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ENHANCING HEALTH SYSTEM TRANSPARENCY THROUGH  
MEANINGFUL HEALTH DATA RELEASES

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PARTICIPANTS:

**Opening Remarks:**

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Immediate Past Chair, Board of Regents  
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NIALL BRENNAN  
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**Closing Remarks:**

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## P R O C E E D I N G S

DR. PATEL: My name is Kavita Patel, and I'm one the fellows and managing directors here at the Brookings Institution, in the Engelberg Center for Health Care Reform. We are really glad all of you could join us today, and we've got a packed agenda, so I'm going keep things short and simple.

We have, both, folks in the room, as well as I wanted to acknowledge a number of people watching via webcast. And because we are video-recording the event I want to make sure we have a couple of items, just so you know. We'll have a full recording on our website, on the Event page on the Brookings website in the coming days.

And if you do have any questions or comments in the room or on the website, go ahead and actually wait until we have an open floor for questions and answers. So hold time until we have an open floor for questions and answers; so hold time until we actually have question-and-answer session, and since we are using a Web and TV monitoring we'll ask everyone to use the microphone and we'll have mics available during Q&A.

We also have the ability to submit questions via Twitter, and you'll see the hash tag for this event, it's HealthData, you can also tweet at-BrookingsMed, just in case any of you would rather use different media to get the questions. And if you are viewing online, you can immediately download a couple of resources that I wanted to point you to, and once I've finished this housekeeping, we'll get to kind of why we are all here today.

But the two items that we have that are also available in the room if you are in person are, one, a first-issue brief that's also on the Commonwealth Fund website, as well as ours, regarding the CMS Medicare Physician Payment Data, and the topic we

are discussing in part today.

And then also something that I want to thank Caitlin Brandt and Domitilla Masi who helped with this effort, and once we had talked to so many of you we learned that there were so many tools out there around transparency, that even to us who talk about this on a daily basis, it became overwhelming.

So we decided to just -- at least for the sake of today's conversation, hopefully in the spirit of moving forward, put together our own online, non-exhaustive resource list. We'd love feedback on this, and we would encourage you to send us feedback through the website or through the Twitter feed, so that we can get your real-world take on how valuable some of these resources are. But those are also available through the website in the link below.

So with that, I want to just, kind of, start things off. I'll be moderating the first the first Panel, so I'll do a little bit of a kind of intro and stage-setting at that time, but I wanted to actually Stu Guterman, one of the Vice Presidents of the Commonwealth Fund, to give us some of his thoughts. This work wouldn't have been possible without support from the Commonwealth Fund, and I'll say that the work that they've been doing on transparency and delivery system reform has been instrumental in helping us to get to today, and hopefully to get past today into what I hope is health care, the future. So, Stu, some comments, and then we'll start. Thank you.

MR. GUTERMAN: Thanks, Kavita. On behalf of the Commonwealth Fund I would like to thank everybody for showing up here, and everybody who is watching online. I just have a couple of thoughts to kind of set the stage. We talk about transparency and lately, I find myself asking the question; what does that really mean? And back when we first started talking about transparency, it really kind of caught on, especially in Washington among policymakers, I got this image that we were really talking

about putting the proverbial black box inside a Lucite box and calling that transparency, but nobody could really figure out what was going on, you could just see the outside of the black box better.

So, what do we mean by real transparency? I think the folks here today will help address that. It's great to have a lot of data, but what we really want is information. And so we need to -- that means we need to have data in usable form. We need to have data at the right time, and we need to have it in the right context. That is, it needs to be provided to the folks who can use it, the way they need to use it, effectively.

And we are talking about consumers and about researches, about payers and of course policymakers, and I'm hopeful that the topics we'll be addressing today in these Panels will begin to give us some insight as to how we can use all the data available to good use, and make better policy, and make better decisions both in what we produce in the health care system, and what we consume, and how we consume and how we can consume it. So, I won't hold up the show any longer but thanks again, and I look forward to the discussions.

DR. PATEL: All right, with that, let's go ahead and get to our first Panel. If I could have Chuck, Charlie and Niall come up so that we can mic you and let's have you kind of go check, if you don't mind -- Yeah, the last -- we'll kind of go in order, and then Charlie, and then Niall and then Niall and then me. Yeah, that way you guys can get mic-ed up.

Okay. Oh, good. Perfect. So we have -- let me for the sake of getting us started, make sure that I get introductions kind of from me to your -- going from all the next to me, to all the way to your left. I'm Kavita Patel, and this is Niall Brennan from the Centers or Medicare and Medicaid Services, Chief Data Officer; Charlie Orenstein from ProPublica; and last but not least, Dr. Charles Cutler from the American College of

Physicians.

We have extensive bios for all these esteemed individuals in the packets that are available in person as well as biographies online. So I don't want to spend time reading their bios, but sufficient to say that the goal of this first panel was to really offer perspectives from exactly what started a lot of this, which was the data release, that came out earlier this year in 2014, on physician payments.

That was actually the motivation of what myself, as a physician, who is actually part of the dataset really wanted to explore and understand what does this really mean for patients, and I'll just tell you that we are going to get into some deeper kind of discussion around this topic. This hit home not only from when I looked myself up, which all of you can view online, and Niall can you tell you more about how to access that information.

But even more importantly, in real patient care, I had a 61-year-old woman who came in with what she thought was a cracked rib after picking up her grandkid. Grandchildren who were pretty heavy at the time, and she's kind of a small diminutive woman. And she said, oh, I've can get a cracked rib. And I said, that's a little unusual. We got an X-ray, and long story short, over 48 hours, found out that she had what was most likely lung cancer.

Not clear how it started or if it was metastatic, but she asked me a very important question, she said, who were the best doctors for me to see? And I actually pointed her to some Charlie's resources on ProPublica, which we'll share with you. And then I went through the difficult conversation of how so much of American medicine is not transparent, and she said; well, I'll talk to a friend who is a doctor. And ultimately when really important decisions get made we cobble together a lot of these resources, and yet, I think all of us in this Panel, as well as the future Panels today will tell you that we can do

better.

So I'm going to leave it at that, and hopefully, through each of our expert Panelists, as well as your own discussion, we can get into this a little bit more and probe how, what we've started, and I think Niall can speak, hopefully, a little bit more about what CMS and the administration did; what we've started is really just the beginning.

So, Niall, I'm going ask you first to kind of give us a little bit of background on what's been done. And then also a little bit about what you're hoping the future can hold with regard to data transparency.

MR.BRENNAN: Sounds great. Thank you, Kavita. It's great to be here, especially since as I'm an alum of the Engelberg Center.

DR. PATEL: That's right.

MR.BRENNAN: I think I was (inaudible) and Senior Research Assistant, or something like that.

DR. PATEL: You've gone a long way, so.

MR.BRENNAN: So, I think how you have to view our various data release as an exercise in transparency is that it's been an ever-evolving journey, really dating back to 2010, and 2011. One of the first things the President did upon entering office was to sign an executive order on open government, and so Todd Park, as then CTO of HHS, you know, enthusiastically embraced that charge across the entire Department, not just CMS. And worked with folks to identify a whole range of available data that was already -- either already being released, and maybe not getting the attention or publicity it deserved. Or, that could easily be release in a machine-readable format.

And I think those first couple of years were an interesting process because the commitment to transparency was definitely there, but some of the resulting

datasets, they were -- they were good, but I think they people, you know, wanting more.

DR. PATEL: Wanting -- Mm-hmm.

MR.BRENNAN: So there was a lot of facility-level data, machine-readable hospital compare data, geographic variation data via state hospital, referral region and county level. And that's not at all to diminish or demean those data releases, and I mean, again, the geographic variation data, yes, you had Dartmouth, historically releasing data of that sort, but that was the first time that CMS had kind of like, you know, laid the books open and said, okay, when you decompose Medicare spending utilization at the county level, you know, this is what it looks like, and this is what it looks like in very granular ways, that can actually help people.

What are county-level trends and readmission rates? What are county-level trends and ER visits; imaging use, et cetera, et cetera? And so I think for the -- where it started to get interesting, if you will, was about two-and-a-half years ago when we were, you know, trying to figure out where we could move next with our transparency effort, and the decision was made to release hospital charge data, and again, some folks may remember the release of that data.

DR. PATEL: Mm-hmm.

MR.BRENNAN: It was, you know, for 3,000 hospitals on top of 100 DRGs, it highlighted a mass of variation and hospital charges for the same procedure often times in the same geographic area; and certainly nationally. And, you know, I think it really resonated with people, frankly I think more than we thought that it would and, you know, I know that certain health economists when the release initially happened, well -- said, you know, well nobody pays charges any more. But to a certain extent charges are often where people are at least initially exposed to, particularly if you are not insured or well insured.



So I think, to a certain extent the release of that charge data, it was a deliberate step on our part, but the reaction took us a little bit by surprise, and I think it took a lot of people who have been looking at health data and talking about charges and costs, it took them by a little bit of surprise, as well. And then, obviously with the release of hospital data there was a desire to keep, you know, building on this, on this whole effort, or so.

But the issue with releasing physician data was that we were legally prohibited from releasing any data that would allow anybody to identify the total amount of a physician to Medicare reimbursement. That was a legal prohibition that stemmed back to the 1970s and in data Geek Speak, it's known as the Florida Injunction, and about a little over a year ago, a Florida Judge overruled or overturned that injunction, or aspects of that injunction, that allowed us from a policy perspective to begin considering the release of that data.

And we tried to do it in as a deliberative and a transparent a way as possible. We should notify, we asked for public comment and, you know, took all the public comments on board, and then finally in April, I think the open data entered the big data phase, or the quasi big data phase with the release of detailed utilization information on almost 900,000 providers, and over 9 million records I think in the dataset.

So that's, you know, sort of the story of how we got from there to here, it's been a very interesting journey. I think, you know, we've shown our commitment to this over the past few years, and basically as a bureaucrat I can't get into specific prognostications or predictions of what's coming next, but I would say, look at our track record over the last four years, and I think it's highly unlikely that we wouldn't continue to build on that.

DR. PATEL: And this was just to -- before we moved to Charlie, just to

be clear, this has just not been the Florida Injunction but internally there had been discussions prior to even your time and the administration about whether this should -- this type of data should be released at all?

MR.BRENNAN: Yes. Yes.

DR. PATEL: So this is not just, you know, a couple of years in the making, this sounds like it's been decades, to try to think about this.

MR.BRENNAN: This was a 20, 30-year process.

DR. PATEL: Right. So real accomplishments --

MR.BRENNAN: Yeah.

DR. PATEL: But also an acknowledgement and your newly created -- you know, your new title as Chief Data Officer is a little bit of a nod to the notion that more work needs to be done.

MR.BRENNAN: Absolutely.

DR. PATEL: Is that fair to say? And a part of that, are you increasing capacity within CMS to kind of explore the use of, not just these data sets, but kind of the transparency movement as well, is that part of what you'll be doing now in your new job?

MR.BRENNAN: Yeah. I mean, the new role is really, I mean, you can, you know, are little inefficient tagline, is maximizing CMS data for external-external uses.

DR. PATEL: Okay.

MR.BRENNAN: So that manifests itself in a number of different ways, advanced analytics internally, but also transparency in making data available, whether publicly through, you know, files like the Physician Data Release, are innovative ways to access more control data in a secure manner that in respect for maintenance (inaudible).

DR. PATEL: And as part of work we've been doing one of the comments and feedback we've received is trying to find ways to help work, whether we call it public

or private, you know, partnerships, finding ways to help kind of capitalize on what you've been doing but also almost crowd sourcing all these different tools, and private sector as well as public sector opportunities.

MR.BRENNAN: Mm-hmm.

DR. PATEL: So with that, I'll transition. And Charlie, you've already got the pointer, so it's -- if you want to stay there, and you can -- I know you have some slides. But I wanted to first say that before we even spoke to Charles Ornstein, I think all of us in the room would agree that ProPublica has done one of the best jobs, at least trying to offer a way for that 61-year-old patient. When I told her to go to a website, I first pointed her to yours, to be perfectly honest.

MR. ORNSTEIN: Thank you.

DR. PATEL: And I said, it's easier to use this website, plus it gives you contacts for understanding. So I would encourage many of you. We have your website in our resource, and I know you are going to go through some of this, but both as an investigator, a journalist, and I would put you in the category as a researcher as well, because some of the analyses you did really were the first pieces of research on these public datasets.

It would be great to hear some of your perspectives, and without all of this just seeming like this is rosy, some of the limitations of what we've seen today, and I know you are working hard to understand -- to lead the effort on future transparency releases, both from Medicare as well as from the private sector. So, thank you, Charlie.

MR. ORNSTEIN: Thanks, Kavita. Yeah, I think that, you know, one of the unfortunate things for Niall is that the more data that comes out there is more data that you want out there, so they open up one door and then we want to run in and we find seven more that we want to open. So that is one of the challenges here. But I would

argue that it's more than just patients that want access to this information, as I've gone and talked to physicians all across the country.

One of the things that I've been really surprised about is how little physicians know about how their own practice of medicine and prescribing of drugs compares to others. They think that they are doing right, they are sort of benchmarking by word-of-mouth, but when it actually comes to objectively looking at it, there have been no tools that have been really available.

They may get one report card from UnitedHealth Care that says they are doing well, and another report card from Aetna saying they are doing poorly, and one from Blue Cross that says they are in the middle. So you throw all three of them out, and then believe what they believe about themselves. So I thought it would be helpful to show sort of the real importance of putting caveats and comparisons.

Two things, because I think that putting out raw data can be very misleading and confusing, and that's one of the pushback on the part of the data release, is that, a lot of media organizations, and I don't think it was our best hour, to sort of regurgitated what the government put out, and didn't put context around it, which I think was unfortunate.

So, even before, well before CMS put out its data on Medicare Fee-For-Service the amount the doctors were paid in Medicare; ProPublica thought, well, CMS is limited, they can't release information about how much doctors are paid, but when it comes to prescribing drugs, doctors are merely, sort of, catalyst, they are not paid for what they prescribe. The pharmacy is paid, so we could get around this prohibition on data release by requesting what doctors prescribed and what the patients filled at pharmacy.

And so, after a lengthy negotiation, thanks to Niall's advocacy on our

behalf, CMS released data about what doctors prescribed in Medicare Part D, which is the Prescription Drug Program. And it looks something like this, which was a lot of rows, and a lot of codes --

DR. PATEL: Very easy.

MR. ORNSTEIN: -- and doctors and the drugs they prescribed in numbers. And can you just imagine just opening this to patients saying; okay, take a look. Like, it really doesn't mean very much of anything to them; but why, if you are patient would you want access to the information that you are -- about what your doctor prescribes?

Well, one, if your doctor is recommending a drug for you and you want to see, does your doctor have experience prescribing this drug? Because if your doctor doesn't have much experience prescribing the drug, is that the doctor you want to prescribe you this drug? Or, conversely, if the doctor has a lot of experience, that may be something that's worthwhile.

Two, with the plethora of data out there about financial relationships between doctors and drug companies, having access to, is a doctor prescribing more of a particular drug made by the company for whom he or she is doing -- speaking, that could be particularly helpful as well.

So what we did, is we created a tool called Prescriber Checkup, which allowed folks to access things from various portals of entry, and we think this is really important with data. Is, don't assume you know how somebody wants to access data, people want to access data in a lot of different ways, and you need to give them the tools to do it. So we let you access it by drug, to see who are the top prescribers of a particular drug are, by state, by specialty, by doctor name.

So you can go to our site and look at it through any of these portals to

get to results that show you the top prescribers within a specialty, within a state, the top prescribers of a particular medication; or just your doctors prescribing. But instead of just releasing when you click on your doctor to see all of the drugs the doctor prescribes, we also have sort of what we call our dashboard, which shows how similar or dissimilar is -- your doctor is to other doctors in their specialty and state.

And why did we choose their specialty and state? Because we didn't really think it's fair to compare an ophthalmologist to a dermatologist, to an oncologist. Each of them are going to have different ways of prescribing, and then if you just release it just in total, and let folks, you know, sort of swim their way through it, that could be really confusing.

So we show you the percentage of a doctor's patients who get narcotics, but if you are a pain medicine doctor, that's going to bring the whole specialty up; whereas, if you are a family physician that's going to be a lower-percentage base; and how the doctor compares to that. We also have a mathematical formula that takes into account the doctor selection of drugs, and then volume of the drugs they prescribe. Sort of bar -- puts them on a line of bars where you could see that if a doctor is on the far right, they are practicing in a very different way than other doctors are practicing.

And then finally, you can see a list of the doctor's drugs, and what it ranks for that doctor, so the doctor's number one drug, and how that ranks for other doctors in the same specialty and state; so that you are able to compare again, the doctors. One of the things that we did with the Medicare Part B data which came out this year, the Fee-For-Service data, this is what Medicare released; which is a long list of each of the procedures on what doctors made. And again, the media took this and wrote about Medicare's millionaires, and how much money people got from Medicare.

That was pretty unfair, because some doctors were spending a lot on in-

office drugs; they are purchasing the drugs and then when they are using them again, is it fair to, you know, say that they are millionaires? Well, not necessarily. If they treat a lot Medicare patients versus somebody who doesn't treat many, is it fair to put them head-to-head? Not necessarily.

So what we did, was we created a tool called Treatment Tracker, and our tool let's you see this all in context. Again, we compare people within their same specialty and same state. So, you could see, for example, the number of services per patient, and how that compared. And when you see these red marks you see that the doctors in the top-10 percent of their specialty and state.

So, again, you are able to see who is a real outlier compared to just who has a big number attached to their name. And we not only give raw numbers, but we give adjusted numbers. So, the amount paid per service, the amount paid per patient. So that you are able to get a sense of the doctor in comparison to their peers, trying to level out based on the volume of services.

And then finally, you are able to see the number of times doctors did things for patients, how much money they got from a particular service, and where that ranked for doctors. And they are definitely outliers, and one of the takeaways that we have from this data and the prescription data, is right now, with the information Medicare is putting out, it's a lot easier to find doctors who are off, who seem to have questionable practices, than it is to find doctors who are good, whose practices you want to emulate.

Because there's too many variables that we don't know for now, and that's sort of a next stage, it's what we want. You know, right now, we have what doctors perform in their office but if a doctor gives a referral to their pal down the hall, then the doctor may be incurring a lot of medical cost, and the patient may be incurring a lot of services, but you may not see that on the doctor's profile.

So we think that next level of information is information of things that the doctors -- the referral for. Whether it's DME or lab work, or health, or hospice; and you are able to look at a doctor's totally of what they are controlling in terms of health care services. So that you are able to see the doctor's complete picture in context; then of course comparing it to others that are like them.

So we think there is a huge amount of advances that have taken place just within the past couple years, but there's still a lot of work to be done, and ultimately this will lead to patients who are more educated and more engaged in health care decisions, but also doctors who are able to benchmark themselves, and take the initiative even before a patient asks them how they compare. Thanks.

DR. PATEL: Charlie, real quick before we go Chuck.

MR. ORNSTEIN: Yeah.

DR. PATEL: Do you have a sense given all the work that you've done to date, and all the conversations you've had, you started by saying that it might not be patients, you know, they are not the only audience; you mentioned physicians. Who are some of the other people that were really interested in what you've done? And kind of, your sense of who is using your database right now, or the various databases that you have.

MR. ORNSTEIN: I think hospitals are.

DR. PATEL: Okay.

MR. ORNSTEIN: I think insurers are. I think folks within Medicare are. I mean, we've heard from folks with a new organization who think that, sort of, our interface is a lot easier to use than their own interfaces. So I think you'll find a whole lot of folks. And our databases are being accessed a ton of times.

DR. PATEL: Right.



MR. ORNSTEIN: I mean, we build products that are more than just things that are supposed to be drive-by products. They took it at the first traffic in the first 48-hours of our data release, and we want people to keep coming back, and we are able to go from our page about prescribing and direct link to the doctor's services. So you are able -- it's sort of like very easy to navigate around, and as more and more information comes out, that's going to be key, it's where people are going to be able to, oh, this is interesting, I want to check this thing about this doctor too. And it's exciting to be a part of, because literally so many different audiences are interested in this (inaudible).

DR. PATEL: And you mentioned a little bit about prescribing behavior now, kind of pharmaceutical relationships, since we started this work on the Part B data, the open -- the physician kind of open payments database has been released.

MR. ORNSTEIN: That's right.

DR. PATEL: But you already saw the kind of technical problems we are trying to do the analyses that you've done already to date on other databases with that one particular one. Raising kind of a very common, logistical problem for regular folks to access the data, as you showed it this raw form.

MR. ORNSTEIN: But that's right. I mean the assumption that just because the government releases data that it has to be 100 percent accurate --

DR. PATEL: Right.

MR. ORNSTEIN: -- that's not necessarily the case. In the case of the open payments data, which is the drug company payments to doctors, they are relying on the drug and device companies to get it right in terms of what they are submitting to the government, which is then what they are releasing. What we found is that, there were situations where the drug companies were spelling the names of their drugs wrong.

DR. PATEL: Right.

MR. ORNSTEIN: They were listing drugs in multiple columns when they should have only listed them in a single column. That they would duplicate it, they would list drugs as devices and devices as drugs. So we spent months trying to sort this out. It is really complicated and confusing.

DR. PATEL: Absolutely.

MR. ORNSTEIN: And lucky, to be at ProPublica, to have the resources, and the interest among editors to spend the time to get it right, rather face the clock and say, we need to get this out in the next 12 hours.

DR. PATEL: Okay, great. And that's a perfect segue to Dr. Charles Chuck Cutler, who is a practicing Internist and also has leadership experience from the American College of Physicians. Just a side comment, before you go, Chuck. We actually looked -- our staff at Brookings -- we looked through dozens of letters that were sent to the Senate Finance Committee when its Chairman, Ron Wyden; Senator Ron Wyden had asked for public comments from physician groups and physician organizations, and anybody, on this topic of data, kind of transparency, with (inaudible).

And he was looking at this topic for a number of reasons, and the American College of Physicians, along with a number of other physician organizations sent very detailed, I think, thoughtful letters that all said, probably just to gloss over it, the similar things. Transparency is good, so we know that, but huge caveats around kind of how this data is interpreted by the public is something that many physicians, especially given what Charlie had pointed out with some of the media headlines, had really been threatened by.

And so I'm going to just kind of speak to that, because I had a number of conversations after some of the newspaper and radio and other media headlines went live around, I would say the outliers spending, you know, kind of reported charges of

millions of dollars, and trying to understand who these doctors are and why they have millions of dollars of Medicare charges, it made a lot of physicians really nervous about how people would view their own kind of charge patterns within these publicly available datasets.

But I thought it raised a very important conversation amongst the physician community, where, in the end everybody kind of remained, kind of, quietly curious as well as cautiously optimistic, that this was the right direction; so, Chuck, your thoughts both as a practicing physician in the dataset, as well as someone who has been leading some of these efforts at the national level, for a physician organization.

DR. CUTLER: Well, for the audience the American College of Physicians is the largest medical specialty organization in the country, of 141,000 members, internists, medical specialists and medical students. And I did serve on the Board, and was Chair of the Board until last year. In that position I was able to travel around the country be in hundreds if not thousands of doctors, but my day job is a General Internist. I'm in the office. In the morning I go to the hospital and see patients.

And I could share you, if you took some of my colleagues and put them in a room, and said, talk about the data release for 10 minutes. You might have 9 minutes of silence. There are a number of medical issues from electronic health records, the Affordable Care Act, data reporting from CMS on quality parameters, budgetary concerns about CMS and whether or not they'll be able to pay the bills for doctors; that I think have a much higher priority among physicians.

Now, having said that, data is really important, and this conversation is really important for doctors. And the example you use, Kavita, is perfect. With every patient that I see as a physician I have to make recommendations, have to help the patient move to the next step. Maybe an antibiotic, maybe an X-ray or procedure; and for

my entire career I have not been able to help patients in the area of cost.

It's clear to me the right antibiotic to get you better, but if there are two antibiotics which is the better one? If both will get you better, which is the more cost-effective antibiotic to use, and you can use that example across every recommendation that physicians make.

So, what Charlie has begun to put together, begins to change that conversation that doctors might have from 9 minutes of silence in a 10-minute period. There may be 15 minutes of conversation in a 10-minute period because it's so important for doctors to know what things cost, and we never have.

Now, the other part of that, and I think you've begun to touch on it, is we need outcomes too, because we can't simply make recommendation -- I can't make recommendations as a physician to patients, simply based on cost, because the cost could be high, but the outcome could be even better than a low-cost procedure.

And so the outcome is really important, and the comparisons really need to be adjusted for risk, because if you are a doctor, and I think you alluded to this Charlie, if you are a doctor that takes care of a lot of sick patients, your costs may be very high, but your outcomes may be very good. So we are in our infancy here.

And this is great news for the profession, I think for the American College of Physicians, we are really encouraged by the data release and we are even more encouraged by honing the data, and making it more useful to patients and to physicians. So I think with that, maybe I'll quit.

DR. PATEL: So Chuck, one follow-up, and then we'll -- I have a question for all three of you. There were some people that expressed concerns as I imagine an organization as large as the ACP you'll hear many sides of this issue. Can you reflect a little bit on what some of the concerns have been from the physicians about some of

what's been released to date?

DR. CUTLER: Yeah. Well first of all, and I think it was touched on earlier, accuracy is really important. There is a lot of information out there, and it really has to be accurate information, and physicians, in a sense of fairness, should have access to the data, and if it's inaccurate, there should be a way for physicians to address what they perceive as inaccurate, and make it more accurate.

The usability is really important too. We have to be able to access it in an easy fashion. The doctors have to be able to get to it, and the patients have to be able to get to it, and if it's complicated to access the information it can lose its utility. So some easy mechanism to get to the information is really important.

Now one of the other concerns that the physician community has had and we've expressed it to CMS is that one of Deputies alluded to the fact that releasing this data might be a way to address waste, fraud and abuse. And we can argue about it, but simply because costs are high, we have to be careful not to attribute that that is somehow fraudulent or the high -- the utilizer is wasting services. He or she may be, but simply by having high costs we have to be careful that there's not guilt by association, so those are some of the things that we were concerned about.

DR. PATEL: Okay. Great. If anyone in the room has any questions, go ahead and raise your hand so we can at least get a mic to you. And then before we get to you, while we get a mic to you, I just wanted to ask if anyone on the Panel, and maybe actually, Niall if you can kind of respond. I think that, as you mentioned, you can't talk about future data, you can't talk about any actions that might take place in the future, but in your -- Can you give us a little bit about, to date, how you've seen what you've done so far on the public side has some influence on the private side? So things that are outside of Medicare and Medicaid, for example.

MR.BRENNAN: So, first of all I think Charlie and Chuck's comments were both excellent, and added a lot of important context. You know, my remarks were a little process-driven, I guess.

DR. PATEL: We understand.

MR.BRENNAN: So, in the sense of, you know, we are in our infancy, this is a fluid area, but we try to make it clear of what the data was and what the data was not, you know. The very nature of the fact that it's open data, means that we have very little control over how people choose to analyze it and present it. So I think in terms of the effects on the private sector you have many hospital chains and hospital systems undertaking to be more transparent in how they charge masters, or charges are displayed.

There's a legislative activity in several different states seeking to address or formalize the publication or the availability of pricing information, and I think most recently the Health Care Cost Institute, which is an agglomeration of a pretty large national, and some regional health plans announced a pretty large transparency initiative that I think is going to kick off next year, where they are going to look at the data that they've assembled from multiple different health plans. And I don't know if the output is going to be exactly like what we did, but certainly something --

DR. PATEL: Similar?

MR.BRENNAN: -- along those lines, based on everything that I've read. So I do think that our actions have had a trickle-down effect.

DR. PATEL: Kind of that way of?

MR.BRENNAN: Yeah.

DR. PATEL: All right. Any --

DR. CUTLER: I think Charlie referenced this, but it bears repeating. The

commercial payers, by and large, are looking at quality parameters. They are not simply paying doctors fee-for-service. Even if you are in a fee-for-service environment, what they are insisting that there are -- there's quality reporting, but the so-called quality reporting does not take into consideration costs. It's really not high value care. It is measures that don't consider cost, and I think the next generation of reports that physicians are expected to turn in to the payers, will be high-value care. Good outcomes but at a high value. So I think this will move it forward.

MR. ORNSTEIN: I think one of the challenges is that, you know, a lot of the health plans are looking at population metrics, but if you are a patient you care about your metric. Right? So, like it's wonderful that we are measuring, do doctors give quit-smoking advice to patients, I'm not a smoker. So I don't like --

DR. PATEL: That's a matter of (inaudible).

MR. ORNSTEIN: -- it's fine if they don't give it to their smokers; I'm not a smoker so it doesn't matter to me. So I think what you want to know is like, I know somebody who is about to have heart valve surgery, they want to know which doctor in their city performs the most heart valve surgeries, and how many patients are alive a year after that. And like, the fact that we are -- we cannot answer that for that patient today or tomorrow or even next year, like that's the question that we want to answer.

It's not like; do your diabetics have their 81-C under control? Well, am I a diabetic? I am not. But if I am a diabetic and it is under control for me, again, I don't really care if your other patients are. I care about me. So, like, yes, we are a "me" culture, but we have to make sure that the data releases can be customizable so that the person who is interested in their own health, and their own situation can get some answers from it.

DR. CUTLER: But, Charlie, at the same time, patients are complaining

all the time about high co-pays, deductibles, we spend billions of dollars a year in unnecessary care, or marginally-useful care, and this conversation and this data release, gets us closer, or gets us away from spending all of those extra dollars that we don't need to spend.

MR. ORNSTEIN: No question.

DR. CUTLER: I think it does come back to haunt the individual patient if your co-pay is going up, your deductible, the cost of your insurance is going up, the reason is, we are spending too much money, how can we provide high-quality care? We have to factor in cost along with outcomes.

DR. PATEL: All right. We have a question here. Tell us your name, where you are from, and your question, briefly.

SPEAKER: Yeah. My names is Lee Yong, I live in Ireland. And, first I congratulate you on this transparency of data system is great. But I just wonder, how far can you go? How do you deal with misdiagnosis? Or, you didn't give any data from maybe your own internal system, because the nurse don't give it to you, or you did not even maintain the complaint system of information you receive from patients or their relatives. This is very critical, very important.

And currently there's a lack of data about who are the physicians in which hospital in which area, we will check the CHECKBOOK, or reference you as a -- or government agency, there is no way you can find it. So a lot of physicians, just like a lot of lawyers, they use phony names, or false name or (inaudible) name, you know, like (inaudible), something like that. So, exactly how do you really judge the real system, the real information that you should need, like from computer and consumers or patient, relative? They submit their complaint. You know, a lot of diagnosis, they don't even give the patient treatment if they even ask for it, the record.



Just the (inaudible) even ask you, they don't give you record. And if they do, they give you fraudulent record; so fraudulent charges, those types of things. So just these type things, it's very critical, very essential, and for you to compare a patient's physicians, and we are the -- really professionally and are fake, because a lot of emergency staff, they ask, why are the patients too -- to give the liquid, the whole carton of liquid to the patient so they can perform the procedure. And if you ask any physician's approval, they say, no, they don't have it. But if you don't do that --

DR. PATEL: Let me -- let me try to wrap this up so we can get -- Okay, go ahead.

SPEAKER: Yeah. I think the misdiagnosis by the patient -- by the physicians and by the many --

DR. PATEL: So misdiagnosis as well as by all the various reporting of different information? Okay.

SPEAKER: -- system, and also procedure that are like.

DR. PATEL: Okay. I got you.

SPEAKER: That's just staff, it's not even physicians.

DR. PATEL: I understand.

SPEAKER: And they are going to perform the procedures.

DR. PATEL: It's not just the -- so this touches on -- Thank you.

SPEAKER: Mm-hmm.

DR. PATEL: So this touches on just a couple of things that I think some of our Panelists might get into; especially our last Panel. I think one, we've been settling because a lot of our work started with the physician dataset, but as are hearing, there are so many streams, and you've touched on this Charlie, with wanting to know about the referral network as kind of the next wave of data that could be important to triangulate.

Or we are really talking about, is trying to paint a better on the complexity of health care services.

Do any of you have some comments on -- we mentioned hospitals, we've talked physicians, we've talked about drugs or devices. Are there pieces of this puzzle which are much more complicated than what we've touched on?

MR. ORNSTEIN: So, I think that to her question some of the end points that involve payments can be measured, right?

DR. PATEL: Right.

MR. ORNSTEIN: So when you are talking about physician services and Medicare Part B, you know, that is a payment that is gout out the door. Right?

DR. PATEL: Right.

MR. ORNSTEIN: We are not talking about Part D, prescriptions filled; these are at a pharmacy they log the prescriptions being dispensed. Maybe it's not dispensed, but they log that it's being dispensed.

DR. PATEL: Right.

MR. ORNSTEIN: They are being paid for it being dispensed. When you are talking about a referral, there are two different claims, that are made so -- but if you are talking quality metrics, and I'm sure that, Chuck, you can get into this, the quality of electronic medical records, the quality of paper records, they have so much to be desired, that -- Like, when you are trying to adjust for things like that we are a long way away for the (inaudible).

DR. PATEL: A long way. And then thinking about different settings --

MR. ORNSTEIN: Right.

DR. PATEL: -- so, obviously hospitals, physician offices, and then thinking about (inaudible), and kind of ER settings and immediate care settings. I mean

the complexity of all of this can be so overwhelming that it can cause you to say, why bother releasing anything because we can't do all of it, but it seems like the first was the hospital data, which you talked about. And then, you know, thinking about physician charges because of the Florida case, and then I know that we've also got information -- even new to me was the information around dialysis, and some of these other services that we do have data released on.

Are there other transitional care, or care settings that we think we really do need to have better transparency around that would be important for patients to have?

DR. CUTLER: Well, you know, not to, let me plug the Commonwealth Publication on this, and for those who haven't read it --

DR. PATEL: And so (inaudible), exactly.

DR. CUTLER: -- now would be the time to look at it.

DR. PATEL: Right. Exactly, pull it out now.

DR. CUTLER: Because it really addresses this, and I think there are two things that need to be stressed. First, the physician data has to be integrated with the hospital data, with the pharmacy data. To look at any of this data in an isolated way, in a way, it addresses some of what you are bringing up. To do it isolated just doesn't give you the right picture.

You have to put it all together, and comparisons are really difficult, but as the Commonwealth publication pointed out, until we get into real detail about outcomes and health status, and demographics, we'll never really be able to make good comparisons, or the perfect comparison. So hopefully one day, we can get there, and we are moving in that direction right now.

DR. PATEL: All right. I'm going to do a lightening round to ask very quickly, 10 seconds, 15 seconds; what has -- what has been released to date, what have

you learned from it? Something that, just to give, kind of, our audience in the room as well as on the website, something that may have surprised you, about what has been released to date? And I'll just go ahead and kick it off.

I will say that the think that did surprise is exactly I think what Charlie touched on, that this was actually more important to, not my patients necessarily, but I had more physician colleagues and health insurance plan colleagues, kind of say, this is really exciting and interesting and we would really like to get into that. It's a little bit of a preview of what I think the next Panel might speak to. But something that surprised you, or something that you learned from this release process.

MR.BRENNAN: So, I'm a geek so I just like looking at patterns generally

--

DR. PATEL: That's good. That's fine, I think.

MR.BRENNAN: -- so I think in the physician data just looking at how different services were concentrated or not concentrated in certain specialties. I think the other thing that -- the thing that surprised me the most, actually, was how few CPT codes many physicians build.

DR. PATEL: Yeah.

MR.BRENNAN: If you had to wake me up in the middle of the night before I started the project, and said like, you know; how many -- how many sick people is that physician billing, the average primary care physician? I would have said, oh easy, like 50, 60 a year.

DR. PATEL: Easy. Okay, I got you, right.

MR.BRENNAN: And for -- or maybe more. And for many, for a significant chunk of physicians, they are billing 10, 15, sometimes even less. I mean, they are -- what they are -- you know, some of them are really cranking through those

CPT codes.

DR. PATEL: Right.

MR.BRENNAN: But like they are specialists. I mean, they are -- so that was the biggest surprise to me.

DR. PATEL: That's interesting. Perfect, all right.

MR. ORNSTEIN: I mean; I've grown as a health reporter learning about differences between hospital referral regions and how important hospital referral regions are. I think what I've learned through here is just how much variation there is within those hospital referral regions, and how, you know, you can literally go one street over, and the quality of doctors, as measured by services they use, the drugs they prescribe, are so vastly different. And that it really makes a difference to look up an individual doctor.

DR. PATEL: Right. Chuck?

DR. CUTLER: So I looked up my data and I thought you were paying me more. I think it's accurate --

MR.BRENNAN: Well I had to take a cut off the top.

DR. PATEL: Exactly. That's a Niall's new job, you get a cut off the top, right.

DR. CUTLER: So I would compliment CMS because I think you got it right in my case. But it was -- but I've been doing this for more than 30 years, and it was really hard for me, despite all of that experience to make any sense of it. And, you know, I began to imagine well, what are physicians -- what are patients thinking? How do they figure out what's going on here?

DR. PATEL: All right. Well join me -- that's a perfect segue for some of our future conversations. Join me in thanking our Panel (applause). And we've got -- let me -- let's this. We'll have all mic, and if I can ask our second Panel to come to the

stage.

And I'll ask -- I'm going to have Paul Ginsburg, Dr. Paul Ginsburg from the USC Schaeffer Center for Health Policy and Economics, who also has an extensive background and bio that I'm not going to read, as well as a number of publications related to research in this area. He is going to leading our second panel.

Oops, let me make sure I don't get in everybody's way here, and then also take off -- And I'll have Paul -- let me have you -- oh, good, Paul didn't need to use the stairs. So Paul, sit down, and we'll re-mic. Let me see if I can swap out some glasses for you guys.

And Paul is going to be leading the discussion on Implications and Perspectives from Researchers Policymakers and Payers. And we've teed up a number of these issues in our first discussion, but I think we'll have a robust one with the second panel. Thank you.

DR. GINSBURG: Thank you. I think we can start now. And so I'm really pleased to be moderating this panel. I think Stu Guterman, at the very beginning of the conference, set the tone that this is about transparency and this has been a long-time interest of mine, and I've always believed that some of the confusion about transparency comes from the fact that we talk about transparency because of its aspect of sunshine.

We believe, particularly public institutions, but other institutions, their operations ought to be more transparent. But we also talk about transparency in terms of it being useful to different types of entities. We first think of patients as consumers, but then when we think a little further we think about physicians, hospitals, health clients, researchers and policymakers.

And this Panel is really about what the three different audiences can do with this information, and so we are going to begin with Chapin White, who is a very

distinguished Researcher, talking about what this means for researchers. Then we are going to hear from Lewis Sandy who is an Executive with UnitedHealth Group, talking about what this release and other data can mean for health plans, and also employers who are their clients; and some of them do it themselves.

And then we are going to hear from Bruce Steinwald, with a long policy background, just to speak from the perspective of policymakers, what can they learn from this information that will help them in their work of making policy down the road? There are two contexts I'd like to ask the speakers to think about, one is that as we -- you are going to talk concretely about the April data release that Niall Brennan was describing to us, but we are not going to dwell so much on what as in the April release, but also to talk about what could be in future releases.

And whereas, Niall could not speak about what would be in the next releases, these Panelists can talk about what they'd like to see in the next releases to make it more useful. The other context is that this is not -- these releases are not the only game in town. Chapin as a researcher, he can go through the process of paying a lot of money and taking a lot of time, and that's negotiated Data Use Agreement from CMS and get some of the data that's really raw behind this release.

Lou, with UnitedHealth Care can either work with a qualified entity or apply to become one, and also has another channel. So this is all part of the context. I'm going to stop my talking and turn to Chapin.

MR. WHITE: Thank you, Paul. It's really terrific to be speaking with you all today, and I think the first question I want get into is whether this data release of the physician charge and payment data is a big deal. And so, again, I'm coming at this from the perspective of a researcher. When these data came out we had a couple conversations at RAND, you know, we were kind of salivating over this new data source,

what could we use it for? What questions can we look at?

And gradually we figured out, well, if there's -- there isn't really much new we could do as researchers, with these data. Any real research questions we would want to get into? We would really want to use the more detailed, micro level claims data that we would buy from CMS that we do all the time.

So, does that mean that this data release is not a big deal? No; not at all. I think this data release is really important and is a step forward. And why is it important? Number one, I think that the release of this data has laid down the marker. CMS is saying that physician's right to privacy does not outweigh our right as the public, to know what Medicare is spending and what Medicare is buying.

For decades, as Niall mentioned this, there was an injunction in place that prevented CMS from reporting what individual physicians were being paid by Medicare, and by releasing this data CMS has said, that balance between physicians' right to privacy and the public's right to know what's going on in the Medicare program, it's now officially tipped in the direction of the public's right, to know what's going on in the Medicare program.

The other thing that is important about CMS' release of these data; is they've laid down a marker and said, we can release data at the first physicians and CPT codes without running afoul of HIPAA, and if you do research you -- HIPAA is a vast barrier reef that you have to learn to navigate. And CMS has charted a course others can follow it now. So that's the one -- that's the first important thing about this data release.

The second is that these data by themselves aren't that informative or telling, but data becomes useful when it's put in combination with other data. As CMS releases more of these data over time, we'll start to see trends. Now that we have the



physician-level data, we can combine it with the hospital-level data for specific geographic regions, and get a fuller picture of what's going on. As other data sources become available identifying physicians by MPI or national provider identifier, we can start combining the CMS data release with those other NPI-level data.

And conceivably, at some point the private sector health plans will begin releasing data. If those data are release in the format that's compatible with the data CMS is releasing, all of a sudden you've got a much fuller, richer, three-dimensional picture of what's going on in the health care sector.

The other -- the last point I would make is that this data release is a small step, but it's a step in the direction of building our data infrastructure to understand where we are and what's going in the world, and to help us make better policy choices, as a society. And I think that one thing that we forget is that our data infrastructure has been built through conscious, sustained effort. And concepts like gross domestic product, we take that for granted, we track how it's going up and down over time. It's grown by such-and-such percent.

The concept of gross domestic product was defined and the tools for measuring it have been honed over decades, and we devote significant resources to tracking that, that's a tool that's where the use of businesses, government, individuals, and so on. It's a collective data resource that has been built through effort, and I think that is an incredible valuable effort. I think the CMS data release is one piece in that valuable effort.

In terms of where we are going next, what I would be interested to see, the private sector is kind of the black box. Medicare is starting to lay all of its cards on the table. But in terms of prices, practice patterns, geographic variation in the private sector it's more challenging to get a handle on that.

And to the extent that we can get private sector data releases that are structured in the same format as the CMS, Medicare data releases, then we can start comparing prices, we can start comparing practice patterns; identifying geographic or Asia patterns in both of those sectors. But that to me would be the most fruitful, but probably also the most difficult avenue to go. I'll leave it at that.

DR. GINSBURG: Chapin, one question for you. You mentioned at the beginning that the Data Use Agreements, and thank CMS for access is, you know, probably better serves many of researchers' needs. Any thoughts about how that process could be streamlined and made more efficient as an aspect of a transparency initiative?

MR. WHITE: Well, the data could be made cheaper in -- we pay taxes for a reason, we pay taxes so that the Federal Government can provided services that shouldn't have a high marginal price attached to them. Data is one of the things that I think should be made freely available even though it takes a lot of resources to produce that data. Once you've made one copy of the Medicare claims data file, it's trivial to generate a thousand versions of that, a thousand copies of that digitally.

So the price could be made lower, the turnaround time can be reduced. That's a significant problem. HIPAA, you can't -- that's just a fact of nature at this point, you have to satisfy all the privacy constraints, but the turnaround time and the price, I think, are barriers to research that could be lower.

DR. GINSBURG: Thanks, Chapin. Lou?

MR. SANDY: Thanks. Thanks, Paul. And I appreciate the chance to be here, I appreciate Engelberg hosting this. I appreciate Stu and the Commonwealth Fund for sponsoring this. I think what I wanted to do was talk about, kind of, what I see as useful in this release, what are some of the issues and limitations and then some of the

suggestions, to your point, Paul, about where we go from here.

The first thing I do want to say, is I really want to commend CMS for their efforts to promote transparency in the use of these data, it's refreshing. And it's incredibly important and it will evolve this idea of development and evolution over time that I think is an import theme of this event. You know, even in this current release there is some utility in this information and we've heard a little bit about this today already.

I think it's useful in raising awareness of variation; the pervasiveness of variation that we see out of the data. Useful in understanding some of the factors in that variation, useful, frankly it's so obvious it's just -- Dr. Cutler mentioned this, just useful in bringing transparency around what things cost, just the basic information there. And I think claims data provide what I call a coarse-grained view of clinical phenomena.

It's useful for some things, not so useful for other things, but it has some useful dimensions around volume. Around the service mix, I'm not in practice anymore, I'm a general internist, but I've looked up some of my friends to kind of see what, kind of, their practice patterns look like; particularly interesting for those that you would expect a great information because their practice would be heavily concentrated in the senior population. So I think that it's important, it will evolve over time, and it can provide some useful insights even in its current, somewhat limited form.

Now what are the issues and limitations? I think probably the most fundamental one is that I think health plans have learned over the years, that looking at raw claims data, is really an exercise in hypothesis generation, than it is in making a determination about much of anything. That you can't just look at a raw data table, and say, ah-ah there's an outlier, you know, let's do something. It's really more a hypothesis that you actually have to triangulate around, look at multiple data sources, look at trends over time.

And then have a further exploration, particularly it may involve, and this is something health plans do regularly, having a conversation with that physician, to see - - and you might find an outlier that statistically is an outlier, but they actually are a referral practice and have a unique set of services that they only -- they are the only ones who provide that in the region, as an example. So I think that hypothesis generation is the way we should think about the use of raw claims data.

The second thing is that, as I said, a lot can be done with claims data, but it requires analysis, I think it's a theme from all of us, will say, that it's not just putting the raw data out there, it's starting with some simple analysis, and simple descriptive statistics can be very useful. Percentile ranking, such as we heard from ProPublica, standard deviations; and there are even more sophisticated uses of claims data, through the use of technology subjects, Episode Groupers and the ability to do case mix and risk adjustment.

So I think there's quite a bit that can be done with claims data, even with some of its limitations, and I think it's an interesting policy question about how much the sponsor does, in this case CMS versus having a raw data file come out, and having third parties do that kind of analysis. That's an interesting question, and I think in terms of physicians or any stakeholder, I think probably the most important attribute of this kind of data is the ability to make comparisons, and to do that, you don't really have to have credible data.

As Dr. Cutler mentioned that physicians want to compare themselves, naturally, against other physicians in the same specialty; that would be logical. And I think that's another thing that health plans have learned over the years. And that relates to my third suggestion or limitation, is that what we have learned over the years is, particularly when releasing data around physicians, it's a good idea to run what I would

call a service bureau function.

The ability to actually serve the stakeholders, and in the physician -- in the case of physicians, to answer their questions about the data, to be able for them to look at it, and correct it if there are some errors in it. The physicians are very data-hungry, they are interested in data, if they view it s credible, but they want the ability to do what's called drill down, to drill into the data in ways that make sense to them.

All of this is what I would call a service bureau function, and the kinds of things that UnitedHealth Care has done, such as in our premium designation program, we've done since 2005. We have a physician portal that has HEDIS data on it, and is open to all physicians in our network. The service bureau function is an important suggestion, I think, how to enhance things going forward.

Lastly, let me make a few suggestions for where I think this could go from here, I think I've said some of these already. I think first, is to just clean up the data, and offer some simple descriptive statistics for all the stakeholders. I think that is a reasonable thing for the sponsor to do, even as others can do other kinds of analyses.

Second, I agree with your point, Chapin, the ability to combine data and data sources and data sets together in an important view, in this particular case, it's really quite a limitation that you can't get a full picture of what the physician is doing in Medicare. We have found in the commercial, the private sector, that we might find a physician expending a great deal of resources in the office, but if you look at the total cost of care, or an episode basis, they are actually quite efficient, and the reason is that they -- that's their practice style.

You won't see that without the ability to integrate and combine disparate data sources and you know, and it was already mentioned the Health Care Cost Institute, that's why we thought it was so important to contribute data to the Health Care Cost

Institute as a multi-payer effort to bring transparency to the private sector market. And that's an interesting example on a couple of levels, because it originally started as an effort really to just be a tracker of private sector cost trend data and utilization data.

But as was mentioned, once the parties got together and HCCI was organized and payers started putting the data in, the HCCI said, you know, we could actually use this for transparency purposes. We could actually start to look at quality data, in addition to just cost data, so as some of you may know that's an effort that has been announced and will be deployed in 2015. So to sum up -- Oh, and the other thing, is the HCCI is a Medicare-qualified entity, so that's a good example of integration between the public and private sector from a different Medicare program as well.

So to sum up, I think there's a lot of opportunities, I think this is the beginning of a new era. Transparency is the coin of the realm. The current release has been useful in some respects and limited in others, but I think it will evolve and strengthen over time, particularly if it moves along some of the directions that have been suggested already.

DR. GINSBURG: Thank you, Lou. There's one point you made that got me thinking. You were talking about, you know, one of the steps forward is to go from really raw unanalyzed data to various levels of analyzed data, and at the same time, as this is evolving, of course we are on track to have physician value modifiers in Medicare which will be presumably fairly analyzed data. I don't know what the transparency plans are, but presuming there are transparency plans, any thoughts about these two tracks things are moving again?

MR. SANDY: Well, I think, again, whenever there are multiple initiatives going on, it's always an interesting challenge for any organization to synch them up, but I think that -- and I think that's why it's a great opportunity for someone like Niall to have a

broader view of all the data resources, and as he mentioned, to use them both internally and externally. But I think, in general, the idea of moving -- I think, probably the most important thing, is moving beyond, fairly rapidly beyond just a raw claims release, in to analyzed data that is consistent in its thematic direction.

The measures might be slightly different but as long as they are sort of, this is the domain, I think most people view a best practice for example, is not just to release cost data without quality data, to combine those. And I think having so that any user can look at a picture that integrates both quality information to the extent one can have it with cost would've be useful. So that's a partial answer, I guess.

DR. GINSBURG: Thanks, Lou. Bruce?

MR. STEINWALD: So my job -- thank you, Paul -- is to take a broader policy perspective and with some particular attention to the U.S. Congress and how they might benefit from this data release, and subsequent data releases. And I'd like to start as well by keying off of Stu Guterman's analogy of the black boxes inside of the Lucite box. You know, it's easy for us policy analysts to value transparency because we are the lookers. You know, and we want to see more, but it's the lookees, the residents of that black box who I think need to accept and even embrace the concept of transparency if we are ever going to really achieve it.

And so physicians and other providers need to get used to the idea of having their performance evaluated, and as Dr. Cutler has suggested to us, their willingness to do that is partially dependent on how accurate and useful the data are that are being released, and how they'll be utilized over time. The U.S. call for some suggestions of what we would like to see.

I actually have some predictions about what we will see. Niall has not been able to say that they are going to release more data. I'm going to predict that they

will, and in fact, I'm going to predict that CMS and its contractors will correct a number of the errors that others, that the media organizations have pointed out, missing data, core specialty designations, other things of that nature. I think providers may well contribute to that effort. I think they have an incentive knowing that their information is going to be individually available to a wide range of lookers; they have an incentive now to make sure that their specialty is accurately recorded.

They have an incentive to match up the national physician identifiers with the billing codes, and I hope that we'll actually have more different kinds of providers available for analysis in the future. But most importantly as soon as we get that second data release, we have the beginning of what, Chapin? That time series, right? And that's every economist wants to have a time series.

And I'll give you an example how that could be useful. The Government Accountability Office, GAO, where I worked for several years, took 2005 and 2006 data, exactly the same database in essence that CMS released in April; and attempted to identify beneficiaries who are high utilizers of services given their health status. The correction for health status, as everyone knows, is not perfect, but we were able to identify a group of beneficiaries that were high utilizers. And then we examined those same beneficiaries in a subsequent year. Did they remain being utilizers? They had a tendency to be -- remain high utilizers, a tendency, it's like --

We then arrayed those same beneficiaries among the doctors who treated them, and identified high utilizers given their mix of patients' health status and how many resources they get. And then we looked at the doctors the following year. They were twice as likely to remain high utilizers as their patients were. And I'll be glad to give you a reference to that work, and I can't go into all the details, but only certain specialties and certain geographic locations, but it's the kind of thing that one can do with



time series data that one cannot do with a cross section.

I work for a congressional support agency for about 12 years. At GAO I supervised the preparation of roughly 50 testimonies and reports to the Congress, different congressional committees of jurisdiction over Medicare and other health care spending. In case you are wondering, what do Members of Congress spend more time reading; GAO Reports or newspapers and news summaries? Anyone care to guess?

And, by the way, if you asked the same question about congressional staff you get the same answer. So I look at these news organizations reports and analysis of the data that CMS released, as another potentially important source of information, maybe it's not in-depth. Maybe there are mistakes being made, but I think it's especially useful when you consider that Congress obtains much of its information from companies and organizations, many of them of whom are constituents that have a vested interest in health care spending.

And I'll remind you of the five top D.C. lobbies in spending, four of them are health care, and the fifth is WARP. So to have another information source with a different incentive for producing information is useful. In fact, I would say that these news organizations, publications, are a complement to, not substitutes for the kind of research that congressional support agencies do, like GAO, and MedPAC and CVO. And other organizations like RAND under contract with CMS, these are complements, not substitutes.

I also would expect that because these news organizations will produce information to the Congress and give them ideas on what could be investigated in greater depth, there might be some benefit to the congressional support agencies to be asked questions that were raised by these news organizations. To be investigated in greater depth by the organizations that have the resources and the capabilities for doing it.

So my bottom line is that this is not only a good thing, it's a necessary thing, it will produce more information -- meaningful information as time goes on. We all believe that transparency is an integral part of health care reform, and I look forward to the day, as others have alluded to, where a database is not just CMS Production and Medicare, because after all, in Medicare the entire story is utilization, because prices are fairly constant except for geographic cost of business differently.

Again, the private sector you'll see a huge amount of variation, so not only would you have the advantage of being able to combine across different payers, to get a fuller picture of what individual providers are doing, to get the private sector data into that mix, and you will have a lot more opportunity to investigate very meaningful differences in how services are performing around the country.

DR. GINSBURG: Thanks, Bruce. You said something very interesting about how some of the media that, you know, was based on this release, you know, made its way to Members of Congress and Staffs, and likely shaped what they were asking congressional support agencies to look at, or even talking about policy-wise, legislator-wise. Do you have some sense about interesting directions that this release has spawned?

MR. STEINWALD: Was that the only interesting thing I said?

DR. GINSBURG: The most interesting.

MR. STEINWALD: Most interesting. Okay. I don't really know. I mean this comes under the heading of hoped for. I do -- I did look up and saw that *The Hill*, which is a publication for Members of Congress, did pick up a number of these stories and reproduced them in their own media. But I can't cite a specific instance of where an issue was suggested to a member who then requested some work at GAO or another similar agency.

DR. GINSBURG: Sure. That's fine. Well, maybe in the course of conversation others will have ideas about that fact. It's probably a good time to turn to the audience (inaudible) got the time; why don't you wait for the microphone?

SPEAKER: I am, (Inaudible) Brookings Advisory Council. Doctors, I don't think today are required to post online what they charge. And I was wondering what you would think of that. It's one of the few services that are important, that do not have the market visibility that you have in other areas. Do you think we should change that?

DR. GINSBURG: Well this, presumably this is not a Medicare issue, because Medicare physicians, I guess they are very limited -- constrained about what they can charge in Medicare, and of course those prices are coming. So I guess it's more of a question about private insurance. I don't know if -- Do you want that that, Lou?

MR. SANDY: Yeah. Two, I think it's just a -- the question reflects again the desire to have greater and greater transparency on all aspects of health care including what providers charge. Two things, first, even though there is no national requirement, I know at least in Massachusetts -- if there's anyone here from Massachusetts -- there is a new law that required exactly what you suggest, which is the posting of prices, so that will be an interesting experiment, to see what impact that has. I mean, that state, there may be other states, I'm just not aware of it.

I think the other thing is from the consumer point of view, and we'll here from the Consumer Panel after us, I think what consumers want to know isn't so our experience has been, what consumers want to know, is not what the provider charges, so much as what are my half -- what do I have to pay? Which then relates to, what is it -- what is the charge in relationship to the benefit package that I have the network that I have and, you know, what does it mean to me --

DR. GINSBURG: And perhaps even a whole episode of care, that's from

(inaudible)?

MR. SANDY: Exactly, from a -- Yeah, and sort of, if I'm choosing option A versus B, that's a clear pathway which will have multiple services in it. So it will be interesting to see, that information is increasingly becoming available, again, in the same transparency theme that we are in.

DR. GINSBURG: Yeah. I think the gentleman, there, had a question.

SPEAKER: Thank you. David Rutz. I was wondering about the difference between the raw data you have to pay for and the data that's been released, is it primarily a question of consolidation, so you download less data to answer the same questions? Is it primarily HIPAA? Is it some combination?

DR. GINSBURG: Do you want to take that?

MR. WHITE: Yeah. If you go through the process of entering into a Data Use Agreement with CMS you -- and you guarantee that you are going to satisfy all of the data security safeguards that they require, which are serious. They will send you a claims data that has a beneficiary ID that has all of the age, sex, zip code of residents, or the beneficiary that has the micro level service of the CMS physician public release, only reports combinations of physicians and CPT codes which 11 or more services provided.

Obviously if you buy the macro-level data you can see all the services, but it's a major hurdle to set up data security systems that are impenetrable, and that are HIPAA compliant.

DR. GINSBURG: And also provides the opportunity to pull together various services from providers that the beneficiaries had.

MR. WHITE: And you have to promise not to release anything that (inaudible).

DR. GINSBURG: A question back there?

MR. INTROCASO: David Introcaso, National Association of ACOs. If the genie is now out of the bottle, from your perspectives, what would be best next, relative to CMS data release?

DR. GINSBURG: Can you --

MR. WHITE: I can -- well, Paul Ginsburg actually mentioned the physician value-based payment modifier, and I'd be curious, how many people, if I say value-based payment modifier, know what I'm talking about? Some? Okay, a lot. Great. So I had a wish list it would be that the raw data and the final output of the physician value-based modifier calculations be made available at the physician level.

I don't know if that's realistic, but that would be -- that would be taking this raw data dump that CMS has made and doing the analysis that a lot of the other presenters have been talking about. The idea behind the physician value-based payment modifier, is that Medicare can be measuring quality, and it's going to be measuring efficiency including all of the services that physicians order, not just the ones that they provide themselves. So I think that would be a significant step forward, I doubt is going to happen.

DR. GINSBURG: Bruce?

MR. STEINWALD: Well, I think a second cross section as I mentioned would be very useful, but it was be especially if CMS could correct the errors in the first release, so that when they issue the second release, the first release is more accurate, and therefore you can make better comparisons over time.

MR. SANDY: I think a theme will -- a number of us have talked about is more comprehensiveness and more linkages of the data. For example, Part A, and other data sources so that you can have a more comprehensive view, either of a attributed population, or of a -- more of a 360 view of what a physician is doing for the seniors that

he or she is treating.

DR. GINSBURG: It's actually If I can add one thing, this would be the more advanced, would be grouping data into episodes of care, to look at how a physician handles say a joint replacement, or some other, you know, well-defined episode of care, to really be able to compare them to others. Yes, sir?

SPEAKER: I am Frank, with the Brookings Institution. My question deals with what this might for the health exchanges particularly for each of your constituency groups; you know, policymakers, researchers and payers. You know, even this data is only Medicare what might be some interesting future developments you might see with the health exchanges with more CMS data releases?

DR. GINSBURG: That's a tough one?

MR. STEINWALD: I think that only in a general way. I mean, if you can learn things about, let's say, a drug -- prescribing patterns that is general utility then the exchanges might be able to use information of that nature, but since they are not generally treating Medicare patients I think that there's a limitation.

MR. SANDY: I would echo that. We've learned, and we have -- I didn't mention this in my comments but we have since provide services to Medicare beneficiaries, UnitedHealth Care does, through the Medicare Advantage Program, as well as MED/SOP and Part-D we actually have data ourselves under the Medicare population. We have found -- we originally thought we could actually combine all those data with the data we have from the commercial marketplace so that we would larger sample size, but we actually have found that these are different populations; that it's pretty obvious, but the commercial population, the working-age population is different than the senior population.

So when we do quality measurement reporting, for example, we use

different benchmark levels of performance between the Medicare and commercial populations. I think that's it -- my guess is the same phenomenon would happen in the exchange population, because that will be a different population, and particularly it will be evolving over time.

DR. GINSBURG: Any more questions? Oh, there's one back there.

MS. HORNSTEIN: Hi. Rachel Hornstein, I work in Data Policy of the Department of Health and Human Services. I have a quick question about last year, the Office of Management and Budget released the M13-13 Memo on the Open Data Initiative, and one the concerns in there was a concern of the mosaic effect. How when you release different datasets and you start to link them, there's a possibility of releasing personal identifiable information on beneficiaries or on clients. So, can you please touch on that?

DR. GINSBURG: Hmm?

MR. WHITE: Yeah. So this brings up the Elvis' doctor problem. Which is, if you report physician-level data and don't have a minimum number of procedures or patients treated, and if you report on the practice patterns of Elvis' doctor, and everybody knows who that doctor is, then you can find out everything else about Elvis. So that's the motivation for the 11-plus minimum claim requirement and, you know -- I mean, there's obviously a risk that really sophisticated data analysts are going to be able to take this data release and combine it conceivably with other data sources, and figure out things about individuals.

My guess is that there's probably a bigger risk from hackers just getting into the CMS mainframe. But I don't really know. But I think that we are definitely in an area of risks and tradeoffs, and there's a benefit of these data being available. There are increased risks and the more data sources that are made available in greater granularity,

the more risk there is of people being able to combine things in novel ways, and kind of undo the privacy protections.

I guess, just as a researcher I would just say, let's keep in mind the benefit of these data being made available, and that -- not to just go with always the safest approach.

MR. STEINWALD: I think the principle of the greater good does apply here, and in fact even on the data releases there will also be some errors, and there will always be some misinterpretations of the data. And there will always be a physician who is unfairly singled out as behaving poorly when in fact that person hasn't. But as Chapin said, you have to look at -- those are the costs, but you have to weigh the benefits against those costs. And I think we are of the mind that the benefits far exceed them. Certainly privacy is one of the risks (inaudible).

MR. WHITE: We use our credit cards all the time, even though our credit card numbers are for sale, you know, through underworld hacker websites. So our financial system is constantly balancing the benefits of electronic data exchanges against the risks of, you know, malicious hacker activity. And I think we are gradually groping our way towards some similar kind of balance with (inaudible).

DR. GINSBURG: Well, I think it's time to thank the panel for the really good job they did on this topic. (Applause) I guess we'll execute the same thing; we'll transfer to Dr. Alice Rivlin, A Senior Fellow at Brookings Institution who will be moderating the final session.

(Recess)

MS. RIVLIN: Okay, are we live now? I think we are. Now, we're going to shift the focus. We've talked about this data release and several other data releases, and we talked from the point of view of researchers and health plans and the policy



community. But what it's all about is patients and consumers. And so now, we are going to shift the focus to the patient, the consumer, and talk about what they need to know. And I hope we can be a bit more visionary and expansive in this panel, because we are where we are, but where do we want to be?

And I hope that these three representatives who have worked very hard on behalf of consumers over quite a long time, can help us think about what do consumers really need and what do they need it for. And how can that data be generated? To help us with this question, we have, first, Robert Krughoff, who is the president of the Center for the Study of Services/Consumer Checkbook, and we have Robert Restuccia, who is the executive director of Community Catalyst, a consumer advocacy organization.

And we have Doris Peter, director of Consumer Reports' Health Rating Center, part of the organization, Consumer Reports. And I think Doris' organizations and Robert Krughoff's rate lots of things (Laughter), and not just healthcare. That's where you go if you want to know about cars or toasters or plumbers or whatever (Laughter). But now, we're talking about healthcare, and a really important aspect of so many people's lives. So, we'll start with Robert Krughoff. Tell us a bit about what you think consumers need and what they might need in the future.

MR. KRUGHOFF: Okay. Well, first of all, I appreciate being here, and I believe our priorities should be to have good raw data readily accessible. If the government can do that, that's an amazing, wonderful achievement. And fortunately, I think the government has recognized that this is important and has made significant progress.

I'm very happy about Niles' recent appointment and loved the principle statement in the press release announcing his appointment, citing the government's

commitment to frameworks promoting appropriate external access to and use of data, whether in aggregate or granular form. That's what I think should be the government's role here.

Unfortunately, there are good things that have happened and there's a lot to be done. I'll give you examples of the good and the bad that I've seen in the government's making data available over the years, and you know, it just sort of always gives me some anxiety that things might not go so well the next step around.

In 2006, there was HHS' denial of Consumers Checkbook's request that we get physician identified claims so we could give consumers some information on the amount of experience each physician had with various high risk procedures, and the government, siding with the AMA in appeal, after we won in the lower court. That was disappointing.

There was CMS' interpretation of the ACA provision on release of claims data that was much more restrictive than it had to be. The CMS rules required anyone who wanted the Medicare data in order to do performance measures nationally to have matching non Medicare data in every region. That's an enormous practical obstacle, and it wouldn't have had to be interpreted that way.

On the other hand, there was the great news this past April. The government's release destroyed the physician privacy argument against release. So, that was an enormous accomplishment, I think. And then, that was followed by CMS' quick action to get physician identifiers in the large data files that we and others have been using for years to evaluate hospital death rates and complication rates. Getting those identifiers right in there quickly was just exactly what needed to be done.

And CMS recently created the virtual data center program to make use of those files more financially accessible by allowing them to be used remotely; still

more expensive than I wish at \$40,000 annually for a single person to use, although cheaper than trying to get those Part B files straight up, which would be in the, you know, hundred thousand or more range. And quite unfortunate to cost that much.

But there was some bad news, when we were told last summer that this virtual research data center system could not be used to produce quality on measures on doctors. Couldn't quite figure that one out. And so the door sometimes swings open, sometimes closes. But I think we all need to support those at CMS working for openness, often in the face of strong provider opposition.

As I said, I believe the focus should be on making raw data available. I'm not optimistic that the government should be itself the producer and reporter of performance measures. But it should be a supplier of diverse independent researchers to develop performance measurement methods and put those methods in the public domain where they can be critiqued by researchers, providers, purchasers, consumers. We want the data and we want the methods. But it's fine if the government wants to do its own reports on provider performance, in the face of provider resistance, but we worry that such reporting would be too cautious to give consumers simple information that would make it easy to choose providers that will best meet their personal needs and preferences -- difficulty of consumer use to the hospital, compare web site, the real lack of development and information in the physician compare web site gives one quite a bit of reason for pessimism on the government doing the reporting.

And to contrast that to the creativity of ProPublica, which you know, finds a way to put these data in a form that consumers can actually use and can be responsive -- you know, a different response to you than to you, and to be able to find the data. All that stuff, I think really private entities probably can do a better job than CMS can do.

So, what measures need more emphasis and what data is needed to support them? From a little disruptive perspective, let me share with you what we have seen from consumers. We watched the use of our Consumers Checkbook web site. Of all the many types of service providers we evaluate, the ratings consumers look at most often are ratings of doctors. So you know, I've read in reports, people say, well people don't care. You know, they don't look at you know, quality ratings of doctors.

Well, maybe they don't look at them, but they look at them more than they -- twice as much as they look at ratings of plumbers and auto repair shops, and interestingly, about 13 times as much as they look at ratings of hospitals. So, that's a kind of interesting perspective .

We've also done tests of consumer interests in different measures of doctor quality. And by far, the greatest interest was in consumer survey ratings of doctors and in results of surveys of doctors asking for their recommendations of other doctors for care of a loved one. Both of these types of measures were chosen by at least three times as many web site users as ratings based on board certification and training, or as ratings based on whether a doctor follows nationally defined evidence based medical guidelines for quality and efficiency of care, the HEDIS type measures.

So, where consumers are starting from may be different from what some of us might have expected. So, now here are a few thoughts on possible measures for future expansion. And I'm not going to limit myself -- I don't seem to be limiting myself word-wise in general, but (Laughter) I'm not going to limit myself to talking about these large data sets, but just sort of try to think about anything that consumers might possibly find useful.

So, I think one measure is to expand on -- is whether doctors effectively use electronic medical records. Since such information can be collected via the

Meaningful Use Program as to this doctor use of these things, and its importance needs to be forcefully explained to consumers, that this really will matter to you, or could matter to you. ]

Another opportunity might be to explore with specialty boards whether they can let doctors voluntarily identify themselves as performing, let's say in the top quarter of other doctors in their -- on certain dimensions of this certification process. That's something I've never seen done, but it seems to me it would be interesting, particularly because it might actually reveal something about doctors' diagnostic skills. And one of the problems, I think, is that almost all of our measures out there or processed measures, outcome measures even, don't really get to the question of diagnostic skills, which are so critical to having a good physician.

Another opportunity would be more measures of clinical bad outcomes. In analysis, we have seen at the physician level, statistically significant differences in surgical death rates, complication rates, readmission rates. This kind of information needs to be public, and if we had better data, measures might be possible to assess with a doctor is prescribing too many of some kinds of procedures identified in the choosing wisely initiative.

A very important challenge is to report on patient reported health status and outcomes, possibly using promise SF and other similar types of measures. Calculating some of these types of measures requires assembling better databases, of course. There is a continuing need to push for all payer databases where it will be understood that the data can be used for provider quality measurement. So you know, we're talking about large national databases like that -- that's a great thing. I mean, as an all payer, database, I should say.

But participation and registries is important. If the registry rules allow the

data to be used for public reporting on provider performance. Registries can collect information that goes well beyond what you're going to find in claims data. It makes sense to find out, I think, whether public reporting -- which physicians participate in appropriate registries and explaining why participation matters could actually put pressure on doctors and providers in general, to choose to participate.

But the big opportunity is in health information exchange. For performance measurement and various other reasons, that's -- you know, that's -- it can be the heart of a lot of stuff. So, that means we need to push for continuing expansion in standardization of information in electronic health records, including patient reported information, and push providers to share this information in large regional and national databases.

A public measure telling which providers are participating in these exchanges might actually create incentives. Certainly, such participation could be a critical component in any future meaningful use programming, and the government needs to invest heavily in this path. Think of it as the Interstate Highway system for healthcare. It's a major investment and it really should be a focus.

Finally, I'll focus -- finish on a relatively easy and quick but strangely neglected path. Getting a nationwide database of patient experience survey results on individual doctors. A database which would also be able to be aggregated to the practice site and group level, but starting with the individual level doctor.

Why the government has not pushed forward with this is baffling to me. We have a good instrument in our CG Caps survey. This survey and possible variance give good information on how well doctors listen, explain things, keep track of the patient's history, coordinate care, engage the patient in shared decision making. This is important stuff. If the doctor doesn't listen, for example, the doctor can't do a good

diagnosis or come up with treatment plans that fit the patient.

If the doctor doesn't explain things, well, then patients won't know or be motivated to do their part in care. As one article in the Journal of American Medical Association put it, in a diverse set of studies, effective communication has been linked with better adherence to treatment plans, more appropriate medical decisions and better outcomes. And measurement should be at the individual physician level.

Dana Saffron and others in the Journal of Internal Medicine showed that the individual physician, not the practice nor the group, nor the plan, accounts for a majority of the variance in the communication aspect of patient experience. So, why don't we have survey results at the individual physician level? The explanation we hear is that it's too expensive. To prove this wrong, a Consumer's Checkbook did a demonstration in four metropolitan areas in collaboration with United -- thank you, Lou (Laughter), Aetna, Cigna and local Blues plans.

We did a rigorous survey and published results at the individual position level showing a large number of significant differences among physicians. The demonstration showed that this could all be done at a cost of about \$120 per physician, and still show these really meaningful results. This is much less than Berensen et al. have demonstrated it cost physicians to report PQRS type data. And that \$120 can be cut to about \$60 or \$40 per year, since it's not necessarily to do the survey more than once every two or three years, although physicians can be enabled to do the survey more often if they choose.

So, this is a big immediate opportunity, and ones the federal government could easily make happen with a little financial support and encouragement. Thanks very much.

MS. RIVLIN: Thanks, Robert. That's a rich list of -- a wish list of very

interesting things. Robert?

MR. RESTUCCIA: So, Community Catalyst is a national consumer organization focused on giving voice to consumers, particularly low income consumers. We have historically been fighting to open up the black box and been supportive of Robert and Consumers Union and ProPublica's work. I think it's important to look at consumers from two perspectives. One is the role of a user and payer, and the other in terms of their public policy role.

You know, with the trend towards cost sharing and health plans, it's become more important for consumers to be good purchasers. And with the implementation of the Affordable Care Act, millions of people are looking the exchanges, the marketplaces to choose health plans. So, I think we've had a lot of experience with that, and frankly, I think they're still either not looking at that black box or they're looking at it through the Lucite lens, because there's a lot of problems.

Consumers and payers even find the most basic information illusive. The Urban Institute recently came out with a report that it's difficult to get information from many marketplaces about web sites -- the marketplace web sites about whether a health plan is tiered, what providers are in the network and what are the cost sharing differences associated with those tiers? For the low income consumers, who most of the people going are low income consumers, quality data is complex and very difficult to understand.

It's clear that one size doesn't fit all. Information needs of a 60 year old duly eligible is very different than the information needs of someone coming to Checkbook. So, in terms of what we're talking about today, I think we need to start with getting the basics right. We need better information about who and what's in a network and what are the costs to consumers. Charlie mentioned the importance of accuracy.



The data needs to be made more understandable for consumers, taking into account the wide range of differences.

Community Catalyst has been supporting an effort to develop a single composite quality measure that could be broken down into component parts focusing on the particular needs of consumers. We agree with Robert in terms of patient reported information. We see collecting patient activation as a quality measure and a focus on outcome.

And finally, in terms of consumers, they need help doing this. You know, the average person is not going to be able to make the kind of cost quality equations that we need in terms of coming up with values without support. Medicare beneficiaries get this sort of assistance through the state assistance programs. We have a consumer assistance program that's part of people focusing on enrollment. We need to sort of think about expanding that program.

So, in terms of consumers -- in terms of public policy, there's important pieces to really think about. Community Catalyst was one of the first organizations to push for transparency around the conflicts of interest of pharmaceutical companies and physicians. It was actually the courts that opened that data up. Charlie in ProPublica took that database and made it into a very effective tool for looking at what is the relationship of the pharmaceutical industry to the physicians.

That perhaps, hasn't helped in terms of allowing the individual consumers to make choices about either their drugs or their providers, but it's had a significant impact on medical schools and hospitals. From a public policy standpoint, it has made a really important change. The other area that we have been working on is around hospitals and community benefits.

Hospitals want to keep what their community benefits are often a

mystery and the value of those community benefits a mystery to consumers.

Community organizations want and need to have that information. We've been working hard to get a database of information around the schedule H which provides some of that hospital community benefit data with George Washington University. So, we're looking to move forward and improving that kind of data for consumers.

Consumers need to understand on the basics of healthcare the idea of sort of some of the broader trends are a black box to consumers. And the government and consumer organizations need to push hard for opening up that black box.

MS. RIVLIN: Thank you, Robert. Doris.

MS. PETER: I come from Consumer Reports, and I direct the Consumer Reports Health Rating Center. And while we're an ardent user of all the data we've been talking about today, our role is really into trying to translate that data for consumers, and to try and put it in context and raise awareness of the problems with that data; bring it to light. So, that's really what we focus on.

So, it's really about having people use the data, not just having the data available. And by using it though, we are able to identify some of the strengths and weaknesses of that data. So at the ratings center where we work, we're a group of scientists and doctors and consumers and writers who take data from various sources, and much of it is the government, and translate that for consumers.

And we look at the areas of drugs, preventive services like cancer screenings. We also work in there with hospital quality, physician quality and also health plan quality. So, we've been doing this for about 10 years, and we reach about 20 million consumers per month, and even more through our partners. So, not just through our only media products like *Consumer Reports Magazine* or online, but also through partners that can reach other audiences.

Now, you're more probably familiar with our work in the area of cars and electronics. And we often compete with those areas and we make fun of each other. (Laughter) I know I'd rather be testing cars than testing hospitals, and we can't bring hospitals into the labs and all of that (Laughter). But so it's a healthy rivalry.

But I was just looking up some data the other day, and I was really excited to see that in our own measurement of how our readers data and how they use and understand these stories, that our stories on healthcare costs and quality, whether it's about physicians or about hospitals or about drugs, sometimes supersede or rank higher than stories about cars and electronics and washers. So, it's really at top of mind for consumers, these areas of cost and quality, and consumers can understand it and use the information.

So, that's another common question I get asked is, well, you know, there's all this data out there. Consumers can't really use it. But consumers can use it and they do use it. And we hear from them about it, and we hear from them about the changes that they've made either in the hospital that they've chosen or the drugs that they take, or more importantly, the discussions they have with their providers. So, a lot of our editorial content drives people to have discussions with their physician or with their nurse practitioner about the drugs or about the hospital. So, it's important to reinforce that relationship.

So, we really appreciate what CMS has done in releasing data, and we use it, so we advocate to continue that release of data. The important thing, though, that I see that's sort of been skipped over is the issue of safety and errors, because that's on area that's really hard to measure. And we seem to have jumped from sort of process measures and readmissions and things like that all the way to patient reported measures, like whether you can climb stairs, but skipped the really difficult task of

measuring patient safety and measuring errors.

And we've actually asked consumers in our own surveys about this, and about -- and in our last survey, about 30 percent of people self reported they experienced one or more errors in the hospital. And that's probably a huge underestimate, because that's just what the patient noticed themselves, not so much what maybe went unnoticed to them. So, I really like that not only in the area of data collection, but also how we measure safety and errors, that this is a really important thing for us to focus on.

Another way to get at this issue is through registry data. So registry is probably the most powerful data that's out there. You've heard a little bit about it in this panel, and I think that's an area where we'd like to push more to get that data available to the public.

We've been able to be successful in a small area of heart surgery. We've worked with heart surgeons that have voluntarily released their data to the public, and we have hospitals and doctors that are really high performing and even ones that are low performing that have agreed to release their data. And I think this is the most powerful decision tool that consumers can use, because they can look at a procedure that they may be undergoing, like heart valve replacement or heart bypass surgery, and find those hospitals and physicians that perform in these ratings of quality.

And those quality measures look both at outcomes and also, at complications in a reliable way. So, that's what we would ask that we would sort of make more public. And I think CMS, with the power that they have to require these serious quality reporting systems, that they start making that more of a requirement in terms of being reimbursed by CMS.

And then some sort of more tangential requests that I'd have is to not try and reinvent the wheel. I think Bob Krughoff brought this up, that CMS is sort of required

to do public reporting, as well, and it kind of makes a lot of confusion at the level of the consumer, because those web sites that are out there now that the government puts out, Hospital Compare and things like that, are very difficult for consumers to understand. So, I would suggest they focus more on the data and the quality of the data and requirements for reporting the data, rather than the consumer side of things.

And then the final thing, which is kind of a little bit geeky is that I would ask CMS not to forget about infrastructure. Because those of us who use the data, have to deal with the structure of the data, the missing elements in the data that make it hard to release accurate and timely reports to the public. So, thank you.

MS. RIVLIN: Well, we've heard a lot about choosing doctors. We've heard some about choosing health plans. I'd like to ask each of you to say a word about how you would hope the feedback to the providers themselves and to the health plans would improve the situation over time, because isn't that ultimately what we hope consumers having better information will accomplish? Any thoughts on that?

SPEAKER: Well, we have watched this with patient experience data most carefully, and tried to work some of the -- specialty societies and stuff to tell doctors how they can improve and where they can find resources to improve. I must say, I don't think we've been particularly successful in that, but I think that's probably because we're not very good at it. We tend to be a measurement organization, not a quality improvement organization.

But you know, there ought to be potential there. And yes, that is one of the objectives, but I also think that one of the objectives is helping consumers find the good ones, and that also gets you good care.

MS. RIVLIN: Yeah.

SPEAKER: I mean, there are two paths that one can go down here.

SPEAKER: You know, I think that when you look for example, at the pharmaceutical data, I think that you have the professional societies stepping up and understanding that there are implications to the conflicts of interest, and trying to address those through changing policies within the societies, within medical schools and within academic medical centers.

You know, I think it is necessary to have a partnership here. I don't think the market is going to move us away from all providers who are "poor quality of care." That's not going to happen. So, we're going to need to rely on a partnership between hospitals, doctors, consumers to really get it right.

MS. PETER: I have to say, in our public reporting of hospital quality data, we really do see a real big response by hospitals. First, they get angry, of course, because they don't like to be rated. But then they tell us that they're focusing on the things that we're reporting on. So, the more we report on things we want to change, the more they're going to pay attention to those things.

That came in the form of a company. How come you're doing this. My physicians are focusing on what you're reporting on, instead of what I want them to do (Laughter). So, I saw that as a successful. I was like, thank you (Laughter). I did my job. Now I can go home today. So, that's one area we see changes in.

We also see areas where hospitals will call us and say thank you. Thank you. We didn't know XYZ. Now, we're going to look more into it and try to understand why that's a problem. So, those are the calls I really like to get, because I know that the people there really care about it. And then, we also hear from hospitals about patients cancelling procedures and surgeries and them losing revenue. So, there is some market change going on. It may not be as much as we'd like right now, but there's something happening.

MS. RIVLIN: Both Doris and Robert Krughoff talked about getting the raw data out there. And you were quite vociferous about how government should just get the raw data out there. But there are risks in putting out raw data that hasn't really -- risk of misinterpretation, as we saw in this data release that triggered this event.

MR. RESTUCCIA: Well, I think there is some risk and there will always be some risk that the data will just be wrong. You know, the way CMS has it in the first place, or it'll --

MS. PETER: Or, it'll be misinterpreted.

MR. RESTUCCIA: -- or it'll be misinterpreted. And you know, I'm always troubled by that response. We've had a lot of experience -- we have a health comparison tool that we've tried to put out. We put it out in the Illinois exchange, for instance, and we asked the federal government, can we have the description of benefits -- the copayments, coinsurance, et cetera, for each of these plans, so we can do an actuarial estimate of out of pocket costs for each plan.

You know, the best estimate for somebody like you with your health status, et cetera, so you can really make this comparison in a coherent way that most people don't have a chance of doing. And the government, unlike the part of CMS we're talking about here (Laughter) -- the government said, no, we can't. We're not going to give you those data. And then they finally said, well, we'll give you the data the day before open enrollment starts.

Well, you know, these actuarial estimates take, you know, many weeks and very complicated calculations to do. We get it the day before open enrollment. But the reason -- there were two reasons. One is, the plans wouldn't like it. And the other is that we might put out something that's confusing, you know, or that is wrong. I believe in the marketplace of ideas that you put out something that's confusing and wrong, and

nobody listens to you again and somebody sues you. I like that way of having the world work (Laughter). And we take some chances on that front, as opposed to not giving the information out.

MS. RIVLIN: Lest we get too focused on the government not releasing it, big companies don't like it very much, either (Laughter).

MR. RESTUCCIA: Right (Laughter).

MS. RIVLIN: I think it's time for audience questions. And we have possible microphones. There's one right -- a question back here?

MR. HERSHEY: Hi. I'm Lorne Hershey. I was actually a guest scholar here under Alice about the breakup of AT&T about 28 years ago (Laughter). So hi, Alice. I follow medicine a little bit more closely given my aging process, and I'm curious to learn over the last couple of years, Mayo Clinic book, Cleveland Clinic book -- there is something called wellness medicine that is happening.

I don't know how to define it. There's allopathic medicine. I never thought it in those terms until I read it a couple of years ago. That's healthcare delivery. So, my curiosity is to ask each of you three panelists, how do you evaluate what's happening? How do you measure it and how do you describe it? Has this wellness movement been around for two years or six years or nine years? I don't want to connect it to some personalities in TV.

I want to connect it to University of Michigan where I've read about it or Yale University. But the question is data. So, if I move 10,000 steps a day, big deal. But it's supposed to make me healthier. How do you measure that? Do you get my point?

MS. PETER: I think I understand what you're trying to say. That movement has been around for a long time, and if you just look at the products we rate,



we rate diets and exercise, and so you've got that aspect of "wellness." I think we take it in the form of the preventive services. I think that's one of the areas that we focus on in terms of helping people understand what preventive services that can keep them healthier. I'm not sure if that's along the line of what you're thinking of, but that is our focus. That's the aim that we take.

SPEAKER: Yeah. I guess I see that there's trend toward payment reform that would move you in the direction -- move hospitals and payers in the direction of treating a person more holistically. You know, it certainly has been around for a long time, but I think it's getting much more traction now.

MS. RIVLIN: But some of it's not medical.

SPEAKER: Right. Exactly.

MS. RIVLIN: So much of it is not. It's nutrition. It's exercise.

SPEAKER: Right. Exactly.

MS. PETER: Right.

MS. RIVLIN: And are there evolving systems that are evaluating that from the point of view of the consumers?

MR. KRUGHOFF: Well, if you think about the dual demonstration projects, I think there are evaluations going on now of that. And that's really looking to take the Medicare and Medicaid payment, combining it and keeping people out of hospitals and out of nursing homes, and theoretically healthier. That's something that I think the research triangle is doing right now.

MR. RESTUCCIA: I think there's a -- I think the visibility of patient self help and non allopathic medicine -- you know, it has increased over time with TV and everywhere else. You know, a lot of newsletters and things like that. So I do think there's progress and I do think that many of the health plans are looking for alternative

ways to help their members, hoping that these will solve problems and reduce the health plan's cost.

And some of these providers, Checkbook does evaluations of acupuncturists. You know? That's more a straight up sort of thing than some things, where you don't really know whether the person's hitting the bottom of your foot right or something like that. You know, some are much harder than others to do, but at least some of those things you can get some meaningful feedback on the quality of those providers or at least on the ability of the providers to explain things you know, and to give miracle cures. I've had a miracle cure by an acupuncturist (Laughter).

So, after having many times where I -- or one time, I went in the acupuncturist's office and he said, now you have to listen for the chay (Laughter) and all this kind of stuff. And then he put a lamp on my leg and put on music and let me sleep for a half hour. Or you know, I wasn't supposed to be sleeping, but I was. And he said, well, how did that work for you. And I said, it was terrific. But when he had been talking to me, I was just thinking -- I mean, a warm lamp and sleep, how can you beat that? I'd been thinking, did I lock my bike out front (Laughter)? So, I don't know. People have very different views on how this stuff works.

SPEAKER: Yeah, yeah. Well, I think in general, that has not been -- it's a bigger and bigger part of the system and the economy, and I don't see it as having the same level visibility and measurability that we're trying to see in the regular medical care system.

MS. RIVLIN: Other questions?

SPEAKER: I have a question that comes from Twitter. This is from Atrius Health. Is there any information about increasing consumer engagement through transparent cost and quality data? And how can we increase engagement?

(Simultaneous discussion)

MS. PETER: I can speak anecdotally. Just from our organization, we definitely see an increase in engagement from consumers in both the data that we're providing, and also with the stories and consumers telling their stories to us. I think what can make it more useful is just making the data more accessible, more personalizable, all the things that we heard today, and making it more about their day-to-day decisions or their decisions they're making about procedures that they have enough time to make those decisions about, such as maternity, child birth, knee replacement -- things like that.

SPEAKER: Yeah, I think that there's been a lot of literature about why consumers get involved or not involved in cost and quality data. I think from low income consumers, it is somewhat different and you need to think about, you know, how to engage folks who have historically maybe been uninsured. You know, that's where we think consumer assistance is important. The Medicare has assistance in people choosing plans. We think that's sort of something that would really help.

MS. RIVLIN: Yes?

MR. RABINOWITZ: Thank you. David Rabinowitz. I know there are some providers and organizations that are in the business specifically to help people, and there are others that are in the business to make money. And I'm just wondering, from your analyses, can you differentiate one from the other?

(Discussion off the record)

SPEAKER: Well, I don't think we can get to the heart of their motivation, but I think we can look at their performance, and we can see are they, in fact making people better and are they keeping costs reasonable. Are they over prescribing? You know, so I do think it's possible. And even some of those things -- I talked about this

choosing wisely type -- you know, assessment, which is obviously a very important thing.

And we don't know how to do that, and we're going to need better data to really decide -- you know, start rating -- identifying providers who are really abusing, as opposed to just getting a whole lot of referrals for somebody who actually needs that treatment.

MS. RIVLIN: Before we wind up, let me ask each of you very quickly, if you look ahead 10 years, what would you like to see in this world of consumer information about healthcare and consumer choice? What are the most important things that you think the world ought to look like 10 years from now in this dimension?

MS. PETER: So I think --

MS. RIVLIN: Doris?

MS. PETER: I'll go back to where I was before about safety and medical errors. I feel like we've been trying to crack that nut for at least 10 years, if not more. So, if in 10 years, we are able to have a way for consumers to understand their risk of medical errors in any particular hospital or with any particular surgeon, that would be where I would want to be.

MS. RIVLIN: And there are fewer risky providers, one would assume.

MS. PETER: Exactly.

SPEAKER: I think we need to consolidate information, make it easier for the consumer to use. I think we need to focus more on outcomes and the patient experience.

SPEAKER: I would agree that we have to push toward measuring outcomes. You know, different people are in very different situations. Somebody who has no chronic condition and who has no acute condition is not much interested in

outcomes, except they want to avoid having something go wrong. Somebody who has a -- you know, a serious chronic condition, really is looking at measures that are very clinically oriented, et cetera. And so, those things have to be tailored, as you say, to -- you know, the measures have to be tailored to the patients or to the consumers.

MS. RIVLIN: Given the demographics, more and more people will have -

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SPEAKER: Will have one of the latter. Right (Laughter)?

MS. RIVLIN: -- chronic condition. Thank you very much, all of you. This has been a very good panel. And I hope that some of these things come to pass quite soon. Let me turn it back to -- well, yes, a round of applause for the panelists.

(Applause)

SPEAKER: I guess that would have been coming last. You actually

(Laughter) --

MS. RIVLIN: And then, let me turn it back to Kavita for some final remarks.

MS. PATEL: All right. Thank you, Alice. And go ahead and stay, because this won't take very long. I just wanted to thank all of our panelists again, and also, thank our excellent staff at Brookings. Rio Hart, Monica Maday, Katelyn Brant, Domma Tiamassi, Joanna Klatzman and a number of people who helped make sure that everybody was as comfortable as possible. And also, for the folks watching on the web, I just want to highlight a couple of things.

I mentioned some of the work we're already doing with this dataset and data releases. We're going to have several more briefs that talk about topics covered today, and I wanted to be a little bit provocative in what might be coming after today's conversation. We've talked about kind of uses that are not just consumer centric, but

what happens if some of this data could be used to create some of these high value networks that we're seeing in the private marketplace, as well as on these health insurance exchanges.

And what if we could actually, as Chapin alluded to, get researchers together and almost do kind of a crowd sourcing of valuable research cases or findings? Things that we all find interesting, that we don't necessarily have one entity taking lead responsibility for, but that we could work with non-profits, research organizations as well as consumers on what they find interesting and try to put that together in a way that's not contingent on what the government would do.

And then finally, I think Doris kind of talked about a conversation that's been missing around safety and errors. It wasn't that long ago that we had crossing the quality chasm in some of the work of Don Burwick and other colleagues who highlighted these problems, unless we'd be remiss to think that we've solved all of them, how can we be pointing towards places to improve and think about concentrating efforts from transparency in data to show people not just what's bad, but what we can do to improve the infrastructure of healthcare in our country.

So, I did want to point that the conversation won't end today. We are going to be doing future publications, as well as hopefully extending this in other ways. So, thank you for your time and attention, and have a great rest of the afternoon. Take care. (Applause)

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