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Proem 00:52

We make decisions about our health every day, whether we name it a decision or not. Just this morning, it's 11 am as I'm writing this intro, I've made many health decisions. At 2 am, I decided to get out of bed, eat something, and take ibuprofen for hip and leg pain. I chose waffles over granola for breakfast. I drank coffee rather than water to quench my thirst. We decided to drive to a boardwalk for a hike, and I decided to stop sooner than I'd have liked because I'm feeling weaker, and my balance is more unstable. I decided to stop taking high dose Biotin because my friend Cherie Binns, next week's podcast guest, sent me some new research saying that Biotin has little or no effect on MS. Phew! 6 health care decisions I can remember in 12 hours.

According to [HealthIT.gov](https://www.healthit.gov), clinical decision support (CDS) provides clinicians, staff, patients, or other individuals with knowledge and person-specific information, intelligently filtered or presented at appropriate times, to enhance health and health care. CDS encompasses a variety of tools to enhance decision-making in the clinical workflow. These tools include computerized alerts and reminders to care providers and patients; clinical guidelines; condition-specific order sets; focused patient data reports and summaries; documentation templates; diagnostic support, and contextually relevant reference information, among other tools. [pant, pant] OMG, can you believe that definition?

How about *computable, evidence-informed guidance used when making clinical decisions?* Hmm, still kind of remote.

How about *information to make health choices, for the people who need it, when they need it, in a manner they can use, in a context that reflects their life experience?*

OK, enough with definitions.

I have and have had several AHRQ-funded (Agency for Healthcare Research and Quality) consulting gigs about CDS (Clinical Decision Support) with the MITRE Corporation. Today's guests include Edwin Lomotan from AHRQ and Lacy Fabian from MITRE's [CDS Connect](#). *The CDS Connect Repository supports AHRQ's mission to disseminate and implement patient-centered outcomes research findings into clinical practice through CDS. Entries in this repository include CDS "artifacts" – actionable medical knowledge (e.g., clinical practice guidelines, peer-reviewed articles, local best practices, and clinical quality measures) translated into computable and interoperable decision support. Again, phew! Perhaps a library of medical recommendations made useful for programming into electronic records, apps, and software so patients, caregivers, and clinicians can use them as they make choices together.* I haven't vetted that with anyone. I've worked with Ed for many years and Lacy this past year. Both commit to patient-caregiver engagement in CDS, support my inclusion in several projects, and seek my expertise and networks in the patient-caregiver community.

Introducing Lacy Fabian and Ed Lomotan 05:20

Health Hats: Lacy and Ed, thank you so much for joining me. I've enjoyed working with both of you, and I look forward to this conversation. Lacy, how do you introduce yourself to people?

Lacy Fabian: I'm a research psychologist with MITRE who works at the national level on ways to improve the quality of healthcare.

Health Hats: That is succinct. Great. Ed, how do you introduce yourself?

Ed Lomotan: Hi, I'm Ed. I'm Chief of Clinical Informatics at the Agency for Healthcare Research and Quality or AHRQ for short. My position is in the [Division of Digital Healthcare Research](#), which is in the Center for Evidence Practice Improvement. I add that I'm a pediatrician with specialized training in clinical informatics. That would be my agency's work on clinical decision support—way too long for most social situations.

Health Hats: Ed, oh my goodness, we've been working together three or four years anyway. You're quite the advocate for patient and caregiver engagement. You're somebody who has stepped up to figure out different ways to include people in clinical decision support. I don't get the feeling like you started out that way. How did that evolve for you?

Ed Lomotan: Great question, Danny. I suppose there are a couple of things I would point to. I credit you a lot actually for opening my eyes and having that desire to learn more about how to do that. The very first time I met you was at a steering committee for the Patient-Centered Clinical Decision Support Learning Network. I learned a lot from you, including patient-caregiver input, in a meaningful way, early on in projects. So, I point to that specific day as sort of a beginning of a journey. Before that, I think a lot of where I come from is this belief in the AHRQ mission. It's a strong mission. Now to go back to how I introduce myself if I spend any extra time telling people what I do, it's usually about AHRQ as an agency because folks tend to not know about it. I tell folks the AHRQ mission of equitability, affordability, and making healthcare safer, and higher quality. Decision support and patient-centeredness fits nicely into it.

Health Hats: I'm honored to have had an effect. Thank you for that. Lacy, so you said you were a psychologist in informatics.

Lacy Fabian: No, I started in the clinical program for clinical psychology. I did all of my clinical training and realized that it was better for me to stay on the research side because, for me, the voice of the patient if you will, and the caregivers were hard to leave at the office. I struggled with separating all of those emotions

Bring the patient-caregiver voice 08:33

Health Hats: How has that been for you bringing the patient's voice into your work?

Lacy Fabian: I was doing one of my last clinical rotations at Johns Hopkins in the traumatic brain injury unit, and my preceptor at the time provided some words of wisdom. She was very eager and very inspiring. I'm not a caregiver or provider. And she had said that if you have a patient. They're not improving anymore; then you need to advise that patient to go find, go help them find somebody new because there's always a provider out there who can find something new for that patient or innovate in some way, that's going to help them continue to improve their quality of life. You need to always have that zest for continually improving. There should always be that expectation for more in these kinds of situations. That resonates now in the clinical decision support space. Working at the level that I do now, which I consider it when I do talk to other people, I think of it as that national level. So, it can seem fairly distal. But what I can do is make sure that in a space where clinical decision support is seen as such a highly technical field that we don't forget, we are ultimately trying to get at those patient and caregiver interactions with providers. No matter that we're operating kind of up here and we're doing something that has all these acronyms and complex language and coding and all this good stuff, which is very important and very relevant. But at the end of the day, we're trying to help people make decisions and help people in many cases who are, as you said, Danny, fraught with lots of emotions and challenges and other things. So if we can make it just a little bit simpler for that provider to help their patients informing those decisions and feel good about those decisions, then that's what I try to keep in mind at this work and in this project in particular.

Scaling patient-caregiver engagement 10:57

Health Hats: Interesting. Ed, the last time I saw you in person, we had a little bit of a discussion. One of the things that I came away was that this challenge of including lay people in some of this sophisticated, acronym-filled, remote world is twofold: Both the ability of people that aren't in that expert bubble to feel comfortable enough to contribute. And then the other side of it is the ability of people who are full of that expertise in the bubble to be able to listen to and use somewhat raw, not necessarily seemingly directly pertinent perspectives. There are so many challenges to scaling this. That it's one thing that you and I found each other, and you've helped me be introduced and accepted into this world, and as you're saying, I introduced you. But I don't think we're every day that this relationship you and I have is that everyday relationship, it's so like, what do you think about that challenge of trying to scale this?

Ed Lomotan: Yeah, I wish I had a good answer about the scaling question. I would love to hear your ideas, Danny, because I think you hit the nail right on the head. One of the things that I've learned and maybe it's the clinician in me, but one of the things that I've learned over the last few years of thinking about some more is, boy, as you said, listening is probably more half the battle—and just being flexible. So whether you're a patient or a CDS designer, I think to go in with that frame of mind. I said, look, I'm going to listen and try to keep my processes or whatever I'm trying to do flexible enough to hear what

people have to say and to be able to write that in a meaningful way, just give yourself that ability, freedom, honestly, to listen. From the perspective of folks not necessarily in the bubble, let's say from a patient activist side. For me, yes, it would be nice if folks sort of knew all the acronyms already, or sort of knew what we were talking about in terms of, you know, quote-unquote clinical decision support. But on the other hand, I often encourage folks, just to tell us what's on your mind, you don't have to necessarily know the space to contribute something meaningful. It's often when you don't think something's meaningful, that it actually is. So, that's the part of folks in the room to just be quiet and listen and be able to absorb that. From the perspective of CDS designers, I think the challenge there we've encountered is you've all got deadlines, project deadlines, and contract deadlines and grant deadlines, and so forth. Being able to listen and synthesize and incorporate something actionable and show your patient activist or group of people that you've listened to them, I think is a challenge because you want actually to do something meaningful with that input then. It's not always clear what those things are.

Learning through using 14:16

Health Hats: Lacey, one of the things that's interesting to me, having worked with MITRE. I led some EHR implementation initiatives, and I realized the importance of having a clean and sound database or databases before you start trying to implement something. But one of the things that I've learned working with MITRE on several projects over the last few years is how much work it is to do some of the simple things. I just want to wave my magic wand and do it. Why can't we do this? I hear people say in the activist world, 'they should be able to whatever.' From working with MITRE, I've been able to say, 'do you know how hard that is to actually do?' What's your experience with your desire to have the technology accomplish something and how much work it is to move it like six inches, if not one inch?

Lacy Fabian: Yes. I would like to say, 'wait, what are you talking about?' But I know what you're talking about. I'll build onto Ed's comments about the listening and potentially not being able to act on what we hear. I'll pull on this thread throughout. It's the level that we're operating at. Right? So, if we work at a national level, then we have extra things that we have to get through incrementally. In a perfect world, we'd be able to say, 'easy, it's done,' and then move on. That's what we might be able to do at an individual level. Maybe we might even be able to make it happen within our own healthcare organization. But once we move up levels, we add red tape to it, because of where the decision is operating. It starts to bring with it so many other pieces and contexts. Often those pieces are important because they bring in diverse viewpoints, as opposed to one person trying to push something. That seems straightforward and should hit all the marks. Often, we need those other points to come in and say, wait, what about this? To still keep it constructive for advocates and activists who are participating in that patient voice, coming at the discussion with a lot of honesty from the patients and caregivers, but making sure that it's constructive honesty, to recognize that it's coming into a context where there are going to be these additional challenges. There are going to be things you wish weren't there. Yet are. But on the flip side, if, as a project team or somebody working in that space, you hear that honest and constructive feedback from your caregivers and advocates who are engaged in the project with you, make sure you have space to hear that constructive feedback. And make sure you have enough humbleness and set aside egos so you can hear. That's the point about listening, so you can hear what they're actually saying and acknowledge it's important. It may not happen tomorrow. It may not

happen this year, but we can take that information in and one day rest assured it will be the right day, and we'll get back to it and be able to move it to the next level. So, yes, honest, constructive feedback.

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Mismatch between questions asked and evidence 19:15

Health Hats: So, Ed, I'm on that strategic planning group for AHRQ. It's met several times. I found myself saying last week when we had a half-day session, was that there's such a mismatch of the questions people have and the research that's conducted. Now I'm thinking in the COVID world because that's what we're up to our eyeballs in. When we look at the evidence that's available, there's a mismatch between the questions that people have as they're trying to manage the uncertainty of life and COVID. There's very little evidence out there to help answer the questions. I find in this space that we start with the evidence, and then we think about computerizing it rather than these are the questions people have, how can the technology help get to faster more equitable access to evidence-informed guidance so that people can make decisions about testing, about school, about whatever? What do you think of that?

Ed Lomotan: Yes, big, big questions. I think you're right. COVID brings this all to the fore. It's right in front of us to sort this mismatch between the amount of evidence and the evidence that we need. On the other hand, it's a question that's existed for a while. I don't think there ever is a time that the evidence we need is all there or all the time or when we need it. In some ways, it's an age-old question. It does seem more relevant now or more pressing from my perspective. You also hit on that, too. It's really about how to get those learning cycles faster.

Health Hats: Great way to put it.

Ed Lomotan: How do you generate evidence and put it into a form that folks can use and then get it back to the people who are making decisions whether you're a patient or a clinical decision support designer, or a healthcare system leader. A lot of what we talk about around systems and infrastructure can help because you're trying to try to make those learning cycles faster. Call it learning healthcare system, learning healthcare environments, or what have you. Precisely, that's the space where we need patient and caregiver input. In that space of lack of certainty is where you need people to come together and recognize where those gaps are. It's the absence of adequate evidence that shared decision making needs to happen. But overall, how do we get the learning cycles faster?

How new is new? 22:30

Health Hats: Lacy, I've been two or three years working with CDS Connect. One of the reasons I do it is that I think this business of a repository, of ready access for people to the evidence is essential. But when I talk to people about it, oh man, it is so hard to get a hook when I talk to people, not clinicians,

not informaticist, but people who are very involved with research. I have an interview scheduled next week with somebody who's involved with research in the MS community. She is on the board of an MS research organization. I wanted to interview her for this series. I had to talk her into doing it, because when I sent her some previous work I've done about CDS Connect, a link to the website, she said, why? I'm not saying that as criticism, actually, I am in the sense of, of that we need to do the step of why this is important. And that link what we were just talking about that it answers questions people have. And so I can't remember ed, you might remember better than me, but there was the one maybe it was last year was it was about, the preventative guidelines and what you'd think like that would be stuff that people could zero right in on accessing the preventative guidelines. So, you're eyeball deep in this stuff. Even with clinicians, how does CDS Connect having a repository of guidelines serve clinicians? The day-to-day clinicians, not the EHR developers, not the app developers, but people who are clinicians who are working to make decisions with people, how does, how does CDS serve them? CDS Connect.

Lacy Fabian: OK. Yes, I'll carry on with the big questions. And we said earlier on about the honest feedback, and I'll give you an honest answer that I'm not sure if we're there yet. I don't know if we're there yet in the sense that this is all CDS, even in general, let alone the CDS Connect project is quite new. It's a new field in many ways. Before working in the clinical decision support space, I worked with quality measures, which is what I consider a slightly older space, but is similarly fraught with challenges of, so what, and what's the impact and how is it impacting this individual person? I think that what's exciting about clinical decision support is that we're looking to pull in the technology. And we're trying to actively engage what we've been able to build just as a society with our access and the way we can share data. We're trying, desperately, I think, to bring that into play because we can see the vision. We can see where getting things in a more automated fashion, getting technologies to talk to each other is all going to help that day-to-day clinician. To do that, we have to start from the beginning, we have to build it, and get those things to start talking. We have to start testing it out, which we've been doing. We've had to start working with people and adding in the layers as Ed talked about the learning cycle and a learning system. Once we fine-tune, that's how we'll be able to get to that next phase of impacting the day-to-day and decision support that's operating in the background. I see it and know it's there and can feel its value even as a clinician and a patient.

Health Hats: The thread I'm hearing that's important to me is that we're doing something, we're using it. We're learning from data, from a database. What's a database? A database is nothing until it's used. Once it's used, then you find the errors in it, the weaknesses of it, and it gets better from use. I certainly appreciate having worked with MITRE and RTI, and AHRQ is that learning, that thoughtfulness of, 'OK, yes, we did this. We tried this. It went pretty well. It didn't do this. It didn't do that. Here's the next step. I appreciate AHRQ's leadership of what's the next iteration, how do we build on what we've learned in this not necessarily ideal, state?

What should I be asking you guys, that I'm not about this computable, decision support world?

So what? 28:41

Lacy Fabian: I was trying to think about if I were on the other side, listening to this, what questions would I have and where would I be trying to figure out where my voice is? That took me back to a version of the 'so what' question and that reminder that we can all be learning. Even if we're not working on national projects, even if we're not regularly going to see clinicians every week or every

month, or we're not a clinician. Every day we're making decisions about our health. We're deciding if we're going to drink the water. We're deciding if we're going to sleep, those kinds of things. That, to me, was the so what for connecting something like clinical decision support working behind the scenes. It's highly technical to think of it that way. It's helping make decisions and understand how we got to that decision and recognizing that those decisions are happening all the time and asking people to consider what's important to them when they do make that decision. Are they hopeful that those options being presented are based on evidence or trustworthy?

Health Hats: Thank you. What do you think, Ed?

Ed Lomotan: Yes, Danny, there are lots of questions it's fun to explore, brainstorm with you about. One you asked earlier had to do with scale, right? So, thinking about co-designing decision support, implementing it with patients and caregivers and other folks. What does that look like? What do we need to get there? One other question that feeds into that: I would love to hear how folks talk about the role research dissemination and implementation aspects. They're not just research, clinical research, or even clinical guidance of research? What's the best way to engage patients and caregivers in co-design? How do we know it's making a difference? What tools do the designers and patient activists need to make the design faster and more efficient? Those are, from my perspective, wonderful research questions that we need, to your point evidence for. So, this is not just evidence about what to do clinically, but evidence how to do what we do, you and I, and Lacy together. Because once you can build that evidence base and learn the best practices, we'll know how and what to scale. So, this goes, again, back to the learning cycles. Some AHRQ grantees are already doing this. I know you're probably familiar with them. So just off the top of my head, folks like Ken Kawamoto and Dave Dorr, Dan Malone. Their whole projects are to learn how to incorporate this type of expertise and tell us better ways to do it. I think talking about how to incorporate your scientific investigative approaches to find the answers about patient engagement, I think is going to help all of us.

It's so hard to do 31:44

Health Hats: One of the things that come up in these kinds of conversations is, 'Oh man, that is so hard to do! Just thinking about something that's such a leap.' Let me give you an example. Sometimes I feel like a broken record, and one of my skips in my broken record is that it doesn't make sense to me that we have these guidelines, we have evidence. We put our effort into trying to get people to make decisions that follow the evidence. Where to me, I would see that people make decisions for all sorts of different reasons, whether they're clinicians or laypeople. Why doesn't our system record the decision that was made and then look at what were the outcomes? Then we would be researching in real-time. We made the decision not to follow; I'm not taking the medication to lower my cholesterol. OK, so then what happened to me? I'm this old white man of privilege as opposed to a native American living in New Mexico. We would build this body of evidence. People say, 'do you realize how hard that is to do?' Why don't we just have a hackathon, and say, here's this crazy problem, this critical problem? It's a crazy problem. We have no idea how to solve this problem, but let's have the grant pay a hundred thousand dollars for the winner and pay for the convening of people. Then put the problem out there and let people say, well, to solve this problem, you need A, B, C, and D, and then you've got the beginning of a roadmap to solve a difficult problem. What do you think?

Ed Lomotan: I think you've got a great idea. People have asked this question. I don't know if there's been a hackathon or a challenge already that's been funded out there. We make decisions, whether it's clinicians or patients or caregivers every day. The idea is to learn from what decision we've made and what the difference made? So, I think it's a combination of tech, I suppose, and giving people the tools and capturing things. And then also recording why you made decisions. I'm not sure that I personally know all the decisions. Why I make some things and why I don't. Why I choose one path versus the other, figuring out how to capture that uncertainty and capture that sort of reasoning. It's part of the problem, but I think it's a great idea, and I know folks are thinking about it, and I've tried to tackle on certain use cases, certain clinical domains, but at some point, it's a big question.

Health Hats: Lacy, what are your thoughts?

Lacy Fabian: Automatically, I start to think about the steps then, and so why haven't we done that and what is holding back something like that. And seeing whether that's the degree we want to go into or explore, even tap the surface. But then of course, recording answers. The first thing that comes to mind is what's going on in other spheres of MITRE and HHS about privacy. And who owns the data and what's going to happen with it when it's out there and how's it going to be used? My mind starts to immediately go into those kinds of practicals. That's the rub, that's the kind of things that are going to start to come up.

Health Hats: They are.

Lacy Fabian: We're working on it.

The Camino de Santiago 35:49

Health Hats: Before we wrap up, I have to include this. Ed, you had such an important influence for me in making an important decision in my life, which was whether or not to go with my wife on the Camino de Santiago hike. I'm a two cane, and wheelchair guy, and my wife is a serious hiker. She and her friends had decided they were going to Spain and hike the Camino. It just so happened that I saw you within days of hearing her plan, and I'm thinking, 'Oh my God, she's going to leave me behind.' I don't know why I was saying that to you, Ed, but you told me about your experience with your dad. You said, 'Oh, you absolutely can do it.' And so I thought, OK, well, I can absolutely do it. And we went and had a blast. It was such a lift to be able to accomplish that together. I want to thank you for that Ed. That was an important decision. It didn't involve any technology.

Ed Lomotan: Thanks, Danny. I enjoyed talking with you about that. For folks listening, this is obviously entirely separate from my AHRQ role, but Danny and I share a common experience of having done this Camino, this walk in Spain at two different times. That walk is meant to be a time of reflection. I can tell you having done that walk and reflecting on work and what's important in terms of helping patients, I can go back to AHRQ's mission: making healthcare better. That definitely came up on my walk. Seeing folks of all different walks of life, literally do the Camino. I think also it's important to get that perspective out there, out in the world. For me, it's been a good refresher, the channel to let our everyday work. I'm glad you and I have that connection, Danny.

Health Hats: Well, thank you so much for this conversation. I appreciate you guys taking the time, and I enjoy working together with you guys. Thanks.

Ed Lomotan: Thanks, Danny. It's an honor, and pleasure and thanks, Lacy.

Health Hats: All right, guys, talk to you later.

Reflection 38:00

I'm struck by several themes in this conversation with Lacy and Ed. Even when you've drunk the Kool-Aid about engaging patients and caregivers early and often, scaling that process, growing it across the industry challenges all of us. Perhaps we can hone our listening skills and build learning health systems that can decrease the cycle time for change as we figure out scaling. Another theme is patience with the slowness of national processes. I challenge the assumption that change must be slow and steady. Adoption of telehealth was slow and steady until COVID, then in a flash, adoption. Government could convene stakeholders with the goal of rapid movement toward testing solutions to complex problems. Provide prizes, keep solutions created in those forums open source for anyone to use. People could make money on the implementation of those open source solutions. Finally, so what? is a great question that should be asked and answered often. One of the best quotes I've read about decision making is from my muse, Mark Twain, "**Good decisions come from experience. Experience comes from making bad decisions.**" The low tolerance for making mistakes and changing our minds especially in science and politics makes me crazy. How can we learn if we don't accept learning? [Sigh]. Another tough one.