Thank you so much, Tyler. Thank you everyone, I'm just so thrilled to represent the work that we're doing here today at Mass General. As Tyler said, I am the Medical Director for Patient Reported Outcomes at Massachusetts General Hospital, and I'm just really excited to share this work with you all and walk you through what we're doing here. And I want to apologize in advance, I'm a little husky. My toddler, of course, gave everyone in my home a cold. So, let's just get started. So, the learning objectives today, the first thing I want to do is state the value and the potential use cases of patient reported outcome measures.

And just to make it a little less unwieldy, we're going to call those PROMs for the rest of the talk. And more importantly as a pragmatic thinker, I want to use some practical case examples of PROMs and I want to do that in such a way that we can guide deployment in your organization and show you what we've done in ours. And finally, I want to speak a little bit about some of the barriers to implementation and how we've addressed those at Partners. So, in way of background many of you all are aware of Partners, but Partners HealthCare is an integrated system, and we're a huge system. And it's comprised of two large Harvard affiliated academic medical centers, the Massachusetts General Hospital, and the Brigham and Women's.

Six community hospitals, five community health centers. We have inpatient, outpatient, psychiatric, and rehab facilities. And ultimately we take care of more than 6,000 physicians and touch the lives of hundreds of thousands, if not millions, of patients throughout the enterprise. And I just want to start to really highlight the importance of patient reported outcomes and Tyler is actually going to be my poll guy for most of this. But the first one I want everyone to think about and reflect on a little bit is, if you were asked to help a family member find a hospital or a doctor, someone needs a knee replacement, someone needs brain surgery, how would you choose?

So, would you go online, would you use publicly available quality metrics reported by CMS, or the Department of Health? Would you look at websites, would you find snazzy articles and places that looked really fancy? Would you ask your friends or maybe you know a nurse who lives in your neighborhood? Would you ask your PCP? Would you do what we like to refer to as cocktail PROMs, where you're asking your friends and family members informally? Or would you only use your insurance provider's list? Tyler, anything else you want me to move on there, the poll's open.

Nope, we've got the poll open now for everyone to respond. And we'll leave this open for a few moments, give everyone a chance to respond. And then we'll share all the results. And while everyone's filling this in we'd like to remind
everyone that you can type in questions and comments in the questions pane of your control panel. All right, let's go ahead and close this poll and let's share our results. So, 18% responded that they use publicly available quality metrics, 8% shop websites and articles. The vast majority, 40% they use their own personal healthcare network or their primary care provider. 18% responded friends and family, and 16% responded the use your insurance provider's list.

Rachel Sisodia: That is really interesting. I like that most people use their personal healthcare network. I'm not surprised by that. I think I'm reassured that people don't shop websites and articles. But let's talk a little bit about all of these ways of doing this are really the only ones that we have available right now in many ways. And as we all know they're flawed. And I think a really good example of this is even personally, I'll tell a personal vignette, I'm a cancer surgeon. One of my best friends, recently, was diagnosed with a really aggressive breast cancer in a different state and when she relayed to me her different doctor options, right, I vetted it with my breast oncology friends in that state.

And the one physician I had to recommend to her, she hated her bedside manner and she ended up going with another one who one of her girlfriends had recommended but I personally knew didn't have as good a surgical outcome. And it just highlights a complexity that if even doctors don't know how to get patients to the right people or how to help them match up the right doctor to the right patient, how can we expect patients to do that? And one of the things that I really want to highlight for you guys today is that PROMs is that missing link. And so, because we believe in that so firmly, I want to show you a little bit of what we've done, and then I want to talk to you about why it's so important.

If you look at Partners, really we launched in 2014 and we've scaled incredibly rapidly. You can see the numbers here. We have about 350,000 collections but that just refers to just straight patient collections. Within each collection there's multiple surveys. And so, really we have about 1.4 million surveys completed at this time. We have over 800 iPads. We're an iPad based technology in over 85 clinics. And really our most successful employers to date have been in ortho, oncology, psych, neurology, urology, and primary care, and I think that really highlights that PROMs are applicable to a diverse group of people and a diverse group of providers.

So, let's talk a little bit now about thinking about PROMs as what's really important. I highlighted the example of my friend for you guys and you all, yourselves, pointed out the different ways that you would find a doctor, but what do we talk about now? So, right now in healthcare, again as a surgeon, we live and die by our 30 day mortalities, our length of stay, our readmissions, our lab values. Did the patients get a bowel prep, did the patients get the correct surgical site prep, and things like that. And I can tell you right now I have never had a patient ask me what my 30 day readmission rate is. No one cares, right, outside of physicians and healthcare systems.
What do patients care about? They care about symptoms, right. They care about, "If I had my prostate removed am I going to be cognate? If I had my uterus removed am I still going to be able to have intercourse?" They care about their daily activities, can they pick up their grandchild, can they get on the floor and play with their child? They care about their functional status, their mental health, and their quality of life. And right now I would argue in healthcare we really have a dearth of supplying these sort of results to patients. And really, honestly, that's the most important thing. I think the next slide I'm going to show you is actually the single most important slide in this deck.

This is extracted from a Michael Porter Harvard Business School Case Review and it refers to a center in Germany looking at urologic surgery. And what I would highlight here is that ... And we know this is true in the United States as well, if you compare two hospitals, one thought to be average, not necessarily at the top of the heap, and one of the hospitals considered one of the best in the country, really from most of these sites there's not a lot of difference in mortality, particularly in prostate cancer. And it's true in my own field. And that's often been much to the chagrin at institutions of which many of you all are a part, where we pride ourselves on providing what we believe is excellent care.

Why can't we show that? Well, in this study which referred to a clinic in Germany, you can see the five year mortality between the best, in quotation mark, center and average center was really identical. But look at this, so this is incontinence, and this impotence, and if you can see in an average center, yeah, you're alive at five years but you have a 50% rate of not being able to be continent, and of more than 75% rate of impotence. And from then, A, the first thing is, "Am I going to live?" But the second thing is, "What is my life going to be like?" And here is where you really see the [inaudible 00:07:50] in the details, right?

Even though both institutions can keep people alive it's the best center, it was the center that employed the special technique that has helped people have lives that are worth living, helped them retain dignity, helped them retain relationships. And this is really one of the things to highlight because again, though this isn't reported in the traditional healthcare metrics, this is really what matters to patients. Here you can see, also, for example, this is our own data here, from a time period of January 2014 to July 2017, and we have almost 2,000 patients here. And this is, again, incontinence after radical prostatectomy. Just to quickly walk you through it, lower scores are better.

You want to be in the green. And if you look at time from surgery, most men will have a spike in incontinence right after a radical prostatectomy. But once you're a year out it's there's either no to mild symptoms and most men really have none. And one of the things that's so interesting about this and that you'll learn from your own data at your own institutions when you apply PROMs is that you learn new stuff. Most of the urologists felt that what you were going to get, you had by the end of the year but if you look at the next slide at three years these
men actually continued to improve. So, PROMs taught us something we didn't know about our own specialty.

And this is also incredibly powerful information to give your patients as well. If you look at sexual dysfunction, same thing. It improves but an important thing is that it never goes back to normal. So, again, one year and you can reassure men where they are at one year, they'll be much better at three years, right, but it will never go back to normal. So, this works in two dimensions. One, it's an important outcome measure to compare against yourself and other institutions and see how you're doing and potentially spread best practice, but it's also great for counseling. Again, for men the outcomes, like I said, are not just mortality, it's what are your hormonal symptoms, what's your incontinence, sexual dysfunction, urinary irritation?

And these are all things that are really an important thing. Also, any time you're talking about surgery you want to measure variation and this leads to quality improvement. So, again, a good example is incontinence after prostatectomy, which I think we can all agree is an incredibly metric that speaks to both quality of life and dignity. And one of the things that we've done here, I'll tell you a personal vignette, from the Brigham, was one of the surgeons we noted had dramatically better scores than the others. And they were all excellent but this surgeon had really separated himself out. And what we learned from this was that he had been trained in a special nerve sparing technique, that actually I think he had learned in Japan.

And once we saw this data we were able to spread that virally through the whole group and all were enabled to improve. One of the things that's important about variation, especially in surgery, that you have to be thoughtful about and I will caution you as a surgeon and your surgeons at your local institutions, they have this issue, is being very thoughtful about case-mix, and that each patient is not necessarily comparable to another. And you never want to penalize physicians or surgeons that are taking care of patients who have greater core morbidities or have lower pre-op scores.

PROMs can actually be really helpful in terms of guiding appropriateness and efficiency. As a lot of you guys know there's a lot of ways to skin the cat. That's what we would say where I'm from in Kentucky. I hope no one judges me from that, but a lot of different ways to do things in the OR and they're all attributed to very different costs. So, the next slide show actually is from our buddies at University of Rochester, and it's looking at physical function due to different types of reconstructions. And if you look here you can see that even though the three different ways of reconstructing a hip are very different in cost.

Actually, the most expensive one had the lowest PROMIS physical function scores, and so, again, that can be something that you share with your colleagues, that the most expensive treatment isn't necessarily the best one. And also, I would argue with patients. This is my favorite way to use PROMs, and this is in patient care, and it's better shared decision making. I know, again, as a
cancer surgeon, a lot of the surgeries that I have to offer to people are incredibly morbid, and they’re faced with terrible choices where they trade off mortality versus morbidity. And PROMs can really serve as a valuable tool by telling them the experience of women who have gone before them.

I think, again, I would highlight the incontinence after radical prostatectomy. It's very important in terms of anxiety, in terms of counseling patients what to expect, that yes, this will go back to normal. But as we discussed, for sexual function, again, it's really critical that patients know particularly when choosing between, for example, prostatectomy versus radiation, that associated with this, even though there's a durable response, it has an excellent mortality or a five year overall survival result, you cannot expect sexual function to go back to normal. Another great example is a laminectomy. So, we know from our own data and I'll show you the graph in a minute, that Ad Partners, if you have laminectomy whatever leg pain you're bringing to the table we're going to cut it in half.

You can see right here, and this is really key, again, your uncle Frank wanting to know how he’s going to recover from his laminectomy, when's he going to be up and at em again? If you look here at surgery, at the hash mark, you can see that immediately after surgery people have almost no leg pain. Lower is better, on a scale of one to 10, 10 being a lot of pain, zero being none, but once you're around three months some of that goes away and one can envision a lot of phone calls to the physician's office saying, "I'm actually getting some pain back, did something go wrong with my surgery?"

And actually, in fact, no, there's a tabling at three months where, again, your leg pain is cut down by half but it won't be as good as immediately after surgery. And this is really key in order to set patient expectations, to guide decision making in terms of whether or not the patient feels this benefit is good enough to justify this surgery. And even from a simple thing as office flow, to mitigate phone calls through patient concerns that perhaps something went wrong with their surgery. One of the other things I want to really highlight is that patient reported outcomes, and I can tell you this as someone who tries to disseminate it through the organization, is that one of the things that we're challenged by is now is a hard time in medicine.

Doctors are asked to do more and more with less and less. There's more and more regulations, a lot of them frankly don't make sense and people are frustrated. And I know everyone feels really disengaged, a lot of times from the actual things that brought us to medicine. And one of the things I want to highlight is that even though PROMs can seem like one more thing and it's a bit of a hurdle this additional data with a patient can save you time and enable deeper and more personalized care. And one of the things I really want to highlight is, this is a great example in clinic. So, this is a way that we can see the data within our medical record system and you can see the last two scores of this patient since they came under this physician's care.
And anything that's highlighted in yellow, correct, is something that's out of range and abnormal. And you can see when this patient was initially seen they had multiple domains that they weren't doing well on, pain, physical function, pain interference with their day-to-day life, and global health, meaning just how were they doing every day? And within their time with that physician you can see that they were moved to within the normal range in every parameter. And, again, for your physicians in a time it really feels like a lot of negative feedback and a lot of things that it's hard to quantify how good a job we're doing, this can be very rewarding for both the physicians and for the patients, also to see, "Look, progress may be slow but it's effective and you're getting there, and you're doing better on objective measures."

The other thing that we really think is key, and you guys know this as well, is just PROMs for value demonstration and transparency. We're really proud of what we do here and we want to share that with the world. And again, as I stated before, a lot of things are lost in the things that we currently share and are reported, the 30 day mortalities, the lengths of stay. And so, one of the things that we decided to do at Partners was create a forward facing website called Care Decisions, where we essentially take patient reported outcomes data and make it available to everyone. And here you can see it's data that helps guide the patient's decision, and we put several procedures on here.

Procedures for knee arthroplasty, for spinal stenosis, heart disease, and prostate. And what we show here is A, for patients, they can look at this and they can see that at Partners HealthCare, this is a score of how they function with knee pain both pre and post-op. And here you can see, again, for patients that have been suffering with knee pain for a long time and they wonder well, or they're afraid to get a knee replacement, "What will this do for me?" They can see that a year later patients are pain free.

And you can see that actually it's not immediate after surgery, right, it takes a time, it takes almost a full year but you can, again, for patients that can really understand and quantify, "What does that mean? What would a knee replacement mean for me?" Well, if you're like the average patient it means that your pain score would go from less than 40 to up to 90% which here in improvement higher is better. And most patients really a year out from knee arthroplasty are pain free. Another thing that's a really interesting thing for patients to see is for men with prostate hyperplasia, what happens if you get a TURP? That's a scary procedure, I can only envision.

Most men are going to be a little leary of that but you can see that actually lower urinary tract symptoms cut in half after TURP. And our goal, ultimately, is to put most, if not all of our surgeries on here so patients can see, and not just the ones that are slam dunks where your knee pain goes totally away, but I also think really critical are the ones that I showed you for example, the ortho example where leg pain is improved but it doesn't necessarily go to zero, right, that's important for people to know as they plan their lives. Tyler, I think I see another poll question.
Tyler: Absolutely. Our second poll question is, which aggregate use case of PROMs is most compelling for you, PROMs for individual patient care, more efficient and personalized, PROMs for shared decision making, PROMs for comparative effectiveness and quality improvement, PROMs for appropriateness and efficiency, PROMs for transparency or value demonstration? And we'll leave this open for a few moments, give everyone a chance to respond, and then we will share our results. We have gotten a few questions in, I'd like to respond to the, yes we will be providing the slides after the webinar. And we're also recording this webinar and we'll provide a link to that recording as well.

All right, let's go ahead and close our poll and share our results. So, 25% responded PROMs for individual patient care, 29% for shared decision making, 37% for comparative effectiveness and quality improvement, only 3% for appropriateness and efficiency, and 6% for transparency, value demonstration.

Rachel Sisodia: I think our audience is actually totally spot on here, I would agree. As someone who's done a lot of implementation work, I think these are the things that are most motivating, people care about patient care, like being able to talk to the patient across the table from you and let them know what to expect. Shared decision making, obviously is a really key thing and it's only going to become more important. And then, comparative effectiveness, again, it's near and dear to my heart, as a surgeon it's huge, right, a lot of people assume that ... For example, I'll speak candidly with all surgeons that we're all the same. And you ask anyone who operates, you know that different surgeons get different outcomes and really we need to move to the chapter of medicine, which is why.

And when we find out why to spread that. And the only way to find out why is to actually look under the hood and see how that's occurring. It's uncharted water and there's a lot of things that you can do with PROMs that will really revolutionize medicine. I want to talk for a minute about implementation because the [inaudible 00:21:29] is always in the details and this sounds great but I'm sure the next question which is what many of you will have, which is what I have, which is how do you actually do this? So, let's talk a little bit about the steps to implementing a PROMs program. So, the first thing you have to have is leadership buy-in, that's critical.

And a good way to do that is to point to leaders and people that have done this, and say, "Look people have done this and they haven't been damaged by it. If anything, they're stronger." The second thing is that you have to have a big,
robust team, so you need to have people that are responsible for implementation and trouble shooting problems that will have both administrative and analytics types but also you need to have physicians on board in each clinic who are helping with implementation. You need technology people, you need data people, and you need advanced analytics. I will tell you as an academic physician that the data is unwieldy.

It's huge data, you're looking at it around anchor events such as surgery or data over time and multiple things are happening to these patients, and the data is really complicated, and the data is really key in feeding that data back to docs to getting them to actually do this. Once you have that in place you have to choose your platform. We actually did an epic based solution but there are many other third-party vendors and other ways to do that. You have to decide how do you want to collect? We collect in clinic, we also collect on our patient gateway at home. There are multiple opportunities to collect. We're working on setting up something in our pre-op area, so that we can catch all patients even before they go to the operating room.

A lot of different ways to do it, you just have to find out what's right for your institution. And then, the other thing you have to do is make sure you have your IT working well. Nothing is more frustrating, we all know this, when our Outlook won't work, our iPhone, God forbid, doesn't work. Same thing with PROMs, if the IT doesn't work it will fail. It's good to pick an initial target. So, here our big champions are orthopedics, urology, and neurology, interestingly, which are strange bed mates but wherever you start it's good to pick a group that has a champion, that has a lot of clinical sway, that makes things happen, has a strong track record of being able to implement things and get people to come along, and then to start in that area.

It's good not to spread yourself too thin, too fast. And finally implementation and data analysis. Like I said, this is an interesting point because to implement doctors want data and which we have that now. Some of the data I've shown you about why it's important, but the other thing that immediately I have learned over, and over, and over, a complete stop to the program occurs when physicians don't get data fed back to them. And I would also really stress the importance of that because, again, like we said and you guys highlighted what's important is looking at variation amongst doctors.

And so if, again, you had these results that showed that one physician was an outlier either good or bad and you sat on that data for over a year longer, that becomes ethically challenging. Once you have the data you need to act on it, you need to be able to use it. Again, once you start there will be always some people who are nervous, so you have to start with someone who has faith in it, and then you have to reward that faith by quickly getting their data back to them. Both an aggregate for their group so they can look at patterns and immediately for them at the level of the patient encounter.
The second thing is agree on which PROMs to measure. So, this is hard, sorry about that, you cannot ask a million questions. What we have learned is if you get, with very rare exceptions, if you ask more than 30 questions the patients stop. Another thing that we have had a lot of trouble with is that we are a research institution, right, so there are tons, especially in oncology where I am, there's tons of quality of life, patient reported outcome, sorts of things being done for research, and they may have a very narrowly defined focus. You know an example of one I'm interested in is regret after surgery. So, there's a whole series of very narrow patient reported outcomes about regret.

However, these are not day-to-day using clinical care PROMs. So, what you have to do when you're going to unroll PROMs in a group is you've got to get the docs and the relevant stakeholders to agree. So, the first thing is it has to be short, it has to be less than 30 questions. No matter how much we love to get in our ivory towers, it cannot be some abstract questions. You can't ask people 50 questions on surgical regret, you need to to ask actionable things. You need to ask things that immediately matter to patients. The third thing is it needs to be validated. You have a variety that speaks to number four of industry standard registries, ICHOMs, lots of different ways to choose which set of PROMs. And generally for any sort of issue, or symptom, or disease site, or conditions, there are a whole set of validated measures, but you need to choose one as a group. And I will tell you that we really encourage our physicians here to use PROMIS domains if possible. I think that if you speak to the field and people that are into PROMs they will tell you that really the whole field is moving towards PROMIS measures. And we can talk about this in questions, there are some areas in which PROMIS is not as robustly developed but I do think it's all going there and that's really where the field is moving.

They're also free and I sponsor some. And I also have the ability to do computer adaptive testing, which for those of you that don't know what that is, it's where on a traditional survey if you have to answer 10 to 15 questions, this may be a smart survey. So, for example, if you said, on one about knee pain, "I can't walk I'm in a wheelchair," they won't ask you later questions about your balance. So, you may get away with three or four questions. And ultimately that allows you to A, not frustrate your patients, B, not waste their time, but C, even ask more questions that may be relevant. All right, Tyler, you're up.

Tyler: All right, thank you. Our next poll is, all below are mission critical, but which of the following might be the determining factor in a successful PROMs implementation? Please select one of the following, patients, staff, clinicians, or unsure, not applicable. We are getting a lot of great questions in. We'd like to remind everyone to please type in your questions and comments into the questions pane of your control panel. We'll leave this open for just a few more moments, give everyone a chance to respond. All right, let's go ahead and close our poll and share our results. 29% responded that patients might be the determining factor, 18% said staff, 46% responded clinicians, with 7% unsure or not applicable.
Rachel Sisodia: And I think that what that audience is speaking to there is that they get that really all are critical. I would say that the clinician's aspect is really key and I think one of the things that’s really important and that I’ve noticed is that, for example, in some deployments there will be a fellow that’s really interested in PROMs or a more junior staff member and that’s great but generally what you guys intuited there is that you do tend to need a more senior staff member, someone who has a lot of pull amongst the other physicians to encourage this along. The other thing I would say is patients, obviously, if the patients don’t complete the PROMs you never get off the ground.

And we can talk about some of the things that can either promote or inhibit that. And then, the one thing I would say that I think probably might be a little bit, we all underestimate it, staff. We find that the frontline staff are really critical and engaging them from the very beginning is really important. These are people that are in customer service, they do things because they want to make patients better but unless someone actually takes the time to explain to them why PROMs are important a lot of times we found frankly they don’t give out the iPads. It just seems like one more thing that makes people wait in line longer. But if they understand that this actually goes toward patient care they’ve been totally happy to comply.

So, really robust collection requires all three. You have to have three happy customers and you got to have the platform working. For patients you have to do it in ways that are convenient to them. One of the things that we really want, one of the functionalities we really want here and we don’t currently have is the ability to do it on your smartphone, right. Everyone’s very comfortable with their smartphone, even though the iPads are great and people are comfortable with those, I think we all personally understand how wedded to our phones we are and how easy it is to fill things out.

I will tell you over, and over, and over the most important determinate is did the doctor, did the provider use the results? So, if I just spent 10 minutes filling out 30 questions about everything about me, like how I feel about myself, am I depressed, am I anxious, how much do I workout, what do I want for my life, and no one even acknowledges that I took the time to do that I’m not going to do it again. And that’s what we see when we look at samples of patients. If the doctor, immediately, in the exam room referred to the PROMs, and then our platform here once the patient puts them in the iPad you can immediately see them within the patient’s chart.

So, if the physician turns the computer screen around and references the PROMs you’ve got somebody who’s sold for life. If the doctor doesn’t even acknowledge that they were done the patient’s not going to fill it out again. The user interface has to be intuitive. I don’t think we have a screenshot of ours but it’s just very next, next, next, it has a lot of Likert Scales, one to 10, things people are used to. And then, you have to avoid survey fatigue. The computer adaptive testing helps with that and also, like I said, really can’t do much more than 30 questions.
For frontline staff it has to minimally impact workflow. We timed ours, essentially the patient comes if they're due for PROMs there's a little red flag that pops up on the schedule, and then the front desk staff has to put a code into the iPad, hand the iPad to the patient, and then the patient will fill out another identifier. It takes about 30 seconds a patient, even on the front desk staff who aren't that tech savvy. But I will tell you that can add up and if you have a line already around the block you just need this to go very quickly. Also, we found over and over again that having an administrative champion is really key so you need a physician champion, an administrative champion, and our boots on the ground.

This cannot be someone who's offsite dictating it needs to be done. And the single most important line that your front desk staff can say is they cannot say, "We need you to fill out this survey." What they have to say is, "Doctor Clark needs you to fill this out." That's it. And when patients think that the doctor needs it or wants it to be filled out they do it. And again, there needs to be this constant reinforcement in the beginning, like if a patient didn't get an iPad or fill out the PROMs for the doctor actually to go say, "I noticed this patient didn't get their PROMs administered, did something happen?" So that people know that doctors are actually looking for this information.

I challenge my physicians or clinics to actually think about it as vitals. If I'm seeing a patient on chemotherapy and she didn't have her temperature checked or her urine checked for protein I'm not going to see her, I'm not going to administer the chemo until someone does that. So, that's really where we want to get to. And then, finally for physicians you cannot interfere with the workflow this has to be seamless, everybody's asked to do more and more with less and less. Doctors are highly motivated by better care, so you need to feel like, again, and this goes back to the question selection, you're asking things that matter to patients.

And again, the data is a piece of this. You get the data bounced back to the docs, they see how well they're doing, or frankly how poorly they're doing on something, and then it inspires them to want to improve. The other thing that you really want these to do, if you really want to sell it to your docs and hit a home run is give them some other benefit with it. If you choose your PROMs well a lot of times they can replace or review a system, and they're already in Epic. And they can save time in that way. Or you can include surveys that would otherwise be asked. And so, a really good way to, again, sweeten the pot for the physicians is to do that.

And the final thing I will say, and this is really key, is that the scores have to be actionable. So, for example, if you're asking patients about depression and a patient tells you that they're suicidal your physicians have to have an immediate resource to be able to deal with that. You cannot ask questions that doctors feel like they can't do anything, or doctors or nurses help the patient. So, if you're going to wade into that territory you have to give people the appropriate resources in order to manage those. Ongoing challenges, things that keep me up
at night as Medical Director for PROMs here. Risk stratification and case-mix adjustment.

So, I'll give you a personal example. One of the other oncology surgeons that we work with here has been here a very long time and is famous for doing the cases that no one else will touch. He does the cases where they’re sick, people feel like it's unresectable or the emergent cases where the patient is literally on death's door. When I got the patient reported outcomes for this physician right after, in this particular case, prostatectomy, they looked lower than the other physicians in that area and immediately I was horrified because I was like, "I can't show this to him. This is one of the best surgeons in the hospital." It was the person, I actually had him operate on my father which should tell you how highly I think about him.

And what we had not encompassed there was the fact that his patients were incredibly sick. A lot of his patients were in the ICU still, they were just out of a rehab. And when you look at him compared to someone doing, for example, a prostatectomy on a young, healthy man who's discharged the same day after a robotic prostatectomy, it's just not the same thing. And risk stratification is hard, and you can also see that, again, in medical specialties, right. If you’re taking care of patients that have a lot of social complexities, have a lot of medical core morbidities, and you're comparing the results of those physicians to physicians with patients who are more affluent it's not necessarily fair.

And it could potentially make people look worse than what they are, so you really need to nail risk stratification. Data for non-surgical treatment. So, I've talked a lot about surgery because it's a very simple example because you have what we call an anchor event. You have pre-op and post-op, and that's pretty simple, but what about longitudinal conditions? We have a really robust neurology collection. We have patients that are, an example would be patients with epilepsy who may, over a period of a year or two, be tried on multiple different medications and that data, frankly, is incredibly complicated to give back to the neurologist because we're trying to unify when a prescription was given, with changes in quality of life scores, and that gets really complicated.

So, we have to figure out a better way to do that. Patient facing reports, you guys saw a little bit about Care Decisions, but again, the patient facing reports encompasses these other two concerns. How do you explain to patients about risk stratification? How do you explain what's the appropriate comprehension level to write this sort of stuff out, where you don't lose the details but you don't make it inaccessible to a lot of patients? Also, how do you represent data for non-surgical things, the epileptic example to patients? And then, the final thing, which we drew a line through because we kind of figured that out here is, sharing data with clinicians.

So, again, getting the data back it's unwieldy, I could speak at length about all the scars I bear all over my body from various battles, trying to get people their data, or people not being happy with their data. We also switched platforms.
within the last couple of years, so there was some data lags with that. We’re currently building a subject area mart in our data warehouse where people can really go shopping for their own data. But again, getting the data out to clinicians is incredibly important and also I will remind you that there are some reporting requirements actually by CMS, if you have quality data that, that needs to be done in a timely fashion, so you’re always under the gun from that.

In summary, I would say that ... Excuse me, the key takeaways are that PROMs is the future, so we know the past has been, we’ve measured the things we can measure and there’s this great quote, actually in the PBS Vietnam series that a lot of us recently watched where this veteran said, "If you can’t measure what’s important, you make what you can measure important." And I think in the history of medicine we’ve done that, right. We’ve looked at length of stay, and readmission, and things that are quantifiable, but really what’s important is, "Did I make this person's life better, right? Did this intervention leave them better or did it leave them worse, right? And how do we learn from that, and expand that?

And PROMs is really where the future is going, and I think that that’s been established over and over. As many of you guys know, there was a paper in JAMA, that actually showed that just by collecting PROMs and having nurses act on them we extended overall survival in cancer patients in a prospectus fashion more so than any new drug we've put out there in the last year. That's amazing and it speaks to how important these are, and I think with more and more sentinel studies like this it's just going to be virtually impossible not to collect these and integrate them into your care. PROMs improves with shared decision making, it can help us take faster, more systematic, and personalized care of your patients.

When you say, "Oh, Mrs. Smith, oh, my gosh, what's going on? I see you seem so sad? What happened?" And then, you find out your patient's husband died, and you can act on that or you can find out the right resources. Or, frankly, you can give her a hug, right. You might not have known that otherwise. And the final thing that I will say, next to last, is that we can use it for quality improvement and value. I’m also, obviously in addition to a surgeon, and administrator. I care about proving value, I care about proving that the things that we do are appropriate, I care about demonstrating that I want to be able to continue to do our good work that we do here at Mass General and Brigham and Women's.

And the final thing I will say is that implementation is challenging, you have to get your suit of armor on but it is feasible, and it is doable, and if you load your boat with all the right people and the right expertise it can absolutely be done. I think the fact that we started in 2014 with a brand new program and now we have almost one and a half million instances of PROMs, should tell you how quickly you can do this and how quickly you can ramp up. So, progress is rapid but obviously there'll be new challenges. But again, it's totally doable. So, I think
I'm at time. It's been about 45 minutes, I'm happy to answer any questions or
answers.

I'm really passionate about this topic, I really believe in it, and I would love to
encourage everyone, if you're not collecting to think about how you can do it, or
if you are already collecting how to take it to the next level.

Tyler: All right, thank you so much. We've got a lot of great questions coming in.
Before we get to those though we do have one last poll question. Now, here at
Catalyst, our webinars are meant to be educational opportunities. We do get
questions, however, at times about who we are and what we do, so if you'd like
someone from our sales organization to contact you about our analytic
applications or improvement services go ahead and respond to this poll
question here. And while this is up let's get right into these great questions. So,
our first question is, can you speak more to the role of family and caregivers
providing the outcome information?

Rachel Sisodia: That's a great question. There's a couple of different ways we've done that.
Excuse me, so the places we normally see this are in neurology and in pediatrics.
So, in pediatrics and neurology there is a section in the beginning in their
questionnaire sets it says, "Who is filling out this survey?" Very simple, a
caregiver, patient, and so we address it in that way. People currently if they
were logged in under someone's patient gateway could do that. Most of the
time though it is just the patient answering for themselves but we definitely
have the ability for caregivers to answer for patients.

Tyler: All right, thank you. Our next question is, how reliable are the patient
responses? Can those solely be utilized to determine the medical condition?

Rachel Sisodia: How reliable? So, the patient reported outcomes or the patient reported
outcomes. So, we tend to take the opinion that although you may dispute what
you may say, I think everyone who's on this webinar and has taken care of
patients can recount the time that someone told you they were at 10 out of 10
pain and yet they're eating a sandwich and on their cellphone, right. So, I get a
lot of questions from docs like, for example, on the pain scores, "Are these
reliable?" And what I would say is they're reliable to that patient. So, keep in
mind these are not one time collections or longitudinal collections. And really
unless you have multiple paired collections, frankly, they're not worth much.

But if you follow that patient over time you should see a delta, whether it's
going up or down that's relative to that unique patient. And again, ultimately,
it's what the patient thinks. So, if the patient feels that their pain is horribly
controlled it's tough to argue with that. And that's an extreme example but
Tyler, what was the second half of that question?

Tyler: The second half of the question was, can these solely be utilized to determine a
medical condition?
Rachel Sisodia: Yeah. I guess I'm not completely sure what that would be but I think that ultimately what we have to do is the key thing here is pairing these over time. Whether they hang around a surgery, or whether it's over a condition, over a time. I think that what probably the questioner is getting at is that one drop in on a patient at any point in time really isn't enough information, so I would say that, no, one set of PROMs at any given time, for the most part, can't really reliably diagnose a condition. I think an exception to that may be depression. If a patient responds, "I'm feeling incredibly suicidal," that one time drop in is all you need. Obviously, you're not going to [inaudible 00:46:49] that, you're going to act on that right then.

Tyler: All right, thank you. Our next question, is there publicly available or for purchase a database of PROMs?

Rachel Sisodia: Not that I know of. Oh, I'm sorry, PROMs tools or PROMs outcomes? Well, I'll answer both. So, for PROMs tools you can go on PROMIS and those are all free, totally free. ICHOM is also free. As an oncologist I can tell you that most of the EORTC scales are free and a lot of us use those. So, you have to hunt around for what want. I recommend, if people are looking at a body, they start with PROMIS. If it's not there, then you could do a PubMed search for whatever area you're interested in and see what tools have been validated. I initially thought that the question referred to is there a database of baseline PROMs for any given condition, and no.

You can, again, do a PubMed search. Individual institutions have published on their experiences but outside of that there's no standardized expectation or bell curve for a patient or a condition.

Tyler: All right, we have several questions around the collection of the data comprising PROMs. How do you collect the data? What other modes are you using to collect the data beyond the iPads? Are you doing all this in Epic or paper other methods? Questions about response rates in your collection as well.

Rachel Sisodia: Yes, okay. We have two major ways of collecting. One is the iPad in clinic. Some clinics also have little kiosks but really people are trying to move away from that because you actually just get a bottleneck. So, mainly iPads in clinic, and then we also have a patient portal called Patient Gateway where people can log in and see their labs, they'll get notifications from their doctor if they have a bill. And so, questionnaires get pushed to patients via Patient Gateway, so they'll be identified either by an ICD code or a CPT code. So, if a patient is identified as having migraines a couple of weeks prior to their appointment they will have these surveys released on Patient Gateway.

If they're not filled out on Patient Gateway then when they present to the clinic they will have that little flag and they get a second opportunity to do that via iPad at that time. Once the questions are completed they immediately flow into Epic and there's a tab on the side like the synopsis tab where the doctor or the
provider can pull those up and look at them in real time. And I think there was one more part to that question, Tyler.

Tyler: I think the question was response rates.

Rachel Sisodia: Oh.

Tyler: What kind of response rates are you seeing?

Rachel Sisodia: Totally varies, totally varies. And I think that, that speaks to that last little part where I said it takes three things. So, we have some clinics that collect at an 80 to 90% response rate. I would say on average most of the surgical clinics, again that's pretty easy to collect on a pre and a post-op, are more on the 50 to 60%. So, we also have clinics where perhaps leadership decided that was something they wanted to do and there were no clinical champions or the clinical champion left, frankly, and we had a personal example of an area where there was a really powerful clinical champion that pushed PROMs collection, those collection rates were in the 50, 60 percentile for a brand new program which is pretty good actually as you're working out the kinks, and then when that physician left those dropped to like 10%.

So, it's really all over the mat. It's very possible to get 80 or 90%, but again, you have to have engaged front desk staff, clinical champions, and patients.

Tyler: All right, thank you. Our next question is, how are you stratifying risks? Are you implementing something like 3 M's acuity adjustment product on the APRDRGs?

Rachel Sisodia: Risk is really complicated. So, that's certainly possible. I will tell you that, just personally, our surgical service lines are a little bit further down the road in terms of risk stratification. And what I will say is, utilizing DRGs certainly is appropriate. A lot of times though our surgeons here are good examples. Orthopedics have come up with their own risk stratification, which has its pros and cons, right. But, for example, our orthopedics group here, one of the things they wanted to bring up, like for hip arthroplasty, is has this been done before? Which for surgeons is incredibly important. If you're doing a revision hip that's a totally different animal than a brand new hip.

And so, we gave them the lead way that we'd pull for them the things that they deem are important, BMI, revision status, infection status, all sorts of other things, weight, functionality at the beginning. And so, we have made the decision that, at least for surgical service lines, we give them a little bit more lead way, and once they decide what they feel is important for their disease set in their data reporting we keep that conserved and we give them those, and that's what we use. We're a very physician run hospital, we rely on physicians to tell us within their own field of expertise what the relevant metrics are.
Tyler: All right, thank you. Now, we have several requests for the reference to, I think, the JAMA article that you mentioned, that demonstrated ...

Rachel Sisodia: Yeah.

Tyler: If ...

Rachel Sisodia: Yeah, go ahead.

Tyler: I was going to say that if you have a link or otherwise, in the follow-up email that we send to everyone, we can make sure that we have that information in there as well.

Rachel Sisodia: Yeah, we can definitely send it out. The last name of the author is Basch, B-A-S-C-H. If you want to look it up, it was just this past year so that should be easy to find. Almost everything that physician does is in patient reported outcomes but we can also send you the direct link.

Tyler: All right, wonderful. We do have a question, how can insurance companies use PROMs for better results?

Rachel Sisodia: That's a great question. We actually share some of this data with insurance companies. To date, they've been more interested in our ability to collect it but obviously the underlying assumption is that they want to understand the actual data. And I think a really key thing, one example that actually we were just talking about this morning is spinal injections versus actual spine surgery, so we will have patients, and again, I'm relying on my orthopedists but what they tell me is that they will have patients that have had seven, eight, nine, 10, injections for pain, whereas a lot of the data is clear that after a couple of injections continued injections have little benefit.

And so, if you were to elucidate that further and they're wanting to look at that with patient reported outcomes what do patients say after more than one injection? Are they getting benefit? So, I think that ultimately insurance providers could use that sort of data to say, "Look, in a thousand patients, right, anything more than a couple of injections isn't helpful. It's just delaying a cure or a fix for this, and even if there were no other options it doesn't do any good and potentially just exposes you to harm." And so, I think that there's a really powerful use case there.

I think it provides a lot of powerful data actually to see at an individual institution where they're contracted with A, that the patient is going to get a high quality surgery that what the physicians say that the surgery is supposed to do or whatever condition they're treating is supposed to do is actually happening. If you wanted to have a surgery for leg pain and contrary to the data I showed it showed leg pain actually didn't improve well, we should revisit, right. And I think it can also solidify those relationships that they can feel comfortable...
knowing and perhaps even reduce the prior [inaudible 00:55:34], if they feel comfortable knowing there's minimal surgical variations at this institution and the outcomes are ubiquitously good, that can be another use for that.

Tyler: All right, thank you. We have a few more minutes left, some time for just a couple more questions. So, our next question is, can you point us to resources for a very small organization just getting started with data collection, for example, like data points critical for collection.

Rachel Sisodia: Yeah, so one of the best places I would start would be ICHOM. The other thing that you can do is, there are plenty of third-party vendors, if you don't have Epic, or you don't feel ready to do that I would recommend literally, the biggest line in the game has been Tonic, but there's several others. I actually did a Google search on this a couple of weeks ago. So, I'd say there's several different parts that you need to look up, one is to justify the use, which would demonstrate PowerPoint slides like this, and then ICHOM also talks about patient outcomes and how to come up with patient outcomes of interest.

And then the nuts and bolts piece of how do you do it. You can even just Google patient reported outcomes platforms and there's a whole bunch that will come up. You can also, frankly, do it on paper if you wanted to. A lot of our oncology clinics were doing that before this system came around. It's obviously much more laborious but people fill out all sorts of papers in the doctor's office. But I think that if you are wanting to do a technology platform with a smaller group it's better to look around and see what other platforms there are.

Tyler: Okay, for our final question, please explain what shared decision making tools directed at patients have been developed or implemented. Are PROM results used in visual or graphic form with patients to help with the decision making?

Rachel Sisodia: Yes, if you look at the Care Decision slide or the one I had given previously where you look at leg pain or the data where you look at incontinence or impotence, so those are shared on the Care Decisions website and doctors can currently go to those right now. And again, I think that's really critical for shared decision making, prostates a great example, right, men have a choice in many circumstances whether they're going to undergo surgery versus radiation. And at least in surgery right now we can give that data that says, "If you look at a thousand men like you these were the outcomes here at Mass General." So, there's the patient facing forward on care decisions.

In terms of other graphics, within the actual patient encounter, like in Epic, you can actually see, I think I showed you the slide with the patient who had all those results in yellow, and then moving to white. So, a patient can see their own progress over time. You can see where you did a particular intervention, maybe you can prove to them, say to them, "Look, you know, in April we did this final injection, right. You want another injection right now but look at your pain scores, they didn't get better." So, they're used in that way. I will tell you there are other institutions and there can be some additional data manipulation, and I
think where we want to go within the next year here at Partners is being able to immediately, in real time see that patient's results compared to a whole cohort of patients that look just like them in very easy pie chart, or very easily understood graphics.

So, I think within the patient chart. So, I think that's a next step for us actually in terms of patient data. That's one of the things that we're really interested in and working in now, actually smoothing and improving the shared decision making experience. It's a great question.

Tyler: All right, thank you so much. We are at the top of the hour and at time. I'd like to thank everyone for their participation and remind them that shortly after this webinar you will receive an email with links to the recording of the webinar, the presentation slides, and the poll question summary results. Also, please look forward to the transcription notification we'll send you once it's ready. On behalf of Dr. Rachel Clark Sisodia, as well as the rest of us here at Health Catalyst, thank you for joining us today. This webinar is now concluded.