

# The Sweet Spot of Patient Engagement

## Webinar Transcript

**Krista Davis:** Good afternoon, everyone and welcome to today's webinar, The Sweet Spot of Patient Engagement. My name is Krista Davis and I am the communication specialist for the Improving Care Coordination and Medication Safety Initiative. We'll get started with today's program in just a few moments, but first a few housekeeping items. All participants entered today's webinar in a listen only mode. Should you have a question during today's presentation, we ask that you please type it into either the chat or the Q&A box to the right of your screen. We will answer all questions at the end of the presentation.

**Krista Davis:** This program is being recorded. The recording and the slides will be available on the archived events page of Quality Insights website, [www.qualityinsights\\_quinn.org](http://www.qualityinsights_quinn.org), soon. You'll be asked to complete a short evaluation at the end of the program. Your responses help tell us how we did and how to shape future programming. We thank you very much for your help with this. It's at this point that I would like to turn the program over to the Care Coordination Network task lead, Dr. Andy Miller to introduce our guest speakers for today. Dr. Miller.

**Dr. Andy Miller:** Thank you, Krista, and hello, everybody. I think you're going to find today's webinar, both educational and entertaining. We have three expert presenters with us today. I'll introduce each of them right now. Our professional expert is Christine Bechtel. Christine's a well-known consumer advocate with expertise in health and delivery system improvement, including patient and family engagement, person and family-centered care, health IT and quality improvement. She's the co-founder of X4 Health, which is a purpose-driven organization working on the quadruple aim in healthcare.

**Dr. Andy Miller:** Our caregiving expert today is Rita Pascale. Rita is an administrative associate at Health Care Quality Strategies, which is the New Jersey arm of the Quality Insights Quality Innovation Network. I've had the pleasure of working with Rita for many years. She's been a key member of our team at HQSI and a real positive presence in our office. Rita is also a very experienced family caregiver. We've asked her to talk about that a little bit today.

**Dr. Andy Miller:** Our patient and family advisor expert is Charles Pascale. Charles is a retired CPA and a software project manager who's been happily married to Rita for over 50 years. Rita, I think would say the same thing. Charles has had multiple comorbidities including diabetes and end stage renal failure. He's on home hemodialysis four days a week with Rita providing assistance and support. Rita is responsible for his care throughout each home hemodialysis session.

**Dr. Andy Miller:** Charles has served as a patient family advisor for the Quality Insights Quality Innovation Network. We've asked him to talk about how to successfully partner

with patient family advisors in quality improvement work. So, I'll turn this over to Rita to get us started.

Rita Pascale: Hello everyone, I'm Rita Pascale, the other half of the Charles and Rita team. I've been the main caregiver for Charles since he began dialysis almost nine years ago. Caregiving as many levels. First is the patient and the first level of support is the patient themselves. They have to be compliant and understand fully what is involved. Then there is the caregiver's family and their understanding of the stress, distraction and fatigue factors and how that affects the family.

Rita Pascale: In my absence, when I'm unavailable to help Charles, I've had to rely on family, friends and neighbors to take him to doctor visits or transfer him to the Center for Dialysis when necessary. I'm grateful to all of them and to my two daughters for their support through all of this.

Rita Pascale: Next, comes the professionals; the physicians, especially the nursing staff, who need to give adequate training in whatever undertaking is necessary. Charles and I have thankfully received support and reinforcement from all the professionals we have connections with. About a year and a half ago, Charles' nephrologist encouraged us to go on home hemodialysis, informing us that in center outcomes were not as good.

Rita Pascale: Charles was not a candidate for peritoneal dialysis, and home hemo was our only option. After six weeks of daily in center training, and four weeks more of daily at home training, we were on our own. I must tell you, it was far more complicated and challenging than we thought. I had to learn to stop screaming when I forgot to close the clamp, blood spurted all over the room, and the room was like a Brian De Palma movie. But with the continuous help of our [inaudible 00:04:37] nurse, who I swear has angel wings on her back, we have prevailed. Joanne, if you're out there listening, here's a public heart felt thank you for all your help and support.

Rita Pascale: The home hemo team was daunting. Not only does the treatment take five hours, one hour to set up, approximately three hours on the machine, during which every half hour I have to take his vital signs and record pressures on a slow sheet, and an hour to inspect. I also administer heparin and epogen for Charles twice a month. I take blood samples and I also take water samples and conduct maintenance for the dialysis machine. To think I received my education as a legal associate and not in the medical arena.

Rita Pascale: A few months ago, Charles found a caregivers group for me that meets once a month. I was reluctant at first and I was hesitant about sharing my emotions openly with other strangers. But I attended my first meeting and now I'm glad I did. I discovered I'm not isolated. It's a small and kindly group, headed by another wonderful nurse, Stephanie, who has complete understanding of what caregivers are going through. Even though our caregiving chores are varied, we all share the same feelings and problems. We are not alone.

Rita Pascale: I will tell you too that I fell into a caregivers pitfall. I started taking over everything in Charles' life. I was attending to his every medical need, and that spilled over to his everyday needs. If he'd put the salt shaker on the left side of the table, I'd place it on the right side where I thought it belonged. I then realized I was depriving him of all autonomy. Now, I constantly work at giving him the freedom to make even minor decisions. I've learned to regard his mental well-being, as well as his physical well-being.

Rita Pascale: I also recently attended a presentation on loneliness, which was held at our local Senior Center. I thought this was going to be a small group of people attending. But to my surprise, the room was filled with more than 50 people. Once again, I realized I'm not solitary in this undertaking. Many people experience isolation, as friends may avoid socializing with you, as the patient is not as active as he or she used to be, and that your time is now limited.

Rita Pascale: The speaker's best recommendation was to continue to be involved in social interaction as much as possible, which is good advice indeed. Recognize your feelings of isolation, overwork, and even depression, and look to organizations that have more broadcasting power, information out on websites, social media and support groups.

Rita Pascale: Health systems may provide additional counseling like social workers and therapists, psychiatrists and psychologists. When someone volunteers to pitch in to help, say, yes. Take them up on their offer and make an effort to take time for yourself. Even a little downtime is restorative. Thank you to everyone today for allowing me to share my story with you.

Dr. Andy Miller: Thank you, Rita, and thank you for helping remind us and maybe inform people who haven't thought about it before how it's important not just to think about the needs of the patient, but there's often a caregiver who's feeling a lot of pressure in order to be able to provide the support that the patient needs. We're now going to turn it over to Christine Bechtel, who's going to talk about how can we best engage patients, and benefit from the engagement of patients and their families in providing quality healthcare. Christine.

Christine Bechtel: Thank you. Can you guys hear me, okay?

Dr. Andy Miller: Yes.

Christine Bechtel: Awesome. Terrific. Thank you guys for inviting me to be with you this afternoon, I'm going to try to uncover what's behind this term, this idea of patient and family engagement. I think it will make a lot of sense in the context of what Rita and Charles are going to add to the discussion. There's just so much that happens behind the scenes in healthcare. I really want to do a couple things today. Hopefully, everybody can see my slides here.

Christine Bechtel: The first thing is, tell you who we are. X4 Health is a purpose driven organization, working to advance healthcare, quadruple aim. We have a superpower really around patient and family engagement, something we're very passionate about. We want to talk today about what's best in class patient and family engagement. What I find as I talk to people across the country is that how we define patient and family engagement is like a Rorschach test. It just means different things to different people.

Christine Bechtel: So, I'm going to talk to you a little bit about what it means to us. The spectrum of engagement that we think is out there. What it isn't, because sometimes we just learn better by talking in contrast, and give you something that I call the Field of Dreams operating principle. Then we're actually going to have a pause, and we'll chat any questions or answer any questions that have been chatted in. So, please keep those flowing throughout our time together today. Then I'm going to come back and give you some operational guidance after that brief chat.

Christine Bechtel: I'm going to talk to you very concretely about what are the most popular partnership options for patients and families, and when do you use them. Get a lot of questions about that, and what are the most important characteristics of people? How do you find them? I'm going to show you an action plan Kickstarter that I think you guys could literally use tomorrow if you wanted to think about boosting and accelerating your PFE strategy. That's what's on task today.

Christine Bechtel: We had the privilege, and by we, I mean, my co-founder John Sweeney and I, back in 2013, we worked with a team of researchers to really survey the landscape of patient and family engagement, look at the evidence and figure out what is best in class patient and family engagement? Working with them, we created this definition which you can see it on your screen, but it's essentially really focused on an active partnership between patient families, their health professionals working together across multiple levels that improve health and care. Those are two separate concepts, improving health and improving health care.

Christine Bechtel: We really talk about this framework or this definition, happening at three levels. The first is patient and family engagement in their own direct care. That's what people think of most often when they think about patient and family engagement. This is about inspiring and expanding people's capacity to get well and stay well. Think, self-efficacy stuff.

Christine Bechtel: The second level is about system design and governance, where patients and families are really part of making decisions, creating new ideas for improving the healthcare system. But this is about making the healthcare system itself better for people. That could be patient families, but also clinicians as well. The third level we talked about is policymaking. You guys probably know, healthcare providers are subject to lots of regulations and laws. It's a very policy driven enterprise. It follows then that involving patients and families and consumer advocates as we create those laws and regulations is a really critical part of

patient and family engagement. It trickles down all the way through system design and governance as well into direct care.

Christine Bechtel: When we think about direct care, we think about things like shared decision making or teach backs. These collaborative goal setting, really bi-directional partnership based strategies. We talk about how these strategies have a superpower, they are grounded in partnership. If it's one way, unidirectional, it's probably not best in class. That's a really important concept here.

Christine Bechtel: When it comes to system design and governance, that's where we're talking about things like patient and family advisory councils, or patients and families serving on quality improvement teams, or involving them in case conferences, for example. These are great examples of involving patients and families in system design and governance. We're going to get into detail later around when do you use which one of these things, what are these appropriate for?

Christine Bechtel: But it's incredibly important to understand that patient and family engagement happens on a continuum. You're seeing it on my screen, but the farther up the screen, the farther up the arrow on the right you go, the more powerful the impact will be on quality, safety, care coordination, medication safety, all of that. You really want to move towards that right side of the spectrum.

Christine Bechtel: In direct care, for example, if you're handing out patient education brochures, well, that's good. But if you can really get to a place of partnership and shared leadership, you're co-producing care, that's going to be much more powerful impact on patient's own health and functional status. Same thing with organizational design and governance. Patient experience surveys are a good example of patient engagement. You're really learning from patients in their own voices, how they experience care, and you're making the connection between those experiences and their ability to get and stay well in the healthcare system. That's great. But even better if you can get all the way up the right side of that continuum, and think about how to co-lead, not just even sitting as a patient advisory council, to actually co-leading a hospital quality improvement committee, for example. That is really powerful intervention, and a really powerful example of patient and family engagement.

Christine Bechtel: There's lots of things that influence whether you're able to do this successfully and how far of the continuum you go. Certainly, your culture, beliefs about the roles that patient should play, your organizational practices culture, and at a societal level, social norms and what we believe about involving citizens in policy and regulations. But those factors around culture and policies and practices are really critical enablers of engagement.

Christine Bechtel: I'd like to talk a little bit about what best in class patient and family engagement is not. We often learn by understanding more about what we don't mean here. A couple of examples. Best in class is not trying to get people to do what we think they should do just because we think that's the right thing. That's not a partnership. The words of like compliance, or taking responsibility, those don't

feel good to us. I think if we put ourselves in the position of a patient, sitting in a physician practice, let's say, next week across the exam room from somebody who's like, why don't you just take responsibility for your health?

Christine Bechtel: Newsflash, 80% of what drives my health actually happens well outside the healthcare system. We know that from the body of literature around social determinants of health. Things like food, jobs, housing, transportation, that actually has a huge impact on health. Just telling me to take responsibility for my health is a one way strategy that is just over simplified. I'm going to talk a little bit more about what will be better in a second.

Christine Bechtel: This idea of, let's just make sure a patient has skin in the game. If we can get them to have skin in the game, that's going to change their behavior. Yeah, it doesn't, it's not enough. The evidence has proven that patient education, again, a one way strategy. Chat your questions in. I'm kind of curious how this is landing with you guys. But I'm going to tell you that you'll notice all these bullets on the right side of the screen are this one way, little bit judgy feeling approach to patient family engagement.

Christine Bechtel: Here's the trick. The trick is that the part of the brain that controls human behavior has no capacity for language. Education, facts, information alone, while important, will not change behavior. Which is, I think, what I imagine a lot of you are actually interested in. That part of the brain is driven by motivation, belief, purpose.

Christine Bechtel: Inspiring action, if that's really what we want to do comes from a different place. By the way, doesn't the language of inspiring action really feel a lot better than compliance and taking responsibility? A lot of old school and more traditional patient and family engagement strategies just don't do that. They focus on what we think that patients should do. We tell them how to do it. But we don't focus on why to do it. Belief, motivation, purpose, passion, this school of thought comes from a guy named Simon Sinek, he's got a TED talk on the Golden Circle that I highly recommend you watch. It's probably 15 minutes or something on YouTube. But it's interesting that this three part circle diagram is also an exact mirror image of the limbic brain.

Christine Bechtel: Again, the part of the brain that controls human behavior does not respond to information and facts, it responds to belief and feeling and motivation and inspiration. If you want to get to patient activation and better health outcomes, that's why things like motivational interviewing really work. If you think back to that slide where I talked about shared decision making, motivational interviewing, teach backs, those are all grounded in this type of spirit.

Christine Bechtel: Again, we talked about these three levels of patient family engagement. But I want to argue that there is a sweet spot here that you guys can strive for tomorrow that is the linkage between expanding people's capacity to get and stay well. That's engagement and direct care, and engagement systems design and governance. The sweet spot is this idea of partnership. That if you want to

know how best to support Rita or if you want to know how Charles is inspired to eat differently or do something differently in his life, you have to actually involve them and talk to them about that and involve them ideally in designing the system of care that produces those outcomes. I think Charles is going to talk about his experience as a patient advisor.

Christine Bechtel: But that's the sweet spot of patient and family engagement. That takes me to what I call the Field of Dreams operating principle. You guys remember this movie with Kevin Costner, had this great line, if you build it, they will come. But that's not always true in healthcare. A lot of times, and for many decades, we've spent time in healthcare building stuff and hoping they come. A lot of the time, they don't come. If there is anything you take away from this, it is if you build it with them, they will already be there. That's the sweet spot of patient and family engagement.

Christine Bechtel: Okay, so questions, reactions, chat them in. Krista, if I'm missing any, you just let me know or read them out just in case I can't see them. But any questions guys, and then we're going to tell you how to do it.

Krista Davis: Okay, Christine, we do have one question. That is, can you give an example of involving patient and family representatives in organization policy making?

Christine Bechtel: That's a great idea. Great question. One example might be involving patients and families in reviewing job descriptions. I love that example because they tend to think about what's important to them as a patient or a family member in a different way than what an employer would traditionally think of. They might want to include things like person and family centeredness metrics, for example. I love that idea.

Christine Bechtel: There's lots of different examples in this arena, but hours of operation, another great one. Because they might be a little different in terms of what patients and families want. But if policies really govern the way and operation happens and unfolds, and it follows to me that patients and families should actually be involved in the policymaking of that organization.

Christine Bechtel: I worked with a primary care physician practice a couple of years ago. The staff, we actually did a survey of the staff as employees. It was an employee satisfaction survey. They were unhappy on a couple of fronts, one of which was their leave policy. Patient advisors totally knew it, because they had a leave policy that basically had very small amounts of leaves that got slightly larger, depending on your credentials. If you were an administrative assistant or a front desk person, you got two weeks total of paid time off, that's second vacation all together. But if you were a clinician, you got four weeks. If you were a doctor, you got four weeks.

Christine Bechtel: What the patient said when they were asked about this was, hey, first of all, the frontline receptionist is the person that I come in contact with and comes in

contact with a lot of people. So, you've got to give them a separate pile of sick time. Because I don't want them coming into the office sick. The administrators, the CEO of the practice, oh, that's a really good point. Okay. Yes, you're right. They ended up shifting from a paid time off system to a protected sick time and then separate from vacation time, and they equalized everything. But because the patients were like, "Hey, is it really fair that the MDs get more than an MA, who gets more than the receptionist?" I'm not sure. But I really view everybody as an equal part of my care team. Without those sentiments coming from patients and families, I think that this practice would have had a much more tense time changing their leave policy. That's one of my favorite examples. Any other questions?

Krista Davis: We have a few more. Where can I find information about the part of the brain that controls behavior?

Christine Bechtel: Start with Simon Sinek's TED Talk. I think you guys can go from there. But there is a lot in the literature. I just love the idea behind it, because it rings true to me as a human, that it's so much more effective, and maybe it's just me, but I doubt it. When you tell me to follow an order that's completely different from then when I see how that path, whatever that directive might be, is actually going to help me achieve something that matters to me. That's my belief system, that's what matters to me, that's motivation and inspiration. I am much more likely to stay on that path than if I am to just do it, because you told me to.

Christine Bechtel: The work of Judith Hibbard, I think is really good here, it's about patient activation. A lot of it is what matters to patients, and how to build treatment plans around their goals and motivation, and how to do the goal setting and elicitation of what matters to them within the context of a 12 minute office visit. There's a lot of good work from Judith Hibbard and her team around that I like as well.

Krista Davis: Thank you. Our next question is, how would you engage a patient that is a high utilizer, who has psychosocial needs in homeless, drug addiction, that knows they need treatment, but keeps coming to the hospital for temporary needs to be met?

Christine Bechtel: I love that. The first thing I would do is find people with that same background and experience, maybe even the person that you're talking about, depending on whether they have the functional status to do this. I would actually convene a number of people who have had that history, and that pattern together in a group, and understand from their lived experience, why do they go to the emergency room as opposed to coming to the practice? What is it in their world that makes it easier?

Christine Bechtel: Because I will tell you, I hear a lot of people, they get frustrated because they're like, "Oh, these patients they just go to the emergency room." Yet, no one wants to go to the emergency room, where very disgusting, very visceral things

are happening all around you, you might have a four hour wait before you can be seen. That is just not a good thing for most people.

Christine Bechtel: Really engaging with people and understanding their lived experience, why they make the choices they do, from a firsthand perspective, shadow them. Do a journey map where you're understanding their life. That would be, I think the number one thing to do. Then have them consult to you as you design your whatever it is that they tell you.

Christine Bechtel: Sometimes, also people will say, "Well, look, I called the practice on a Saturday, it was closed." It said, if it's an emergency go to the emergency room. But most of the time, that's not actually what the practice means. What they mean is, a lot of people don't want you to go to the emergency room. They're PCMH level three qualified, they can accommodate after hours issues. Really understanding the real full picture and the workflow in essence of patients. The workflow of patients is critical here. So, I would start with that. Sorry about the soapbox rant there. Next question.

Krista Davis: Okay. Our next question is, where can I find info ... We already read that one, I'm sorry. What have you found to be the secret sauce for engaging executive leadership in patient and family engagement?

Christine Bechtel: That's a great question. I don't know that there's just one thing. But I do think that executive leaders when exposed to the stories of patients and the lessons we can learn, particularly if there is an internal champion who is able to say, I want to tell you something went wrong. We went back, we studied, we learned, we listened to patients, this is what they told them. I am compelled by this. I would like to include patients and families in our work. Here's two ways I'd like to do that.

Christine Bechtel: I think that's really compelling. There's another school of thought that also says, get started before you're ready. Don't necessarily rely on leadership buy-in to get started and to engage patients and families as partners in improvement work. There's such great accelerants for that work. They think about problems in different ways so they can challenge our thinking a lot. You don't necessarily have to have full C-suite buy-in to do that. You can talk to people. You can catalog and learn from them. You can just interview a handful. We're going to actually talk a little bit about that, next. Any other questions before we continue?

Christine Bechtel: Okay. All right. I'm going to keep going. All right. There we go. Here's our operational, what I call, How To Be a PFE Jedi Master segment. These are your most popular options for involving patients and families in creating better direct care, better health outcomes and also a better system. First and foremost patient advisory councils. These are pretty common today. Most hospitals have them, and an increasing number of physician practices have them as well.

Christine Bechtel: You use an advisory council, it's a fixed body, it's usually about eight to 10 people. That means it needs to be broadly representative of the patient population. They usually meet anywhere from four times a year to once a month. The topics that they consider are topics that would be appropriate for a general, fairly diverse group. In other words, you're not going to have your advisory council working on hemodialysis issues unless you're actually part of a kidney center. That might be different. Or diabetes, because they don't all have diabetes.

Christine Bechtel: Usually, an advisory council's not a place for condition specific work. But it is a great standing body that can help you with a lot of organizational policies and practices, general patient feedback and recommendations. The one thing we recommend here if you're thinking about starting a patient advisory council, is make sure you've got a solid year worth of topics, you think about it in advance. It's like, oh, it would be so great to have their input on X, Y, Z, A, B, and C. Just make sure you can think through that process. Otherwise, you're going to get to a point where you're like, oh my God, they meet next month, what do I do? I have no clue what to talk to them about. So, food for thought.

Christine Bechtel: Focus groups, these are limited duration and very focused to particular types of patients or specific issues. These are patients who have either particular condition or particular experience in the practice, or in the hospital. They're high utilizers of emergency departments. This would be a great time to convene them and go through a focus group where there's eight or 10 of them who have utilized an emergency room, and what you would describe as "unnecessarily" or whatever, when you wish they would have come to a practice, for example, and talking to them about those specific experiences.

Christine Bechtel: Putting patients on project QI team. Whether it's a practice improvement or a quality issue, this is the idea that patients are really embedded. They're working alongside the team members, so they're part of every discussion. They're really influential on decisions that way. They're shaping all aspects of whatever your improvement project is.

Christine Bechtel: I love this approach because it changes the conversation totally when you have to have your colleagues talking in front of patients about patients. I do love anything that has an embed nature to it. There's definitely some prep work you will want to do. If this is something ... Depending on how technical the issue is, you're going to want to prep your patients who are going to embed on the team a little bit in advance, and make sure that they have the information that they need. You're also going to want to prep the team for working with them. Like, hey, try to avoid jargon and acronyms so that they're not going to understand. Let's set some team norms about checking in with each other about how impactful our meetings are.

Christine Bechtel: There's also a hybrid here where you can do both options, where you can have your QI team might be ... Let's say it's a 90 day kind of sprint that you're forming your team for, and the patients don't have all the time in the world devoted to

... serving on being part of all of your weekly meetings or whatever. Then, being able to have some people that you can go back and forth interactively between the team and have occasional team meetings with the patients. But also getting patient input back to the team. Being a little more dynamic. That's an option here. So. don't let scheduling stop you.

Christine Bechtel: Staff orientation and training. I love this because, having some of your more routine patients, the patients who visit you a lot, be part of onboarding new team members sets such a critical tone for you guys. Can you imagine, I'm a new physician, or I'm a new receptionist, or I'm a new MA, and one of the first things I do is I hear from a bunch of patients and families about what matters to them about the practice or the hospital or whatever the case may be. I love that. What does patient-centered care really mean to them? I think that that's a super fun.

Christine Bechtel: Then case conferences. You guys know case conferences happen all the time in different settings of healthcare. So, actually involving patients in that is really nice to do this at the physician practice that I mentioned earlier. I loved it because you could get this firsthand glimpse of clinicians talking together about a patient's case and history, and how do you handle this, that and the other thing. But when patients have a set of eyes in that conversation, eyes and ears in that conversation, they see and hear things very differently. They'll often be in the position to be like, "Did you ask Rita about that? Did you ask the family caregiver? Well, what do you think is going on in this person's job?"

Christine Bechtel: I remember this happened to me this one time, and this is really what was going on? Have you thought about this? Or they might bring in, "Have you considered yoga for low back pain?" Who knows? But they really do bring a different flavor in, and it's a lot of fun. Again, it's much like embedding patients on a QI team, it really changes the culture of a practice or a hospital to do case conferences in front of patients and family caregivers. Because you definitely speak very differently. That speaking differently in front of people begins to translate on the floor to acting differently in front of patients and families, and being more inclusive. So I love to case conferences too. What don't I love, I guess?

Christine Bechtel: But anyway, patient surveys also, again, really good thing to under ... You use patient surveys when you're trying to develop understanding at scale. You really want more robust ... It's not, I interviewed six people about their experiences. We just surveyed 60 people to get feedback. Obviously, surveys are structured differently. They tend to have structured answers, four point [inaudible 00:34:43] scales, or whatever. But they can really get to a much larger population in a more efficient way.

Christine Bechtel: When I say patient surveys you guys, I just want to say I'm not necessarily talking about your patient experience surveys that you might have a vendor come in and do for you. Those are totally important. Also, Survey Monkey or G Suite surveys, Google surveys are so cheap that the clinician practice in hospitals, you guys now are collecting email addresses for patients, you've got

them through the portal. There's so many opportunities to just create short surveys to inform meaningful work where you're just like, "Oh, I need to get input from people really quickly." This is a great option to just be flexible and do them for quality improvement purposes. Don't try to make them perfectly validated instruments of knowledge perfection. But just using them to understand thoughts and opinions about larger group.

Christine Bechtel: I'm going to move fairly quickly here because I know we want to hear from Charles as well. Most important patient partner characteristics. First of all, they have to actually have experience with whatever it is that you want their input on. If you're asking them about diabetes, they should probably have or care for someone with diabetes, or we want them to redesign the phone call system, they should be people who call the practice a lot.

Christine Bechtel: Representative of the population most impacted, this is ideal. I would encourage you, don't forget to look to consumer, or our community based consumer advocates as well. The difference between an individual patient, patients can speak to their experience, and the experience of some of their family and friends. Consumer advocates, it's their job to learn about the experiences of larger populations, and then to be able to speak to those. They'll have a little bit more time so you can find those in your community.

Christine Bechtel: They need to be willing to speak up. People who are going to have a hard time in a group setting, or be super shy that you should think about doing an interview with them, but I don't know that I would put them on your [inaudible 00:36:49] or have them be part of a focus group. Ideally too, they're going to have functional capacity for the duration of the project. There are some settings where this doesn't really apply. So, you have to get creative about the strategies that you use. Dialysis centers are one of them, because they are receiving dialysis for three to five hours a week, three or four times a week. They are not coming back for your meeting. They spend too much time there as it is.

Christine Bechtel: Being able to come up with inventive ways to elicit their involvement in your work in meaningful ways is really important, and you should expect that people get hospitalized, particularly in more acute settings. You just have to design for it, but it doesn't mean don't do it. Then of course, be interested. Also, think about, if you're going to do conference calls, or if you're going to do webinars, or if you're going to start a Facebook group for the works to happen, you have to be able to do that.

Christine Bechtel: I think people get frustrated and they get hampered a lot by this one, because they're like, "Oh my God, I didn't realize that people have never used a conference service before." That's not uncommon. You have to think about their capacity to work in a way that you're going to ask them to work in advance. Then also, don't forget positive and negative experience is welcome. You're just going to want to make sure that people are able to share with you their feedback in a way that you can hear isn't off putting.

Christine Bechtel: Clinicians and staff, these people are not unicorns. Your clinicians and staff totally know who they are, and they can give you a lift very quickly. Let's close with this action plan Kickstarter here. What we tried to do is give you a tool just to get you literally kick started. Literally get you off on the right foot. The way this grid works is number one, consider the question in the first column, write down your answer or what you find in the second column and then document, okay, what is it that you're going to do as a result?

Christine Bechtel: What are the priority issues and challenges in your work? How involved are patients? That's important, because a lot of times people go, "Oh, patient and family engagement is important because patient and family engagement is important." No, patient and family engagement only matters if you focus on what really matters to you. Don't form an advisory council just to have one. Form an advisory council because every month you hear in your practice, people go, "I wish I knew what patients thought of this." That's the moment.

Christine Bechtel: If you think about what are your pain points in your practice or your hospital? That's what you want to think about focusing your PFE work on. Starting with what are those issues and pain points that matter to you, that you put your answer and your findings there, and then okay, great. Documentation in the EHR. Well, it does impact patients, but they're not going to really be able to negotiate with your vendor around usability of your EHR. That being said, it might take you to a place where you're like, you know how it impacts patients is, I'm staring at my computer instead of at the patient in the exam room. That might take you to a place of to re-engineer the office visit itself. You could do that with patients and families. Hopefully that that gives you a sense.

Christine Bechtel: That's step one and two, how are patients impacted? What are the potential options. Going back a couple of slides ago to be like, should I interview patients? Should I do a focus group? Can I ask my advisory council? Should I do a survey? All of those different factors. You'll pick that there. Figure out what types of patients are we talking about? That again, might be people who have a particular condition, people with a technical capacity, et cetera. Who's going to lead it internally? That's step four. You've got to have a person who's your point person. Ideally, you get other people in your work world and in your organization to buddy up with you, so that everybody really gets jazzed and excited, and it's not falling only to one person to make this completely successful.

Christine Bechtel: How do you prepare those people for working with patients and families, and how do you then prepare, step five, the patients and the team together? Giving some real thoughts to that is important. Then figuring out, okay, well, are you going to start, when are you going to finish? How are you going to stay on track? It's surprising how basic tenets of project management can get overlooked. But they will really help you accelerate progress if you just have a plan, and you're really mapping it out and revising as you go. It doesn't have to be super intensive. You can write it on the back of a pizza box, whatever, but you've

thought about it, and you're really going with the flow to execute it and to do it in a timely fashion and to stay focused. I just that's an important thing.

Christine Bechtel: I'll stop there. Krista, I don't know if you would like to go to Charles right away or do questions. But I'm happy to perhaps go right to Charles and I'll take your guidance.

Krista Davis: Thank you very much, Christine. Dr. Miller, I'm going to turn things back over to you so that we can hear from Charles and then we will handle the rest of the questions that have been logged in the queue.

Dr. Andy Miller: Thank you, Christine, and thanks, Krista. Charles.

Charles Pascale: Thank you very much for this opportunity. I want to thank you on both my behalf and Rita's as well. Christine, I also want to thank you for a very thought provoking presentation. I can tell you that as the patient in this patient group, boy, do I wish a lot of my providers had been thinking of these issues. Certainly, one of the later things that you touched on, which is the ability of provider systems, medical records, et cetera.

Charles Pascale: I've been a frequent flyer at one institution that is somewhat notorious for turnover in their patient management software. As someone who put in different types of software, I can pretty well intuit when that particular software implementation wasn't a good one. It's very difficult to be lying in bed listening to someone grappling with the patient care system. I tried to give feedback to my own providers, and no one knew what to do with it, because they simply didn't have the plan in place to do anything with it.

Charles Pascale: I do appreciate that comment. Incidentally, speaking of plans, you did touch on one other item, which is goals and plans. Being a project manager, I can certainly subscribe to that a goal without a plan is nothing more than a wish. It's the planning and the execution of the planning and the management of the planning that then gets us there.

Charles Pascale: As a patient family advisor representative here on the patient side, this was a very invigorating discussion. It put to waste a lot of my notes coming in here, notes to myself in my presentation. Because you're really headed in the direction that I would love to advance and would love to participate in.

Charles Pascale: Most of my focus has been on the patient family directly group certainly being the recipient of the caregiver is quite challenging. As Rita alluded to earlier on, sometimes we patients get too much caregiving, and sometimes we don't know how to say thank you well enough. We tend to, particularly those of us with a lot of co-morbidities, focus on the negative. Negative thoughts and negative focus will result in negative outcomes.

Charles Pascale: It's quite a challenge to have the patient thinking positively. I suspect that if you implement a lot of what Christine, you were able to implement a lot of what was proposed here. You shouldn't find any shortage of willing patients who have finally feel that they might be coming in from the storm and might have it work.

Charles Pascale: Certainly, at the policy and organizational level, I think that's quite a challenge. I think any patient is just either overwhelmed by the authority structure within medicine, and the fact that people of my age and generation were raised that the physician was the orchestra leader in charge of everything. He knew what was going on.

Charles Pascale: It's not that he doesn't anymore, it's that there are a lot more moving parts, and the patient has to be able to deal with them or understand them without having a lot of control over them. But there is a limited amount that the patient can do. Compliance being a rather large landscape. Being a CPA and a project manager, I usually have my meds list up to date, and usually have it ready for presentation. Health care providers are overwhelmed that I can give them the information simply and directly and accurately.

Charles Pascale: That's quite a challenge as well. That's a soft spot for me. I'm sure it's a very much a soft spot for them. There is that piece of it as well. I think patients are in the bottom of the attention group except when the focus changes to the provider's own focus. I tend to see little trenches of flutter. Most of my health care providers that have been developed over the years are spectacular. Rita alluded to the dialysis service we have. I am astounded by the quality in healthcare that can exist if there's so many years of indifference.

Charles Pascale: The tide is turning from my side. I'm sure that there are more people like me, who just don't want to complain, but who want to become a part of it. Certainly, with any project, medicine is probably one of the earliest project management platforms. Constant improvement of the process is the key to the process improving. Without fundamental changes in the process, the outcomes won't be substantially different. You're not going to move your standard deviation points much without a basic change.

Charles Pascale: Those are my thoughts. You might be welcome to respond to any questions.

Dr. Andy Miller: Thank you, Charles. Krista, we can take questions from for both Christine and for Charles and Rita. I don't know if you have others at this point.

Krista Davis: I do and thank you very much. Christine, the next question that we have in the queue, someone would like you to refresh our memory for the name of that TED talk that you referenced earlier.

Christine Bechtel: Sure, I'll put it up on screen, but it is Simon Sinek, S-I-N-E-K, and it's his Golden Circle talk. [crosstalk 00:49:14].

Krista Davis: Okay. We have a request for you to expand on motivational interviewing.

Christine Bechtel: I would say Google that. There's a whole body of knowledge on it. But motivational interviewing is this idea that you're actually developing, and understanding of treatment preferences and creating treatment decisions by interviewing a patient in a way that uncovers what they're motivated by. That translates that and connects that motivation to the treatment preferences. There's also a little bit of shared decision making, I think thrown in. But this is the idea that if you're trying to get me to exercise ... This will be a stupid example. But this one comes to mind because it's me personally.

Christine Bechtel: I do have a bad back. If you're trying to get me to exercise and do my physical therapy stuff, just telling me to exercise, again, information that goes to the part of the brain that does not control human behavior. Instead, it would be more effective to interview me about what matters to me in my life, and how does my back pain interfere with that? I'll tell you that for me, that's golf, I play golf. I'm an avid player, I play a lot. So, if you tell me, "Oh, if you do these exercises for four weeks, three times a week or whatever, you will be able to play pain free." Now, you have connected to something that totally matters to me. You can take it one step further and be like, "Yes, you can win the club championship this weekend if you do that." That amazing. That's the spirit of motivational interviewing.

Krista Davis: Thank you. We have a question for Charles and Rita. That question is, how often do you find that providers do include you in the care planning when you are admitted to the hospital?

Rita Pascale: Good question.

Charles Pascale: My initial reaction is seldom.

Christine Bechtel: Yeah, with care planning?

Charles Pascale: Yeah. I would be happy if they involved me more in the discharge planning. I've certainly seen the literature that said discharge planning begins with the admission. But I can't think of any specific-

Rita Pascale: With care planning, no.

Charles Pascale: With care planning, no.

Rita Pascale: No, don't.

Krista Davis: But obviously, they should. They should-

Christine Bechtel: Everybody in planning.

Krista Davis: Absolutely.

Charles Pascale: But as a result of this discussion, I think it might be more in Rita and I's thoughts now to address the issue with our planners, and raise the issue and let them know that it's a concern. Perhaps more of our planners will be privy to this.

Krista Davis: Thank you both very much.

Christine Bechtel: Yeah, I see a question from Harvey about how much time should the PCP spend at the interview? I want to say a couple things. One is, definitely Google motivational interviewing. There's many ways to do it, and different amounts of time. But I want to point out one thing, and Charles said something really important. He talked about the orchestra leader. I think, [inaudible 00:52:54] that it's a little bit of what I would describe the more traditional model. I would even go so far as to say it's a little bit of an outdated model in health care.

Christine Bechtel: We've been shifting to a care delivery system that's more reliant on team based care. I would argue that patients absolutely are part of that team. In fact, they're the center of that team and family caregivers, especially also in instances where patients have a family caregiver like Rita, they are absolutely essential members of the care team and should be given equal permissions, equal access to information, equal transparency.

Christine Bechtel: But when you ask this question, how much time should the PCP spend with the interview? I would also say, it doesn't have to be the PCP. It could be. But it doesn't always have to be the clinician, or the physician. It could definitely be an MA.

Christine Bechtel: We've seen models where community workers come in and do that volunteers, and pediatrics parents of special needs children, coaching other parents and finding out what matters to them. Lots of different ways we can staff and organize. If we're really doing that sweet spot of patient and family engagement that I talked about. Where you're connecting direct care and designing direct care with patients and families, you're going to learn a lot about how they will view the roles of other team members and who can do what and the best ways to format motivational interviewing, how long it should take. All of that stuff, designing that with patients and families is going to be really much more impactful. You'll have a lot less to redo. It takes totally the guesswork out of it. Like oh, I wonder if this is going to work. Well, they don't have what you ask them, work with them to design it. It's something I obviously highly recommend.

Krista Davis: Thank you very much. Our next question is what are your thoughts on compensation for [inaudible 00:54:49] members?

Christine Bechtel: Oh, I love compensation for [inaudible 00:54:54] members because we often do that for clinicians. So, I think it ought to be equal. I also think that they have to drive, they are taking sometimes time off work or time away from their families.

If you have the ability to do some form of compensation or reward, I love that. I also think that there are many patients where if that's not an option in your practice or hospital, that should not stop you, and there are many other ways to recognize and reward them.

Christine Bechtel: But, I'm a big fan of it in places where they can allocate it. Let me put it this way, they have the resource, but where they are willing to create the resources to do it.

Krista Davis: Thank you. Our next question is, can you expand on how you choose patient advocates from the patient population?

Christine Bechtel: I think I had this slide on the ideal characteristics. I'll pull that up. I would say, listen to Charles and Rita today, they are totally perfect for this role. Obviously, they're on this call. But they can speak in a way that we really understand they can think from more of a systems perspective, they probably told their clinicians, hey, I really loved it when you did that the other day." Or, "Hey, you're not involving me in my discharge planning. I'd like to be more involved. What would it take to make that happen?"

Christine Bechtel: Typically, your clinicians really know instinctively who people are, who would be really good. Then it's just a matter of, again, if you have a specific project, or if you're trying to form a [inaudible 00:56:30] assessing some of those other sub dimensions, like functional capacity or ability to devote the time or ability to be comfortable with technology if you're doing stuff online or in web meetings. Those become a little bit more secondary. But instinctual, you know the people when you see them and they're people like Charles and Rita.

Krista Davis: Thank you. Our next question is for Rita and Charles. It's a bit of a follow up to your earlier question. It's asking whether you could talk a bit more about what your experience has been with discharge planning, since you mentioned it. For example, how often or not are you asked about what you might need at home, or what is your living situation, or will you need additional help once you get there? If you could talk about that for a minute.

Rita Pascale: The first thing I will tell you, I just wish that they would discharge us earlier. Charles has been in and out of the hospital, I can't even count how many times. We never get out of there before six o'clock or eight o'clock at night, at which time he's exhausted, I'm exhausted. We spend hours just waiting for them to give us the discharge plans. If they could only do it earlier, it would be so much better.

Charles Pascale: To add to what Rita said, I've read about discharge planning but haven't been the recipient of anything other than reactive discharge planning? Okay, you're ready to be discharged, let's start it now. As Rita said, hours and hours and hours go by. It could be infrastructure issues. It could be how the waiver is

divided up. It's a mystery to me how the three hospitals in our area plan their discharges. But it doesn't seem to be high on their radar for improvement.

Christine Bechtel: Let me say, you guys, this is the perfect example ... For those of you who work in a hospital setting, and you're like, yeah, we know the discharge process takes forever because we constantly have patients complaining at us, where are you? Where are you? They're tapping their fingers. They're tapping their feet. You guys know it's a pain point for them. This is a perfect context where you find someone like Charles and Rita, who have a lot of experience with the planning process, and you guys can sit down, embed them in the team that's going to look at your processes.

Christine Bechtel: The challenge that a lot of healthcare organizations face is that they tend to be stuck in this [inaudible 00:59:18] thinking. It's not a judgment or a criticism. It's just, it's really hard to lift your head up out of the way the world works, your day to day. That's what patients and families though can do. They can be like, "Well, wait a minute, why does it have to be like that? Could it be like this instead? Well, I remember once when I did this, they used this tool. What about this?" They really come up with ... They help to give us fresh eyes, fresh thinking. But they also can develop innovative solutions and accelerate your progress in ways that are going to have great impact, it's going to reduce the tension between staff and patients when people are complaining. It's going to improve your patient experience score.

Christine Bechtel: Again, this idea of going and finding patients and involving them in the redesign process for those areas that you know it's a pain point for you, and it's a pain point for them. That's the sweet spot.

Krista Davis: Thank you very much. We have, unfortunately reached the end of our time together. I'd like to turn the program back over to Dr. Miller for some closing remarks before we all part ways, Dr. Miller.

Dr. Andy Miller: Thank you, Krista. Thank you, Christine. Thank you Rita and Charles. These remarks will be short because we're over time. But hopefully, you found this to be helpful. Krista, we'll send out the slides to the participants?

Krista Davis: Absolutely. They will be sent via email to everyone who attended.

Dr. Andy Miller: Okay, good. All right. Thank you again for participating and have a good rest of the afternoon.

