people identified themselves as Melinda.

You can identify yourselves as your real name, as you go to the microphones to ask questions, and fill out the green question cards. Hold them up and a staff member will take them from you and bring them forward. While that gets going, let me follow up on something that Chuck said and, actually, Melinda alluded to.

You talked about how the data available in the national database imposed a duty on the people in charge not to report the data to anyone they shouldn't. Who is that? Is that the public? Is that the press? Talk a little about the trade-offs that you're implicitly referring to.

CHARLES DARBY, M.A.: Sure. Hopefully, there would be a wide range of uses, but as data are submitted there would be data use agreements as to how those data could be used. We would be interested in continuing to push to get data publicly released, since that's our end goal.

ED HOWARD: We have some questions that have come forward from the audience, and as I said, I would encourage you to go to the microphone. In fact, having done that, you have the opportunity to bring up the written questions. Please identify yourself.

BOB ROHR: Thank you. Bob Rohr [misspelled?] from BMJ. This is primarily for Miss Karp. In your survey of Massachusetts, did you see any difference between those practices that used electronic medical records and those that did not, in terms of integration and the team approach?

MELINDA KARP, M.B.A.: In fact, we have not done detailed analysis yet in terms of the electronic medical records specifically. But what we can say, anecdotally, as we look across the practices in terms of some of their demographics and structural features, in general, we did not see what, as you might surmise, that those larger, better infrastructured practices doing better than some of the smaller, less well infrastructured practices as a whole. We did not see that.

ART KELLERMAN: Good morning. Art Kellerman. I'm a Robert Wood Johnson Health Policy fellow, and I served on the Institute of Medicine's Committee on the Future of Emergency Care in the U.S. I have a question for Mr. Darby. I was looking over the hospital survey. Our committee pointed out that about 43-percent of all hospital admissions in the U.S., and a greater percentage of medical admissions, come through emergency departments.

And emergency departments also provide about 11-percent of all outpatient care in the United States. There are three questions on the hospital survey about bathroom use, but there's not one question about emergency care. Is that addressed in another survey that AHRQ is doing, or, where are we going to begin to get at the issues of access, quality, and safety in emergency departments that are so important to American citizens into our emergency preparedness?

CHARLES DARBY, M.A.: It's an excellent point. We struggled with that. Our charge was to develop a survey for the inpatient care, not the emergency room care. There has been some discussion about funding such a survey. Again, there are a number of vendor surveys that were out there for

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emergency room use, but there is not a single standard survey. So I agree with you. If we were to have the funding, we would start on it right away.

Another area that has not been covered is pediatric care. And we were asked several times in the process as we were developing the adult survey, when we would develop a survey for children. And hopefully, that would be an area, also that we would address.

ART KELLERMAN: I would encourage you to go forward, because so much of an inpatient's stay is determined by what happens in those first hours. And often, these days, days in the emergency department for admitted, or hospitalized patients. So I would encourage you and the agency to keep pushing forward with that.

CHARLES DARBY, M.A.: Thank you.

ED HOWARD: Let me take a question that someone has put on to a card. It's not addressed to a particular panelist. Are there any private insurers offering consumer-directed health care plans you'd like to cite as good models for patient-centered care? Karen, you want to try that one?

KAREN DAVIS, Ph.D.: Well, certainly, I think some of the advances in consumer-directed health care broadly defined as making quality information available to patients and not just high deductible health plans. I would point particularly to the California IEJ [misspelled?] experience, where nearly

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all of the major health plans and medical groups are cooperating in an initiative that bases bonuses, at least 20-percent, varies year to year, 30-percent, on patients' experiences with medical care.

With regard to consumer-directed health care plans, we'll be releasing in a few days the second annual EBRI/Commonwealth fund Consumerism survey. But contrasting the extent to which those plans really make quality information and cost information available to their enrollees versus those in traditional, or comprehensive plans. So I'll hold the answer in suspense until that's released on Thursday, but I think you'll be interested in that.

ED HOWARD: And we'll try to post a link to that on our website, so if you want to go to the briefing materials, you'll be able to find that, as well. Yes, please.

VALERIE TATE: Thank you. My name is Valerie Tate. I'm a registered nurse, and I'm with the Nurse Alliance of SEIU, the Service Employees International Union. I support the work our nurses are doing on improving quality in their workplaces with their employers. And I think nurses know, patients know, the studies show that nurse-to-patient ratios have a terrific impact on the quality outcomes that patients experience.

And I'm wondering - I guess this is maybe for Mr. Darby. What kinds of questions are asked that might go to the core functions of nursing and how patients perceive them? I know that Jack Needleman, one of our foremost researchers on nursing, says that we're not really going towards those questions in pay-for-performance, or in our other investigations. And so, are there questions that go to assessment planning intervention evaluation, or what patients might perceive as providing care for nurses enough time to explain things, to prepare them for discharge, et cetera? Thank you.

CHARLES DARBY, M.A.: Obviously, many of the things in the hospital survey related to the care that they receive, helping getting to the bathroom, responding to the call button when it's pressed, functions that the nurse is performing on an ongoing basis. We also made sure that we have a separate composite, or domain, for the nurse communication, because in our work that we did, our qualitative work with consumers as we were asking them about what was important to them when they had a hospital stay, the nursing care was critical. And whether the nurse was listening to them and explaining things in the way that they could understand, that was very critical. So we made sure that we had a separate composite for that communication, separate from the communication with the doctor.

ED HOWARD: Follow-up?

KAREN DAVIS, Ph.D.: If I could just add to that, I do think one of the next steps has to be surveys of the employees of health care organizations, so nursing or other staff within the hospital. Particularly important in the nursing home setting and the home care setting. So getting feedback from nurses and other health personnel about their empowerment to correct things and better serve patients I think would help round out what we're hearing directly from patients.

VALERIE TATE: Well, I appreciate both of those answers very much, and I would just tack on that in many cases we're measuring the tests that nurses might perform, but not the core functions of what they provide to improving patient care quality and safety. Thank you.

ED HOWARD: I've got a question addressed to Karen Davis. Much of the literature – and I should say, I'm picking up a little bit of a pattern here about your interest in the actual consumer's perspective on these issues - much of the literature pertaining to patient-centered care emphasizes systemic responsibilities to do better. Doctors, care systems, purchasers. What about consumers? Shouldn't they help drive change toward primary care with their expectations and behaviors, not merely by reporting their experiences? What about the role of pull, if you will, in lean manufacturing literature?

KAREN DAVIS: Well, I definitely think this can be a force for change in the future. We've talked about how the main ones that respond, for example, to the Massachusetts Health Quality Partners data are the physicians themselves, who are concerned about their ratings and getting them up. But I think patients, while they may not have used quality information in the past, and base their decision on where to get care very strongly on that, I do think it can be a powerful force in the future, and the prerequisite for that is having the kind of information that patients finds desirable, available.

So what we know is they want to know about their individual physician, not about a big entity like a medical group or a health plan. But they want information on things, reports of other patients about their experiences with care. They want to know whether you can get same day appointments, whether translations services may be available. Certainly, our surveys are showing that patients want access to their own medical records. They want to be able to go and look at their medication lists or their lab tests.

So as this evolves, and more of that becomes in the public domain and the kind of information that patients really want on their physicians, it's hard for me to think there won't be a substantial number of patients who both will use that information, and use it to make decisions about choice of provider.

ED HOWARD: Melinda, you want to add to that?

MELINDA KARP, M.B.A.: It's a really good point, and one that our physician community in Massachusetts has asked us about over the last number of years as we've pushed in terms of putting this data out about them. As Karen noted, they really want data about their individual physician. And in our qualitative work in Massachusetts, we heard that loud and clear. We didn't provide that to them, our data was provided at a practice site level.

So it's not incredibly surprising that we didn't' get as much traction with the consumers as we might have liked to see. One of the things that we do have on our site that I urge you to take a look at, and that I think as we start providing more of the kinds of data and information that consumers want to see, they'll be more drawn to our site and sites like ours, is a section about what the physician can do and what the patient can do in terms of improving their interactions on whatever the quality measure, the patient experience measure is that they happen to be looking at.

And we worked both with our physician community, with our consumer community, and with a health literacy expert to really try to nail down that pull concept, in terms of starting to get the patient to think about, "Okay, well, what's my responsibility in this interaction?" We've got to get them to be interested in seeing the data, and go to the site and be thinking about these issues.

But once we do that, I think that is the very next step, is starting to get them to start to think about, "Okay, here's what I should expect my doctor to do, and here are some of the things that I need to do."

JOSH SEIDMAN: Josh Seidman from the Center for Information Therapy. This question is for Chuck. I know that in June you started convening stakeholder meetings for the HIT CAPS work, and I know that also that was sort of the preliminary thinking about the domains and so forth. I wanted to hear what the status of that is, and where you're thinking you're going to go in terms of the domains that you want to measure.

CHARLES DARBY, M.A.: Thanks, Josh. This was modestly funded as a launch to get things started. We plan to have focus groups, which will occur in, I think it's January and February, to get input from consumers. One of the challenges is to define what we meant by health information technology, and, as you know, at that meeting we spent a good deal of time with that.

We now want to get some consumers input into what's been their experience with health information technology, and locating consumers who had a fair amount of experience so that it's something that they can report on.

After the focus groups, we'll be documenting that, developing a small set of items, doing some cognitive testing where we administer the items to potential respondents. Get their feedback about what the items meant to them, and then we

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modify them. We are currently pursuing some funding to do a field test of that set of items, which I think probably would occur in late Spring.

ED HOWARD: If I can ask your forbearance here for a second, Chuck, let me just follow up. It's not really about IT, but more generally. But with the point that you were making about consumer involvement in the follow up. What kind of consumer involvement, the questioner asks, either consumers or consumer advocacy organizations, happens in the design of these surveys? Consumer satisfaction, the assertion is added, may include non-traditional values.

CHARLES DARBY, M.A.: It's interesting in that – it's an excellent question – we, first of all, involve consumer advocates and organizations that represent consumers in our stakeholder meetings. But to reach out to consumers, individual consumers, we do two things that I mentioned when Josh Simon asked his question.

That is, one, to have focus groups where we get people who have had, for example, with the hospital survey, people who have had a recent hospital stay. And we ask them to talk about that hospital experience, and to describe it to us and explain to us what was important, what did they think were the most important things that led to good care, things that led to not so good care.

And we use that to help identify, then, the kinds of things we should be asking questions about.

A lot of survey designers have started with the questions and then they show them to people and say, "What do you think of these?" Well, we've already then sort of narrowed the universe in what you might ask about. We try to stat more openly, and say, "What kinds of things are important to you?" And again, of course people who have had a recent experience. So we get that consumer input, and then as I just mentioned, as we are refining the items, we administer them to likely respondents to get their feedback.

I learned early on that survey designers actually are the worst people to guess what people will think of the items. You've got to administer them to real people, and say, "What did this mean to you?" And sometimes, you slap your head and say, "What? We never even thought of that before."

BOB ROHR: Bob Rohr, BMJ. The U.S., as you've pointed out, lags behind with electronic medical records, lags behind many of the industrialized countries. How have those other countries used those records in terms of patient-centered delivery of care, and what has been the reaction or the response from their publics?

Have the electronic records, knowing more about their physicians or their own individual records, are those available with other systems in other countries? And has that improved the way that they're – whether they view those systems favorably or not?

KAREN DAVIS, Ph.D.: I don't have a good answer to that. The two examples that I might use, in Denmark, which is really the most advanced in electronic medical information systems for primary care physicians, patients can directly access their medical records. So in terms of seeing their medication histories, getting their lab results. They can also find out who else has accessed their records. One of the issues around privacy is that they not only authorize providers to access the record, but they can then look who has, in fact, entered their medical record. It's a little different point, but in Denmark, they've started paying for e-mail visits. So it's something like $8 for an e-mail consultation, and they've had a skyrocketing in patients' use of that.

Obviously, Denmark not only is the most advanced in their primary care and access through their off-hour service, which is a very organized system at giving care on nights and weekends, the public surveys rate the health system the highest of any country in Europe. So whether there's a cause and effect of all those things, I don't know.

In the U.K., they have now started posting individual physician quality results around things like cardiac surgery outcomes. So you get the photo of the physician, you get how many procedures of this type they've done before, what their mortality experience is, compared to the average physician's. so again, I don't know exactly how that's been received, but it's fairly advanced now, in terms of those kinds of websites being available with that kind of information at the individual physician level.

KELLY BUCK: I'm Kelly Buck with the National Alliance for Health Information Technology. This question is specifically for Ms. Karp and Massachusetts, but if you have any comments outside, you in general, I'd be willing to hear this too. Your areas for improvement in patient experience indicated that there were gaps in knowledge of patient and integration of care. Do you have a sense of how accepting both patients and providers would be to using technology such as electronic medical records to close those gaps?

MELINDA KARP, M.B.A.: That's a really good point, and that's in part what I was alluding to when I said we see a theme in some of the results that we saw in terms of areas for improvement, that a lot of what we saw had to do with physicians not having the information that they needed when they needed it, according to the patient. That they didn't have information about specialty care, they didn't have relevant information about the medical history. And I think we have to surmise that it's not because physicians didn't think it was important, or didn't care about it. But I think that having better information technology and an electronic medical record certainly would allow physicians and the team, as a whole, to have much more access much more quickly to the data that they need. Even in terms of team care, if they don't know the patient that well yet, because they're not the primary caregiver for the patient.

That being said, I think that the electronic medical record alone, it's not a panacea. It alone is not going to drive the improvements that we need to see, in terms of patient-centered care and patients' experience with care.

It's an integral part, and it's a really important tool, but we have a very large system in Massachusetts that has had an electronic medical record for a really long time. And in fact, was not performing well at all on their patient experience measures, and has since, in the last number of years, put forth a huge quality improvement effort specifically around the patient experience domains, and has integrated that improvement with data that comes out of their electronic medical record. But it's safe to say that alone isn't going to drive all the improvement that we need to see. But it is a really valuable tool.

ED HOWARD: Let me slip in a question from a card, if I can, and it actually is directed toward Melinda. How are health plans using the data that you generate for product design, and are you providing the tools to physicians to improve? And, if so, what kind of tools?

MELINDA KARP, M.B.A.: Sure. In terms of health plan product design, MHQP, being a broad based collaborative with all of the health plans sitting at our table, have to be really careful about how far down the path we go, in terms of even knowing about, or participating in any way, in individual health plan business strategy or product development.

So a lot of the time, we don't see before the general public sees, what product design looks like for any given year. But what I can say is that in general, we're starting to see pressure from the employer community for health plans in our marketplace to be creating tiered networks of physicians based on cost and quality.

As part of that network-tiering, the patient experience component of quality is a part of that quality metric so that at the end of the day, physicians get tiered in terms of co-pays that patients need to pay to go visit those physicians, perhaps rates that they get paid based on their performance along a host of clinical quality patient experience and efficiency or cost metrics.

KAREN DAVIS, Ph.D.: There certainly has been some work that looks at what are the main things that affect peoples' willingness to recommend a physician to others. And the things that get rated highest are always the communication. So the interpersonal relationship between the physician and the patient dominates over things like IT, information, even accessibility of appointments. So I think tools to help physicians improve communication skills are particularly important.

And we're funding some evaluation of training physicians in something called the four habits approach to a medical visit. This is a technique that Kaiser Permanente has used for some years. So trying to systematically evaluate our physicians who get trained in following that structure in a medical visit more likely to improve the way patients rate their communications skills.

ED HOWARD: Melinda, that's consistent with what you were saying in your original presentation.

MELINDA KARP, M.B.A.: Absolutely. And I was just going to go on to address the second part of that question about tools. Massachusetts has recently received a grant from the Physician Foundation, in collaboration with our state medical society and Masspro, which is our peer review organization in Massachusetts, our QIO.

And to actually develop some innovative curriculum that really provides tools for clinicians both on the clinical quality side and the patient experience side and really wraps the intent of our curriculum development is to really kind of wrap the patient experience domains around clinical quality in particular areas.

Because we've had this model forever, I think, where we tend to work in silos and we think about, "Well, quality improvement tools for specific clinical conditions," and "Quality improvement tools for specific patient experience domains." And in fact, the interface of the two is critically important to alternately transforming the patient experience and the quality of clinical care that they receive. So we'll be working over the next couple of years on those tools to get out to the physician community, as well.

ED HOWARD: Thanks very much. Yes, sir.

BOB GRIST: Bob Grist with the Institute of Social Medicine and Community Health. It's interesting to hear about these tools collecting data that health plans often don't bother collecting from the providers that they contract with. HMOs might, but many of the health care plans don't bother collecting this information about the quality of the care that their providers provide.

And clearly, patients can report clearly on the communication experience that they have, and many of the other domains that Chuck mentioned. But what kind of focus has there been on the patient's experience dealing with the fragmentation in the health care delivery system? In other words, yes, they can report on their visit to a doctor or to a hospital, but within the larger health care delivery system that the doctor or hospital functions in, there are many gaps. There is a lot of fragmentation. I'm wondering if there is a role for a CAPS tool that captures the experience of the fragmentation in the delivery system, because I don't think we are using regulatory authority to address that. And frankly, it may be a crucial key to getting improvements in the standards of care throughout the delivery system.

ED HOWARD: Karen or Chuck?

KAREN DAVIS, Ph.D.: Well, Chuck's really better to answer that, but the National Quality Forum has approved three care transition measures focused particularly on the transition from hospital to home, or to nursing home. So I think relooking the hospital CAPS to make sure there's those care coordination care transition types of measures are incorporated, are important. Obviously, there are some measures about specialty referral in the clinical and ambulatory and group CAPS.

CHARLES DARBY, M.A.: I would say broadly, of course, coordination of care kinds of items also might get at that. But they could be made more specific to really get at the issues that you're talking about, Bob. I think it's an excellent point.

In the HCAP survey, there is a question about discharge information, so that's a transitional one. I'm pleased to hear that NQF has approved some transition measures, but anyone who has had a recent hospital experience and long-term dealing with that, knows that that's a lot of places where things break down. You have to end up coordinating your own care, because no one is doing that for you. So thanks for the suggestion.

ED HOWARD: I've got a card here that has more words on it than I think I've seen in a very long time on a single card. But there's a single idea that comes through it. So if you'll bear with me, let me read what is here.

Is there a format of the questionnaires available for patients who can't read or don't speak English? How do you teach patients to advocate for themselves, especially those who are fearful or intimidated by authority, those who lack basic knowledge about health care or their own body, those who lack access to information on the Internet, those who need to understand information by seeing it, maybe they can't read. And is there a place on these questionnaires for ideas from the patients? There. Take a piece of it.

CHARLES DARBY, M.A.: Let me take the easy whole hog. I'll take the easy part. As far as the CAPS questionnaires, of routinely are all translated into at least Spanish. There's a requirement that we started with at the beginning that they be in both English and Spanish. So those are made available to sponsors.

Many of the CAPS surveys have been translated into many other languages beyond Spanish. Also, there are alternative methods for surveying such as the use of telephones, where one

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would not have to read. As far as the idea of helping patients to be the ones that say, "Okay, I need to speak up for myself on this particular issue, or figure out how to activate myself as an active patient," we have not included items per sé in the CAPS questionnaire.

There is a line of items that have been developed called Patient Activation Measures, and Investigator Judy Hibbert has developed some of those. Now, that's a way of measuring what a facility might be doing to help a patient activate. But in terms of getting patient input into that, that is something as we might develop some items in that area, again, we would do some focus groups.

KAREN DAVIS, Ph.D.: Just to add to that a little bit. You've got in your packets an arc list of frequently asked questions and on page six it references a study we supported by Leo Morales at UCLA looking at the psychometric properties of the Spanish CAPS. We thought it was particularly important to know not only that it's translated into Spanish, but the questions really mean the same thing to a Hispanic population. So there's been some care to look at those kinds of issues, as well.

ED HOWARD: But we have heard some talk this morning about literacy problems. And one wonders, Melinda was talking about mailing 200,000 questionnaires. What about the substantial percentage of patients, or patients' families who

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can't read or can't understand? Is that something that ought to be addressed in future survey developments?

CHARLES DARBY, M.A.: Sure. We try to get the reading level – I mean, obviously, if you can't read at all – but we try to get the reading level down to at least the sixth-grade level and try to do better than that. But again, an alternate approach is to use a telephone survey to follow up with those who might not be able to read.

ED HOWARD: And do any of the people who use the CAPS survey do that?

CHARLES DARBY, M.A.: They use telephone also. And there are some sponsors of surveys who will use telephone simply because they feel like they have a high proportion of their population who might not be able to read, and therefore they use telephone. Again, the problem with telephone is that it's more expensive to do than mail.

ED HOWARD: Yes, go ahead.

KAREN DAVIS: And I'll go out on a limb, since I'm not a methodologist. But I think we really have to get to the point of collecting this in real time, so that when the physician is leaving the physician's office, there's a little instrument right there, and you fill something out right then. And you can have a patient advocate assist for people who need some help with that process.

Obviously, the hospital discharges, they think, well, let people get home 30-60 days, recover, they have a somewhat different view than they had when they were in pain and immediately leaving the hospital. But I think we're missing something by not getting it in real time.

And then it also gets to the issue of who's going to pay for this kind of data collection, and it obviously benefits everyone to have this kind of information. It is a public good, it doesn't make sense to have different systems for different providers or different health plans. So at some point we're going to have to look at financing as through some kind of an assessment, for example, on health plans so that all of them contribute to having quality, not just patient reported data, but a good measurement and reporting system in place.

CHARLES DARBY, M.A.: And just to add to that, I had forgotten we actually allow for someone to help someone fill out the questionnaire by reading it to them. We do not allow a proxy, meaning we don't allow someone else to answer the questions for them, but we do allow them to read, particularly if it's in a different language.

MELINDA KARP, M.B.A.: I would just add that I think that in terms of the special populations, in Massachusetts, our surveys, to this point, have been among the commercial population only. And as we begin to work with our state Medicaid agency over the next couple of years, to bring them into the statewide survey in full for 2009, we are going to have to address all of these really important issues that came up on this card. That all of the special populations that they deal with on a daily basis and need to be able to both get information from and provide information back to them in a meaningful way. We'll need to start to address those issues.

The cost issue is a very real one, in terms of the outreach that it takes to get that information from some of these special populations. And we'll need to figure that out as we go down that path.

ED HOWARD: Yes, go right ahead.

CHRIS CROFTON: I'm Chris Crofton. I work with Chuck Darby on the CAPS project arc and I just wanted to mention a couple other things in response to the questions that this person asked. One, we're currently working on a survey for people with mobility impairments, and it turns out that people with mobility impairments often have other kinds of impairments, visual impairments and others that will affect the way they can respond to a paper and pencil questionnaire, and also understand the data that come back from the questionnaires. So that's something I think we're going to be focusing on in the next round of CAPS.

I think Chuck mentioned that we're about to start our third round of work on that, and I think we may see some interesting research there.

Another thing in terms of pulling people in and getting them to understand and use the information. For part of the reporting work that we've done on age CAPS in this past go-round, one section of it was an experiment on scenarios through which patients can bring up the issue of hospital quality to their doctors. That's an uncomfortable conversation for a lot of people to have, I think especially for older patients.

And one of our grantees, AIR, worked out an experiment where they developed different scenarios where those conversations might happen and then tested them with different types of consumers and also with physicians to see how they would react both to asking questions of a doctor about quality, and how the doctor would react to hearing those questions and whether it would be a comfortable situation for them. So again, in CAPS three, we're hoping to do more research of that kind.

ED HOWARD: Thank you. Somebody mentioned Judy Hibbert, and we actually have a card asking the question about soliciting comment on the work of Judy Hibbert as it relates to how data are clustered and displayed. I confess to not even knowing what that question means. So why don't you assume there might be a couple of other ignorant people like me in the audience and explain what we're talking about?

CHARLES DARBY, M.A.: I won't put the person on the spot, but she knows more about the reporting side. I know that

Judy has done some work in the area of sort of negative framing of information, in other words, talking about the kinds of things that a consumer might want to avoid, or the kinds of providers someone might want to avoid.

Most of the work that's been done, especially anything that's reported out by government agencies, we've been very careful not to do ranking and so forth based on patients' experience of care. But simply listing people and listing their scores, or giving them one star through four stars as a way of people evaluating and then ranking them themselves. But I know Judy has looked at some of the other issues of more in terms of negative framing. I don't know if that's what the question was referring to, or something else. Melinda?

MELINDA KARP, M.B.A.: I would just add, in our public report framework that we spent time developing, we did actually talk with Judy and look at some of Judy's work in terms of around how you cluster and report data, and it's kind of like with our phone numbers. You can only remember so many pieces of information at one time, and we actually tried to structure our website under umbrellas.

Ultimately, the fewer the pieces of information, the better, in terms of the patient looking at a screen or some sort of display. In an attempt not to create overall rankings on a single overall measure which we didn't feel comfortable with in Massachusetts, we did try to cluster the data into umbrella categories. Two umbrella categories, the category of care that you receive from your personal doctor, so that at least when we were then forcing the patient to look at four pieces of information there, they kind of had in their head, "Okay, this is all about this one category." And then the other was care and service received from others in the office practice. Again, creating another umbrella concept.

But I think that it's an iterative process that I think required continued consumer and patient engagement to see how all of that is working. Another piece of work that Judy and her colleagues have been really working on has to do with just how you report the data visually. And the concept of kind of word icons rather than a set of numbers flashed in front of people for them to try to take in. And that people can look at the very same results, but if it's presented with lots of numbers in front of them, they have a hard time picking out who's best and who's worst versus having easier word icons to be able to look at, to be able to make those distinctions.

ED HOWARD: I've got one more question I want to get in, and then I would invite our panelists to make any final comments before we have to adjourn. And I would remind you as we do that, that your help in filling out those blue evaluation forms would be really appreciated. This is actually nominally directed at Melinda. And others should feel free to chime in.

There's a lot of variation in quality, as measured by evidence-based clinical quality indicators within each hospital, much less each city. Do your consumer data reveal similar variations? And what do you think that means, if there is some, for consumers' use of these data?

MELINDA KARP, M.B.A.: I'm not sure I understand the question totally. Our data showed variation. We saw significant variation from practice site to practice site. And then if we looked within a practice site, at all of the doctors within that site, we saw even more variability. And so I think one of the conclusions that we draw – and I think it does really impact consumers' use of the data – the practice site is not a good proxy for any individual physician.

And it's not appropriate for a consumer to walk away at the end of the day and say, "Well, my practice site got four stars across all of these measures, therefore my doctor in that practice site must be doing a stellar job." And that's something that we continue to work on, in terms of our messaging to consumers that it's actually not appropriate to draw that conclusion, because there is a lot of variability at a doctor level.

I referenced our best performance around communication. Even though at a statewide level when we looked across practice sites everybody was doing pretty well, when we actually drilled down to look at individual physician results, there was a 15-20 point variability from best performers to worst performers at a doctor level. So I think that there really are implications for the consumer, and it speaks to that consumer desire that we've already talked about, to have the data at a doctor level.

ED HOWARD: Let me just provide the opportunity for our panelists to offer a closing thought, if you care to. Shall we track our original order of presentation? Let's start with Karen.

KAREN DAVIS, Ph.D.: Well, I think we are at a critical time in public policy, where we would need to ensure that patient-centered care is a central part of both public reporting and pay-for-performance. Whether you call it pay-for-reporting or withhold payment, or some portion of payment for not reporting, I think it's very important that we move forward.

Particularly with Medicare taking a leadership role, to continue to move toward requiring hospital CAPS reporting as a part of the Medicare quality reporting system. And that we also begin to build it into physician quality reporting as well. Obviously, Medicare has a number of demonstrations on pay-for-performance and public reporting, and I think it's very important that patient-centered care be a part of that, and that we don't just get so focused on clinical quality that we leave that behind.

And then finally, I would just stress the importance of moving forward with the concept of a patient-centered medical

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home that the National Committee for Quality Assurance has been doing some path breaking work on the physician practice connection, and what are the kinds of systems and processes that a high performing physician practice should incorporate.

And this is really, in my view, an ideal time to be recognizing such practices, both through recognition programs and linking pay-for-performance to that kind of recognition, as is currently done with the Bridges to Excellence program, but using that as a model for Medicare as well.

CHARLES DARBY, M.A.: Two major points. Melinda indicated that the physicians they work with want to change. They want to improve and to get better scores and give better care to their patients. And we've done a lot of measurement, and I really hope that we put more and more focus on providing those tools to the health care providers so that they can, in the end, give better care.

In fact, whatever we do, public reporting, P4P, whatever we do, it's about improving the quality of care in the end. Secondly, the major challenges, I think, again, are in reporting out this information, making it understandable.

A lot of good work, talking about Judy Hibbert and people on the CAPS team doing a lot of work about one, how do you reach people so that they have the information when they need it and they understand that it's there? I think one of the benefits of the measurement, and when you talk to them about these domains of care, they see it and say, "Oh, other people think about that and they worry about that?" And that's part of the awareness. We have to raise awareness, and then we have to figure out the best ways to get to them and have them understand it so that they can use it.

MELINDA KARP, M.B.A.: I would actually just echo some of Chuck's comments, in terms of quality improvement. And that at the end of the day, we can align a whole variety of incentives to get the physician community to pay attention to these measures. But we need to really work with them to help them to improve their quality. And right now, we're closing the measurement gap, slowly but surely.

Although when you sit in Massachusetts, you think that this is going on everywhere. And we know that it's not going on everywhere and that there's actually a lot of work to be done to actually diffuse the net measurement for patient experiences of care to all the other markets in the country. But beyond that, when we close that measurement gap, we are still left with this quality improvement gap, and the fact that there aren't a lot of great tools out there for physician practices to be able to use to improve. And they're feeling pretty frustrated about that.

So I look forward, actually, to the work of the CAPS three team, and us in Massachusetts working with them to develop some innovative tools for docs to be able to implement.

ED HOWARD: Good thoughts. I want to thank you for being part of a very hard-edged and high-level discussion on this topic. I especially want to thank The Commonwealth Fund, not only for co-sponsoring the program, but for contributing our lead panelists. And actually, I want to thank the panel, and I've asked that you join me in that for what I think was an extremely useful presentation.

[END RECORDING]
