Contents

Proem

As a nurse, I studied individual health. Then I became a student of organizational health. That led me to management and leadership - all with the mind to get stuff done. Done for people, with people, by people -patients, caregivers, and direct care clinicians. My role changed at each step. My bag of tools grew. I learned to be a good leader, coach, and mentor. Sometimes great. Sometimes I reached my goal when I had one—my success measure: Bat .500 - Success half the time. Now I'm old, nearing the end of my career, and I'm on a national board, the Board of Governors of PCORI (Patient-Centered Outcomes Research Institute). As a life-long learner and master networker, I started looking for other people Identifying as patient-caregiver stakeholders on national boards. I found our guest, Adam Thompson, recently. He's on the board of the National Quality Forum (NQF). I'm a member of NQF and serve on several committees and panels. Matt Pickering, a Director at NQF, appeared on Health Hats, the Podcast a few months ago. NQF's **Mission**: To be the trusted voice driving measurable health improvements. Its **Vision:** Every person experiences high-value care and optimal health outcomes. There's way more to it than that. Let's meet Adam and learn more.

Introducing Adam Thompson 02:38

Health Hats: Good morning. How are you?

Adam Thompson: So glad it's Friday. This was finals week for graduate school, and the first half of our thesis was due. It's all the sort of widgets and planning pieces, which is you change one thing in a document, and then there are seven other documents you got to go change it in. So, it was just like, oh my God, all week.

Health Hats: What is your role, and where are you in this?

Adam Thompson: So, I am just about to finish my master's in public health. I started just before the pandemic. It was not the worst time to get a master's degree. I will say that.

Health Hats: I got my MPH at the University of Minnesota's ISP Program. And it was one of the first distance learning programs. The whole philosophy was that you had to be in the industry and use your work as your laboratory.

Adam Thompson: Yup. Ours was very similar.

Health Hats: And it was an excellent education.

Adam Thompson: Have you ever met or come across Dr. David Nash in your work?

Health Hats: It's a familiar name, but I can't say how.

Adam Thompson: He's one of the crown princes of population health management. He does a lot of work there. He founded a school of population health out of the Jefferson Health Enterprise in Philadelphia. I went to school because I thought, Ooh, population health. That's cool. And it was run by the lead qualitative researcher. So that made it even cooler.

Patient-caregiver advocates on national Boards of Directors 04:21

Health Hats: Okay. What I wanted to chew on with you is this business of being a patient caregiver activist and being on a national board. So, I'm on the board of governors of PCORI (Patient-centered Outcomes Research Institute and you're on the board of

Adam Thompson: the National Quality Forum,

Health Hats: The National Quality Forum. First, it's a hoot to have that seat, and to be in a leadership role is different than being an activist. Not that one doesn't inform the other. But it's a different role. At least for me, I feel like my responsibility is to the whole organization. And so, I feel like I had to hone my listening skills throughout my career. Because I would have to say that it is not my strongest muscle. I feel like it's even -it's on steroids. The making all the connections, listening to other board members who

I'm so fortunate that the board of PCORI is brilliant, just brilliant, and inspiring. And I have so much to learn, and I love learning. But it means shut mouth, open ears. Anyway, tell me a bit about your experience?

Activist, Advocate, Conduit, Leader 06:15

Adam Thompson: I absolutely agree that coming from the community of people with HIV, we are very rooted in our agitation, activism, and advocacy. And as a community, adept at understanding where you deploy what method? What are you doing in this environment? And in our community, we've thought about it in a framework where agitation is when someone disagrees with you. There's not a problem. They don't want to do anything about it. Activism, people are aware there's a problem. They're just not motivated to do something. And advocacy is, we've all agreed that there's a problem. And we want to do something about it collectively. As I've worked through my community before, joining what I would call the culture of quality right here in the United States. I learned how to recognize when a system is listening. How to hear, right, when people listen to you. And I think, as a result, I feel a great responsibility. I feel like my business is the human condition. At its core, what I try to do is, see experience and understanding. Find a way to translate it and then an appropriate frame for the environment in the context we're trying to inform with that experience. And so, for me, I agree with you, right? It's like I had to listen a lot. When I first started doing quality measurement work, I remember the summer was learning statistics. And I was like, oh my goodness. I called physicians. And even they were like, Adam, I don't do this. You have to talk to somebody else. And I learned. I listened. And I think if there's any wisdom that I've gained from it, I'm not sitting at those tables at NQF because I'm an accomplished clinician. I'm not sitting there because I have developed a groundbreaking measure to solve all our disparities. I think I'm there because I have found a way to be a conduit for my community's experience and understanding and how to bring that back to the community. I think what I've learned is that I look for opportunities in my experience, both sitting on various committees and expert panels but also as a board member, to find the moments where that experience, that narrative, that collective sort of like voices of the people that come from the spaces and places that I walk in and the people that I hang out with walk in. And try to find the moment when it's mostly going to inform that opportunity. I'll be the first to say, I don't always have something to say about everything, but I think, and I would hope that my colleagues might agree with me, that when I do say something, I think it's meaningful because it's that as you were saying, I've listened. I've learned what they value and how they speak about things. And so, as a board member, I feel an incredible responsibility, as the framer of experience, and I think then you have the responsibility to maintain an authentic connection to people, right? So that I'm not framing myself. According to some, I may be a handsome fellow, but most folks don't want you to represent your interests at a national table. They want to feel that their experience has been integrated and incorporated and has been, I think, thoughtfully injected into the conversation at the point when it's going to have the most value.

Health Hats: Yeah, I guess I would think that for me. I always have a lot to say. I feel like my challenge is that I prepare for every meeting. Some of the preparation is reading the material and thinking about the material. What are my reactions? What is essential in this? And w but I would say that. I'm making up the numbers. But I would say a third of my effort of preparation is to narrow down to two points that

I'm going to advocate for, or I'm going to ask two questions or two things. Yeah, because my brain goes a mile a minute, and it's too much. It's too much for me, let alone my colleagues around the table. So, I've been in this role for a year and a half, and it was clear to me that my first job was building trust. I belong at this table because I'm somebody that people can count on that I listen to and participate. That I show up that I, yeah, that I do the work. I do the back-room stuff. I'm supportive because, without that, the rest of it is, like, who cares. But how do you like the thing that I'm thinking about is, as you're describing, I think that the personal mission juxtaposed to the organizational mission. Now I would never have sought nor accepted a board position or the kind of contributions that I've given to PCORI over the 12 years I've been involved with it if there wasn't a huge amount of synergy and if I didn't respect the organization and the leadership and the staff like why. It's, so that's a given. But is some of what you've been saying that how you try to marry those two or blend those or whatever.

The Ryan White HIV/AIDS Program 09:42

Adam Thompson: Yeah. I think we just don't have 48 hours in a day. We have 24 hours. That's all we get. And if we're lucky, maybe we get eight hours of sleep as part of it. And unfortunately, I think, here, particularly in the United States, patient advocates sitting at these national tables like they don't grow on trees is the perception, right? There are a lot of spaces and places people want us to do work. And there's a lot of spaces and places where we want to do work. And so, I try to find the places that I think will be the most meaningful, and as a person with HIV, again, I keep mentioning that it's such a strong influence from our community. We learned a long time ago that engagement with our government and how society was structured would be the path. That we needed to understand how the FDA approved our medications. We needed to understand how the healthcare delivery system was designed to integrate our feedback into the program's quality. When I come out of the Ryan White program as a patient, I think that's how all of health. That like everybody got these sorts of comprehensive

Health Hats: sorry. Say a bit of the Ryan White program.

Adam Thompson: Oh yeah. The Ryan White program is a federal program. It's funded through the president's discretionary budget. Funds a comprehensive care system for persons with HIV in the United States. And it is mandated legislatively to have a clinical quality management program. And that program has to identify indicators and conduct an annual quality improvement project.

Health Hats: Thank you.

Pulling the curtain back. Feeling our oats. 13:52

Adam Thompson: For me going through the Ryan White system, I saw what we could do if a community understood this pathway to agency. And it was like, here was this group of people saying we're into quality and we need patients and caregivers and family, and all the community to help us do this. And I was like, this is great. And so, once I got deeply involved in that, I started becoming aware that this little community of quality we had was part of a national community and an international community. And so suddenly, what I thought were just assumptions of how things work. It's like the curtain got pulled back

and suddenly you see, whoa, look at what's happening. Look at the thought, the attention to detail. I had no idea. The smartest people in the country sit around and think about us. Like that was inspiring, and it was even cooler to know and think that they wanted us to be a part of it. But I think then when I learned about places like the National Quality Forum, the people who are helping to shape and frame this conversation and to shine their light as part of their role. A place like that could inspire measurement. I learned a long time ago in our Ryan White program that what we measure gets improved, that we can inform measurement, that we can be a part of developing it, implementing it, and evaluating it. And so, as a person, I'm white, I'm cisgender, I'm a male. I've got like all the privileges. I see it. I've been given access to it. I don't doubt that a lot of that access is because I look, act, and sound a lot like the people who already have that access. And so, I look for organizations where access is present, but when you look at the organization, that access is part of their culture. And when I first engaged, I'll speak about National Quality Forum. That's the sort of board. I was on a committee, actively asked what I thought. I ended up making a comment that changed a measure. Oops. The patient knew more about scientific reliability than the committee did. And so, it was just. It was a great experience where I was both. The experience was sought. I was allowed to share, and I saw an immediate impact. And I said I am one person. These are dozens of tables. There are so many spaces and places. My community needs to know about this. And that's when I think I started understanding that the synergy I believe you are describing is about not just an individual like I'm responsible to the people I sit at that table for. And so, the synergy that exists has not just to be, I think, synergy for me, but synergy for the people that I'm supposed to be sitting at that table to represent. And if I'm not doing that or the organization isn't open to that or doesn't reflect in their culture, this is even like a possible space that we're working in. Then I just don't know, as a patient, a person with HIV, a former drug user, a former sex worker. Like, I just don't know if I have that fight in me to try to turn an organization that isn't thinking that way. I go to the spaces and places where I think people inspire me. And every time I talk to our national quality leaders, whether from NQF, IHI or even in our measure development community, these are smart people. But not only are they smart, but they're also compassionate. They're passionate about what they do. And yeah. Just a little bit wonky. They just don't know how to ask for friends. And so, part of what I try to do is just broker that friendship and say, you want to talk to people. I talk to people, so let's make this happen. And when that can occur, when I can create access so that it's not just generating a better service or greater access in a health system, but access to the design of that system and the thinking about its purpose and structure. To me, that's what sort of deconstructing sort of power and privilege is all about, expanding access to it. And I think as a patient on a national board, that's part of what we've got to do, is open those doors for other people.

The right place to make a different and re-charge 18:26

Health Hats: That's eloquent. I'm trying to think of how to frame this question. So, I resonate with the. If I'm going to put all this effort out, it needs also to feed me. Meaning that, like I just got, I couldn't make a meeting, and I just listened to the recording of the session that I couldn't make. And oh, my goodness. I was so inspired. I wish I had been there. I wish I could put my 2 cents worth in because I can't help myself, but it was inspiring and okay that I wasn't there. The issues were solid. As you said, compassion is the drive to go from theory to action. Then, it was all there. So, one of the things that I did when I got appointed to this board was engaged a coach because I feel like this is a career capper for me. I mean,

I'm old, and then I'm quote-unquote retired, and I put a lot of time into this, which is as big as I'm going to get. I want to do a good job, and I want to take care of myself. I don't want to burn myself out. I want to contribute. Through having a coach, I realized that the first thing to do was build trust that limits me to two points. It's hard to see your wake. I know I'm a force. I'm a charismatic, eloquent-driven person. And so, just anything, you can't be in healthcare and not think about unintended consequences. And so, I feel like that's a danger of being me is my own, the unintended consequences that I have and want to be effective in this role. So hence having a coach has helped me. Yeah. What kind of support do you get from the organization, NQF, or your community? Like, how do you deal with it? This is a different stage.

Learn, coach, mentor 20:43

Adam Thompson: Yeah. Yeah. There is in our community. We have this growing. I'm not going to say it's a problem. It's like a challenge. And it has to do with so many of us now who have become part of systems that through efforts to make systems more representative, more culturally responsive. We're finding our way into these organizations. Yeah. That kind of engagement and I find working with systems, being a part of like public-serving boards, you're very similar in a lot of these different environments, and it changes a little bit that you didn't see before sometimes for the better sometimes not. Sometimes, you are less guarded when you're in those environments. And so the words that come out could sting a little more. That part of the wisdom is to be like, my moment is we can help in this space, and not I don't want to get into like the whole cancel culture thing, but there are compassionate things we can do to bring others into a better state of awareness. All these things, right? I was terrified when I was a kid joining some of these tables, especially the first kind of national tables I joined. I didn't know what was supposed to happen there. Someone uses a word that I don't know. Does that mean I don't join the conversation? Does that mean I just, do I Google it quickly and try to learn enough about it so that I say something smart? It was like. There are questions about how I like what you're saying, build trust, demonstrate to the committee or the table that I deserve to be there, and be valuable. And I think a lot of those questions. I look to the elders in my community, the people who had sat at these tables before me. One woman, Dolores Dockrey, passed away right at the very beginning of the COVID epidemic. She was a black woman who started as an undocumented immigrant and came to the US to get her master's. Ended up. She just was a force, and her nickname was The Quiet Storm, and she was like this little old Jamaican lady who would just sit in her meetings and be very quiet and just say nothing. And then, when it got to her, the things that she said would just. I won't say explode a room. It lit up a room, right? It's like she had quietly observed and listened and figured out what she was going to say that would turn the room to the benefit of her constituents. She was just so good at it. And I remember asking her before I sat at this first, it was a federal policy meeting for HIV, and she could not go. She said, hey, Adam, I'm going to send you. Talk to me about this environment. And she said it's a policy table. You will not get many opportunities to speak. You will likely be able to say one or two things, so you better make it count. And I was like, okay. So now suddenly here's this like responsibility and the pressure. And when I got in the meeting, I spoke more than twice. I had a lot to say, but it was like, I was disruptive and people. Oh, and I think that coin on that edge could have flipped right to we hate this kid. Don't ever let him come back here. Thankfully it flipped on the other side, which was, wow, he has a lot of passion. We should listen more, but that room doesn't always go that way. And I learned very quickly that before I walk into a room, I first talk to the people in my community to find

out, have you ever walked into this room? Do we know that this is a place and a space for us? Have we been respected here? Have we been disrespected here? And if, if my community looks back and is we never heard of it, then you start asking around. And try to understand. But I think I learned because people were willing to teach, and I was willing to ask, and I think there's a humility in that leadership point to say, Yeah, I'm sitting on this national board, and I will still to this day, right? When I get the measures, and I got to review them and read them, I talk to people who are specialists in that field. I want to understand their perspective. I go to the people in my community, particularly black women and indigenous folks. like all the people whose narratives will give me a different facet on this. And then I come in. I think the wisdom that I get is when I hear something from the community that is so loud. Then I have to make that decision about whether I put this here as loud as it is as I'm hearing it right. And that I think I go, and I ask people in the community and say, should we be shouting this? Or is this something that we put on the table and let it go, or do I need to ring the bell, and I've had, I'm not going to lie? I've rang bells at a national level before when the community says ring it. But I would never do that. I don't think I would ever do it on my own. I think that ringing a bell by yourself without the wisdom of people around you. It can be like you're saying there are unintended consequences of ringing a bell for a community that maybe isn't ready to have that out.

Listen, reveal, shout 25:50

Health Hats: That's so interesting. A couple of things: I'm impressed with the internal so in PCORI, so other board members, the executive director, and some of the senior staff. Since I've been part of PCORI for more than ten years, I feel like I have a network within PCORI and part of my educating myself includes them. And which is, and then there are these advisory panels. And so, I've been involved with advisory panels, and I try to attend as many as I can just to keep my ear to the ground. Oh, and a couple of other things. One is I find that for me just since I built trust. I feel like instead of shouting, I can say the community is shouting. And just say, the community is shouting, and that's enough. And, of course, I see that things that I bring up are incorporated into the organizational work makes me feel comfortable that I don't need to shout for real. I say this is important, and that's enough.

Adam Thompson: And I think that is, to go back to the beginning of our conversation. I think that's the distinction between activism and advocacy, right? If I have to shout, folks aren't with me yet. Because I should be able just to say, The people in my community are suffering. Here is why, in the context of measurement, it doesn't account for people with this condition, or it doesn't think about persons with this experience. And when you say that in a room, I think especially at a national level and especially in healthcare, and maybe I've got privileged, rosy glasses on. I think most people I've engaged with, at least, I never know what's in their head, but I think they hear that, and they go, wow. Okay. So we should do something about that. And it's taken and accepted with the same credibility and authority as if the clinician had said this is clinically unsafe. And that, like that trust you're talking about there. I think it is built, and it's something that puts the mentoring in the other direction. I've got people I keep trying to bring into the world, and okay, come over here. I need you in this space. They need to hear what you have to say. But the critical, I would almost call it a critical conversation, is how this is categorically different from anything that you've done before, including board service at a community-based organization. The stakes are higher. The conversation is more technical and specific, and your impact is

enormous. And so you have to understand, I think all of those components. Because, as you said earlier, we can't see our wake, and sometimes you can throw a boulder in a pothole puddle. You just obliterate the entire environment when you could have just looked down, and hey folks, let's look here, not kind of fire rockets at the situation. And I think that is maturity somewhat in how communities can engage as power and privilege expand. Some folks will look back and say, I scream because they've never listened. And I think that's when a system. If we're trauma-informed, right? If we are genuinely adopting those principles, then when we reach out, sometimes I think our boards and our systems need to learn how to hear the screaming a little bit at first and understand that's been because we're conditioned to do that as patients in healthcare. So, all that context is what I try, from my experience, to share with the people before I put them in a room because it's different.

Levers of power. Drunk the Kool-Aid. Now what? 30:56

Health Hats: I'm chewing on this, a distinction between activists and advocates. I feel like, at PCORI, I am not like there's. I have almost zero work. Everybody's drunk the Kool-Aid. It's oh my goodness now. Like how it's like understanding what the levers of power are. So far, we've been talking about the levers of power that we have as individuals sitting on a board, but then there's what are the levers of power that PCORI has that NQF has? And how can we recognize what those levers of power are? And, in a way, has been an advocate and an activist. Maybe I'm oriented to what can I do? What's in the realm of possibility. And I think that's it's like if you're President of the United States, supposedly the most powerful person in the world, your power is limited. And when you sit in a role in a seat, you realize more the constraints you're operating in. So, I think when you're talking about mentorship of other people. Sometimes I find it challenging. Cause I hear from people, maybe a couple of times a month. Somebody will email me or call me, and what about this? And what about that? And why does the PCORI this or whatever? And I find myself trying to describe the environment and these levers of power. And I feel like this is learning now I'm learning this, how do I communicate in that direction? Like, in a way, it's the hardest. Like I can talk to clinicians. I can talk to researchers. I can speak with measure developers. These are people. I find my constituency is sometimes the hardest. So, my constituency is sometimes the hardest for me cause in my mind. Oh my God, I'm thinking they just don't understand how the sausage is made. And I don't want to. There's the. Do I have to think about how much I want to share about making the sausage? Because I'm in a position where we're having these conversations. We're trying to figure stuff out. We're public. This is because most of our work is public. Still, it's hard. Sometimes I find it hard to suggest to people how they can. Here's a button you could push, right? Here's an approach that might work. On the other hand, I don't want to squash people's enthusiasm

because people listened to me when I was raw. And they helped me mature and become more effective as an advocate as a participant. It's yeah. So, what's been your experience with that.

Transparency. The sausage gets made. 34:17

Adam Thompson: I love the phrase making the sausage. It's been all over the news. Everybody is talking about it. And I think my first reactions are that people need to know that there is sausage. But that is even that. There is even a thing out in the world that people are doing this right. Like in the context of quality measurement, I didn't even know that. As a 24-year-old drug user going to Leapfrog to find out the highest quality care for my habits. I, that's just not that context. So, it's like people must be aware that there is sausage, and then they must be aware that people make it right. That there's a process by which this happens. And then they must be aware that those processes are very technical, and not only are they technical, but they're aimed at a very strange thing for our country right now, which is consensus. And I think for me, how the sausage is made is about teaching people a little more about what the expectations can be in that room. And I think, as a person with HIV, we were always taught from the moment I became an advocate. You are in charge. Nothing about us without us. Like you are number one. And when you sit in a room like that, that mindset. This is just not true. First, other patients in the room have just as much authority now to change that system as I do, but it's different. And so, one of the things that I've learned about it is if people don't know what you're making or what you're doing, they go at what they know. And so, when I first got involved in boards and moved from organization to Board, I became clear about the distinction between mission, vision, and values and process and procedure. I'm a sausage maker. I want to process and procedure. Like I write work plans. I write government grants. It's like, all those things are how I think the sausage is made. Because as a staff member in an organization, I may or may not have ever participated in a strategic planning process. I may not know why those values become so important because all I'm receiving are the processes that have flowed from that mission, those vision in those values. And so I think what happens, at least for me, is the sausage that I try to explain to people is what we're making here? And why the integration of a value of something like equity has a thousand tributaries of possibility that come from that, because now we have to apply that value, and we can look at every decision and say, is this in our values? And so, to me, exposing levers are things like that. Before joining boards, I didn't think I understood why policy is written the way it is? We want it to be broad yet specific enough to serve its purpose. You learn all the things there, but I think communities what they see and what they experience is bad. Somebody doesn't call me back. There's no appointment available. I showed up, and the provider stigmatized or discriminated against me. So we're immediately drawn out of value and into its mechanics because that's our experience. And so, for me, you've got to refocus people around that and then align them to this idea that you are going to have people in that room that disagree with you. And they will like you as a human being, right. And that communities, at least I'll speak for the community of people with HIV. We've been pitted against each other, right? Throughout history, we've seen white and black people, gay and trans folks, right? Like all these different ways, society has the marginalized fight. And so, when you come to that table, you've got a fighting spirit already. And unfortunately, sometimes you think you've got to fight even the people in your community. You get to a table where those people aren't even in your community. Now, I want you to know what happened to me because I know you're important. Still, suppose I don't know why you're important or your levers of power. In that case, all I'm

doing is likely telling a doctor a story they already know, which probably already horrified them because they heard it happened from another colleague. And they may have even had the positional authority to have gotten rid of people that do that stuff. They know that, but we don't know that they know that. And so that to me again, what do you get to do? If I were going to take a clinician into like my old street world, I would give them some background information because I don't want them to be uncomfortable in that environment. Still, I also don't want them to do anything that will be stupid in that environment and be disrespectful to everybody else. So, for me, I meet people where they are, whether you're a patient or a doctor. I think we should speak in whatever language is appropriate for you. Patient, doctor, I don't care. I can learn the nuances of your language. If that means we've got this bridge. To me, that's the sausage. And so, if we don't, yeah,

Health Hats: I like what you're saying about the values because it's saying that we're going to use organic stuff in our sausage. That's what a board does. A board says we have values.

What should we have talked about that we haven't?

More on conduits 39:39

Adam Thompson: No. I think it would be that what. The only thing I would add is that I carry so much information back when I sit on these boards and the access that I get to how decisions are made, why they're made the way they are, and the processes that produce them. So much of my job is to turn around and help everybody else understand that. I think that there's a critical lack of transparency, or something is missing in the communication and dissemination of it. That most people in this country are not aware of the, I think, amazing effort that people undertake every day to try to make this system better. And to try and do this. I could tell everybody I know, but I'm one person in this country. I see a lot of people, but I don't know everybody. And so, something is missing in the mechanics of what we do because patients don't understand it on the regular. People in communities don't know how to get involved. And that to me, a lack of transparency, and I think it was like, what, 2007, there was like, great article, Don Berwick was like, oh, transparency is critical. What did I think the line was the most important attribute of a culture of safety? So, I think what we have to think about is our processes of consensus transparent. I think they are transparent. I just don't know if they're made accessible. Maybe that's what I want to say. You have transparency, but it's not accessible to everyone.

Engage, dissemination, act 41:02

Health Hats: I hear you. I would add to that. This is not just me, but I think what PCORI has done excellent is the science and the process of laypeople engagement, patients and caregivers being engaged, partnering, and inclusion. They're stellar. They're a guiding light. They're leading the pack. We still haven't done well when the learning from research gets implemented. And our focus has been on the health systems and clinicians' implementing. And I think we're just opening our eyes to people who are the ones who implement this stuff because it's about their lives. And how do you do that? If we think that health systems and clinicians are diverse, it's so homogenous when you compare it to all

people with high blood pressure or disabilities. So, you know, it's a bit of dissemination, but it's more about dissemination that leads to action.

Is seeking public comment enough? 42:54

Adam Thompson: Yeah. And just to make sure, I hate it when I make statements that shade all of healthcare. So, I want to make it a macro level, which is, I think, a problem with how the American government seeks feedback from the communities. And the concept of public comment. All these ways, these mechanisms that we have. They are passive mechanisms, right? They require that people know that they're there and take action to access and make the feedback. And trust that feedback is incorporated, right? There are a lot of steps there. And right now, the people I know are busy. They've got kids who weren't in school but now have to catch up. They lost family members. They switched jobs. The last thing people need is to have a feedback process with so many hurdles. And I don't think it's saying you got mail every American is surveyed. I've got a whole community of people willing to talk, and I'm unsure where I put them.

Health Hats: Oh, that's a great note to end on. This is great. I'm glad we met. I have the feeling there's more here, and I think we have colleagues who are on national boards, different national boards in the healthcare world. And I think it would be it might be good to find them and periodically think about how we do this work and support each other in doing this work. And here is where some of the synergies are. Obviously, for me, I'm involved with NQF. I just became a member. Now that I can afford it, now can be a member for a hundred dollars. It used to be a thousand. And yeah. So, I'm glad you are where you are. We need you. Thank you. We will talk to you again

Adam Thompson: For sure. And I agree with you. I think bringing communities of people trying to achieve similar goals is at least as I was raised the American way.

Health Hats: All right. Take care, man. Awesome. Have a great day. Okay, bye.

Reflection 45:00

My father, uncle, and cousin have been in the casing business. Sausages are stuffed into casings. I've known more about how real sausage is made since a very young age than I wanted. I can still smell the Chicago Stock Yards. When I was 16, I was worried about the draft – drafted into the army to go to Viet Nam. I needed to learn how the sausage was made. I become a draft counsel at a downtown church. Yep, I was 16. I carried this learning how the sausage is made throughout my career. Dr. W Edwards Deming called it profound knowledge. I prefer how the sausage is made.

Serving as a patient-caregiver stakeholder on a national board entails great responsibility and opportunity. I feel a pulsating tension between self-confidence, vision, and enthusiasm on the one hand and imposter syndrome and wanting to be liked and belong on the other. I feel a responsibility to the

organization and the communities that trust me. It works when they're all in alignment. That alignment happens often enough to sustain me.

If you're on a national healthcare-related board as a patient-caregiver stakeholder, let me know. Maybe we could ride this train together.