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## Introducing Ellen Schultz 01:00

***Nothing about me, without me!*** Although she wasn't the first to say it, I heard it first from my friend and fellow podcaster, Casey Quinlan. Valerie Billingham said it in 1998 at the Salzburg Global Summit. I first met Ellen Shultz in 2017 at a CMS (Center for Medicare and Medicaid Services) Technical Expert Panel (TEP) on Quality Measurement. I heard her say ***nothing about me or for me without me.*** She wasn't the first. I don't know who it was. After we met, Ellen and I organized to push the TEP to advocate for patient engagement in quality measurement. Success! A recommendation became: ***Patients and caregivers need to be engaged in all aspects of measure development from priority setting to reevaluation.*** CMS defines quality measures as *tools that help us measure or quantify healthcare processes, outcomes, patient perceptions, and organizational structure and/or systems that are associated with the ability to provide high-quality health care and/or that relate to one or more quality goals for health care. These goals include effective, safe, efficient, patient-centered, equitable, and timely care.* I liked that Ellen talked about the practicalities of the slogan of patient engagement. It's more than words. How can we engage patients in measurement? Since we met a few years ago, we continue to cross paths and share ideas. Ellen Schultz is a senior researcher at American Institutes for Research. Her work focuses on the intersection of healthcare quality measurement and patient and family engagement. Ellen finds that blending science and passion has enormous potential to change the world for the better. I'm delighted Ellen could join us.

**Health Hats:** Ellen, thanks for joining me. This is wonderful.

**Ellen Schultz:** Great to be here, Danny. Always lovely to talk with you.

**Health Hats:** We met at a CMS Center for Medicare and Medicaid Services Technical Expert Panel on measurement, right?

**Ellen Schultz:** Yes. It was something about more efficient measurement or the future of measurement - some long, convoluted government title.

**Health Hats:** It wasn't about measures in particular. It was more about the system for the development of measures. The first time I heard you talk, I'm looking over the table and thinking, 'okay, I've got to know this woman.' You were very strong on patient engagement.

**Ellen Schultz:** I was only about a year and a half or two years into my work around patient and family engagement. Previously, I had done a lot around measurement. That's how I ended up on that panel. But like so many measure developers, no sense whatsoever to the role of patients or family members or community input might be. Then I came to AIR (the American Institutes for Research). Many of my colleagues had been deeply involved in patient and family engagement. I felt that made a lot of sense. I used to introduce myself and tell people, 'I do a lot of work on measurement, but it's not really what gets me out of bed in the morning.' Those two pieces came together, and I found a space where I could have both passion and bring some of that technical expertise around measurement. I thought, 'this will get me out of bed in the morning.'

## Measurement of what, why? 05:19

**Health Hats:** Ellen, measurement of what?

**Ellen Schultz:** That's a good question. We don't often ask that question. We just dive right into measurement. It's usually a foregone conclusion that we need to measure things. Recently I've been thinking a lot about some of the biases or mental models that we have in healthcare. So much of today's world pushes toward the quantitative and devalues or ignores qualitative narrative, story-based ways of knowing.

**Health Hats:** Numbers are quantitative; stories are qualitative?

**Ellen Schultz:** Stories, or words, yes. There has been an adage in healthcare for a long time - my whole career now going on 15 years - that you can't improve what you don't measure. That was the argument for why we need measurement of everything - patient safety and quality of care. We need to measure outcomes. We need to measure processes. We need checklists: lots and lots and lots of counting. Look at where we are. We have thousands of measures. We have millions and millions, probably into the hundreds of millions, if not billions, of dollars spent on measurement in healthcare. I question some of the value that we're getting out of that spending. I think that the question of measurement of 'what,' and maybe more and more important, 'why' are we measuring something? What are we going to do with that information? How will we use it? How will things ultimately become better> These questions are fundamental. To go back where we started, I have worked on developing measures as well as evaluating and assessing measures across a whole range of different topics - everything from patient safety events in the hospital to understanding access and quality of outpatient care. For example, going to a doctor's office or a clinic, care coordination that spans a lot of different situations: from the hospital to the clinic or from one specialist to another, from primary care to a specialist. It gets challenging to measure. So, I've looked at a lot of different aspects of measurement, which is a strength, mainly as I think about what we miss when we don't talk to patients and family members about what's important to them. What I've learned is we're missing an awful lot.

**Health Hats:** Let's back up a bit. In my career as a quality management professional across the continuum of care, I would often say – not very effectively – first, what do we want to know that we want to improve? If we measure it, are we going to use it to change anything? And if it wasn't something we wanted to know, and we didn't have the will to change based on what we learned; it wasn't worth doing it. That was a little bit of an easier rap before so much was mandated to be measured because then the mandated measure sort of took over. All the energy went into mandates rather than what we wanted to improve. Then, as I got more mature and seasoned and old, it seemed as if people wanted to get an A. They wanted to get 100%. I had one gig where my boss, the CEO, was looking for something that we did poorly. This was a behavioral health company. We measured outpatient follow up after inpatient discharge, and we were at something like 12%. It was abominable. He says, 'this is it. It is much easier to go from 12% to 50% then from 80% to 90%. Let's do this one.' In my naivete, I said, 'no, we suck at this.' He said, 'that's the point. We could feel good that we improved it to 50%, and we could celebrate.'

**Ellen Schultz:** It's interesting what you just touched on - a couple of the things, the good, the bad and the ugly about measurement. I began to bring patients and caregivers into my work around measurement and been a strong advocate for that publicly and helped other measurement teams be able to do the same. One of the things you said is as we measure more and more, and as so much of it is mandated, we do lose that connection between the measurement and making things better. When this measurement enterprise ramped up in health care, it started primarily as quality improvement. If you go back to that adage I cited, you can't improve what you don't measure. The assumption was that the purpose of measurement was improvement. That's where this started. But now measurement has become an assumption that we'll do it.

We've lost some of that connection to the 'why and what' the purpose of measurement. When things are mandated, we don't know the purpose. It's someone up the chain on high dictates this is what we must do. Therefore, we do it, and it becomes a check-the-box effort or just gets it off the to-do list. Off it goes. I don't care what happens. As mandates and measurement burden grew, it sucked up a lot of the time and energy and resources that may have gone towards quality improvement. Priorities, the things that get measured get attention for improvement. You're right, many people want to get the A. So, they put what improvement efforts they have towards the things that are being measured. But it's not necessarily what they might've chosen based on their local context and what they see and what they hear from their patients and the patient's families. The priorities are coming from someone else, whoever is mandating the measurement - many different people. You end up with all this measurement noise and lose sight of what it's telling you. It's tough to pick out the signals amid that noise right now. One of the unintended consequences around measurement is the way that it can distract focus. The emphasis is on the measures, not what you do with it. The attention is focused again on the place where you already measure things. The last thing anyone in the health system wants to do right now is measure something extra. So, locally-driven efforts at quality improvement - looking for the situation we're awful at and focusing our efforts there. That's not happening nearly as often as it was even 10 years ago. We're burdened with measuring the things that are mandated, whether by CMS or by various commercial insurers, may be mandated by the state, the corporate office of the large health system that spans multiple States. You're losing some of the local insight that might have otherwise driven quality improvement efforts that could have included measurement, but also could include other ways of

knowing. When it's the 10th person this week in the waiting room who has mentioned the problem with scheduling or frustration with wait time in the office, anxious because of something else that's going on. That is another way of knowing. Just because you can't quantify it, doesn't mean that it isn't real. A lot of that has gotten lost.

### Why patient engagement? 15:11

**Health Hats:** Can you tell us a bit about what does patient engagement means?

**Ellen Schultz:** The idea at its base is that we can't do healthcare well without working with the people we're seeking to serve because there is no substitute for their perspective. The idea is that we actively listen to patients. We take to heart what they tell us, and we act on it. And that can happen at many different levels. That can happen at the point of care. You have a provider who's directly interacting with the patient and asking them, 'what brings you here today? What concerns you? What do you feel we need to take into consideration in deciding how to move forward?' It can be treatment or diagnosis, but it can also happen at a more significant level. Think of a clinic - if they want to understand what are they do well and what needs to be improved? You can ask a range of the patients at your clinic about their experience. You can do that through surveys. But I think engagement is more of a dynamic conversation and ongoing interactions with patients and family members - building relationships that let you ultimately make things better. We've also seen that work very well in a research context. That's something that PCORI (the Patient-Centered Outcomes Research Institute) has done very well. It shows that our exploration and analysis of what works and what doesn't work in healthcare should take into consideration what's important to patients and their families. Otherwise, we might not be asking the right questions. And my work over the last several years has focused on extending that approach of patient family engagement and the lessons learned from it into the measurement sphere.

### Relationship-centered measurement 17:27

**Health Hats:** It seems like there are at least two parts to patient engagement. On the one hand, the patient who's engaged, and what they bring to it with their lived experience, their business skills, their communication skills, their systems thinking, their culture. Then there's the other side that we touched on earlier, being able to hear it. Not just passively listen but trying to understand it deeply and then translate what you learned into action. Sometimes, you and I have talked about the patient engagement part, and more and more, I've thought that so much of what happens in healthcare is relationship-based. Raw relationships - how we get along and how we communicate, and also the information relationship. It's a partnership. What I cared about was people at the center of care: patients, clinicians, and the people that support them because that's the unit. Some people call that *the point of care*. Whatever you call it, it's about a dynamic relationship. Just having patients engaged over here and clinicians engaged over there without having them engaged together and dealing with their experience, their life flow, workflow together is not as rich.

**Ellen Schultz:** Absolutely. It's interesting you bring up that word, relationship. One of the teams that my colleagues and I have worked with over the last year and a half are a pilot project funded under a project supported by the Robert Wood Johnson Foundation. That team focuses on working with caregivers for people who have experienced a severe traumatic brain injury and cannot speak or advocate for themselves. That team brought together caregivers with clinicians and had them think

about designing measurement together. One of the things they've told us is that they think of this as relationship-centered measurement and relationship-centered work. They've pushed us to rethink our language around patient centered. I have learned to emphasize patient and caregiver, or patient and family centered. Still, they said, 'there's something deeper here that is about a relationship of the people who are receiving care, the people in their life who are supporting them on that journey and the people who are providing the care and support.' There is something magic that happens when that comes together in an ongoing relationship where it isn't something transactional.

### Is it scalable? 21:33

**Health Hats:** That's wonderful but seems not scalable.

**Ellen Schultz:** Yes, our current system has moved more and more towards an assembly line, trying to be systematic and efficient and cut out waste and trying to do things in a very standardized way. You lose the places where you adapt to a particular situation and the specific people, and where you create space for building relationships. But that isn't always scalable. It's going to look different for this family than for that family. It's going to look different in this clinic than that clinic. It might even look different from 10 o'clock to 10:30 if you're a provider as you go from one visit or interaction to another and that's messy.

**Health Hats:** Our research methodology is not friendly with that. People want to research something for which you can create a manual, whereas if 10 or 10:30 on the Southside of Chicago is different from noon to one o'clock in Spokane. That's the messiness.

**Ellen Schultz:** It's messy, right? There's a strong tendency to try and cut out the messiness. A strong tendency to try and standardize and make things systematic, to streamline. Of course, there are some advantages to working to be more efficient. We spend a lot of money on healthcare in this country. We've got to figure out how to get more for that money, and we've got to figure out how to slow down the increase in how much we spend on healthcare.

**Health Hats:** But it's not going to come from efficiency, that's not where the money is.

**Ellen Schultz:** I have questions about the route we're trying to take. I've found myself thinking if you walk into a clinic and the receptionist greets you and they check you in, and then you go back. You have a medical assistant, and they take your temperature and your blood pressure, and then you see that provider, and there may be a couple of other people you interact with along the way. Behind every one of those actual people you directly interact with, there must be 10, maybe 20, people you don't see who are negotiating the health insurance contracts, reporting the measures, managing the money, scheduling people, managing the Information Technology systems. If you go up another layer, then it's the people at a state level, at a corporate level, at a federal level who are overseeing all of this. Then there are people like me who come at it from the angle of trying to improve things, to understand and study, to provide recommendations. We also add costs to the healthcare system. I recognize that. I've gotten to a place of embracing some of the messy interpersonal relationship-based approaches. Let's try that for a little while and see what we learn. Hopefully, we find a middle ground somewhere, some way soon.

### Adjust and pivot - flexibility 25:34

**Health Hats:** What two things have you learned over the last year that excite you?

**Ellen Schultz:** Recently, I hit on an insight about patient and family engagement, the partnership with patients, whether it's around measurement, research, or quality improvement or care delivery. Part of the magic formula is a combination of being committed to wanting to listen and understand and act on what you hear from patients. So, commitments, that idea of patient-centeredness, as well as flexibility. Chances are what you hear is not going to be what you expected. That's the point. If you always hear what you expect, we wouldn't need that extra step. The value is when you hear something you didn't expect; when you learned something you didn't know, then you have to be able to act on that. That requires flexibility. You have to pivot. Going back to your story, Danny, why do we want to focus on what we're bad at? Well, that was the whole point. You had to pivot. It's that combination of a willingness to be flexible and committed to act on what you hear from patients and caregivers. I think that opens the door to a lot of progress and a lot of value.



### Consistency and sustainability 28:27

**Health Hats:** Lately, I've been focusing on learning in specific settings and circumstances. Medicine is famous for taking something like 17 years for implementation of new guidelines across the industry, which by then the science has changed. But usually, things that are common sense and relatively simple make a lot of difference. But we have such behemoth systems that it's hard to change any of it. When we research or measure, and we identify something as having a positive effect on whatever setting or circumstance, it doesn't lead to sustained change. Discovery is different than maintenance; it's distinct energy and focus. Just like it's hard for individuals to change their habits, it's hard for organizations to change theirs. I don't know that we measurement sustainability.

**Ellen Schultz:** Yeah, so it's interesting. I think there's sustainability - you put something new into place, and does it last, or is it just the flavor of the month? Then there's also a question of consistency, a little different, but similar. We have evidence that this checklist improves patient safety outcomes. Consistency would be it's used across all departments of the hospital, and it's used in this hospital and that hospital. So, it's about the spread. Whereas sustainability is in any one of those hospitals, or even a particular division within the hospital, once they've started using it, they keep using it over time. They're related. We need energy around the changes in our systems. We are overwhelmed. There are these many different systems that can improve and all the things that our care providers are supposed to be doing. We expect so much right now. It's hard to make sense of all of it. That creates challenges both in sustainability and consistency. There is some value to tease those apart. Measurement has

focused a lot on consistency. We look across hospitals, across providers, or patient populations and ask, 'what is the rate of this?' How often are people using this essential checklist? We measure that well. I don't know that we measure sustainability very well. Once you've implemented something, are you still tracking over time in one place, and then caring when you see is that it's dropping off? That's where measurement noise comes into play. People focus on getting their rate to a certain level because they're being measured on it, and they want to get a good grade. Then the next thing comes up that grabs their attention. Then the first thing can fall by the wayside or backslide. It gets lost along the way.

## Handwashing 33:40

**Health Hats:** Today, we can take the example of handwashing - a no brainer. Do you really need to do the science anymore? Handwashing is important. I remember 35 years ago in my first management job as an ICU manager; we were looking at our handwashing. We realized that if we washed our hands, as long as we were supposed to wash our hands (two minutes), we would spend something like half an hour of an eight-hour shift. I am an exaggerator; I might be exaggerating. But it was a chunk of time. Consistent handwashing is hard to do because you're in and out of rooms. Then, after we paid attention and did all this work, everybody's remembering. But then it tails off -sustainability. Handwashing seems simple; it's tried and true.

**Ellen Schultz:** I wonder how much tailing off - losing it over time, is because we're continually trying to improve things, and we get improvement fatigue. I've heard conversations about that. It becomes demoralizing always to think, 'just when we've accomplished one thing, we hear that we're not good enough - on to something else.' At the same time, there are conversations in healthcare about having a continuous improvement mindset or culture - people accepting that we will always have to be making improvements. We should always be striving to be better. We should be growing and trying to reframe that a little bit. I'm sure some places have been far more successful in that culture change than others. Again, that's where you start getting into the messy interpersonal relationships, the organizational culture, the leadership climate that makes some places very successful. They can have sustained consistent change. They have energy and excitement around continuous improvement and other areas where it feels like a slog. I challenge any MBA consultant, management guru with a lot of numbers to figure out what makes a difference where it's a slog and where it's exciting. I think it comes down to organizational culture and interpersonal relationships. It's messy, but it's essential.

## A great boss – we need to start with you 37:15

**Health Hats:** I'm glad you said that. I've been VP and Director of Quality in many organizations. There's certainly a difference in the cultures and the embrace of measurement, quality, change, and improvement. I would say the first thing is the boss. My first C-suite job was in managed care. I was the Director of Quality. My boss was the Executive Director. At the first three-months point, he did what bosses should do, which was, 'tell me, what do you think now that you've been here this short amount of time, what are your observations for me?' I said, 'I don't think we're moving along at the speed you want to move.' He asked, 'what do you recommend?' I said, 'frankly, we have to start with you.' Then I thought, OMG, what did I just say? This is career-ending. He responded, 'okay, every morning I'm in town, I will come in a half-hour early, and it's your agenda. We'll do it as long as we need to.' Then I thought, 'what am I going to do with this?' But we ended up with my first member advisory panel and provider advisory panel. We developed a well-rounded dashboard to keep our fingers on the pulse of

the organization. It led to some fantastic things. We cut back on pre-authorizations. He was the one that said, 'where do we suck? Let's look there.' He was such a strong leader, and he wasn't intimidated. He was competitive in the sense that he wanted things to be better, not that he was the best. He hired people who would implement that, who would hire staff who were open to it. I don't know that in the rest of my 40-year career that I saw anything quite like it. It's not that generalizable.

**Ellen Schultz:** He was able to mobilize your energy around that. He put the onus on you with the 30-minutes a day.

**Health Hats:** That's a lot of time, four days a week. I had to prepare.

**Ellen Schultz:** He did it in a way that sounds exciting for you, but also a responsibility. It was a career opportunity. So, you brought your A-game. That's some of the magic, right? The more I learn, the more I feel like this work comes down to interpersonal relationships and interpersonal skills in a culture of how we lead and how we listen. It comes down to power dynamics. Again, those things are messy, and they're difficult to quantify. Instead of trying to quantify everything I feel like there's value in developing more of those skills.

## Exercise those weak muscles 41:41

**Health Hats:** What do you recommend to organizations that haven't been on the patient engagement bandwagon, and maybe hearing it for the first time, which is sort of hard to believe. What do you think are success factors that you would share with those people and organizations?

**Ellen Schultz:** Find someone who is a good listener who brings energy to convene a group of patients, family members, community members, depending on the situation. Ask very open-ended questions. What's important to you in your life? What could we do better to support you? What haven't we asked that you think is essential? Ask simple questions and listen. Give that person who's bringing people together the leeway to do what they think is best about what they learned. Allow them to share what they hear up and down the organization. Don't only report it in the C-suite, but the C-suite should hear what they've learned. Also, share it with front line personnel. Maybe they're scheduling, or they're answering the phone, or they're taking complaints or questions from people in a call center and make it be a conversation - not just one-way sharing. Here's what we're hearing. What are you hearing? Get people across the organization engaged in a dialogue. Then be ready as an organization to put some resources towards addressing the three things, or maybe start with the one thing that keeps bubbling up. Hearing not only from your patients / members / community, but you also hearing from some of the members of your organization. Many of them will be able to put their finger on that pain point. As you think about how to address that, again, bring together the all the different people who are touched by it. If it's about a scheduling frontline thing, make sure you have several people that do that scheduling in the room and their manager and some of the patients or members who have to interact around that process. Keep an open mind about what's possible about what you're already doing. You have to check the egos at the door and want to make it better. Then celebrate those early wins. That can get the ball going.

**Health Hats:** You're describing exercising a weak muscle. Exercise it, and then it'll get stronger as you use it.

### A skill set 44:58

**Ellen Schultz:** You asked me earlier for two of my recent lessons learned, and I shared one. Here's another one: this is a skill set. None of us are born knowing how to do this. We don't get trained in it in most of our education and degree programs. We don't even get on-the-job training most of the time. Some people can develop these skills, and some of us get it developed out of us. No one should feel bad for coming in and finding it hard to be an active listener or to be flexible, to pivot, to engage in some of this messy relationship stuff. But we all should be willing to grow that muscle and to exercise it. And if we come in with that mindset, don't beat yourself up, but be willing to grow, I think it goes a long way in this work.

**Health Hats:** That's great. Thank you.

**Ellen Schultz:** Thank you. This has been fun. I always love talking with you.

**Health Hats:** One of these days, we need to find a project we can do together.

### Reflections 46:23

A zen conversation. How can we do better with what's vital in our local health care system? What can we commit to improving? Commitment is will, resources, and time. Then measure relevant outcomes and processes. The measurement can't take more effort than improvement. The key to such improvement is the engagement of people at the center: patients, clinicians, and the people that support them. Focus on relationships. Measure consistency and sustainability. As in any health effort – exercise weak muscles. Thank you, Ellen Schultz.  It's been a hoot.