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Introducing Jan Oldenburg 00:51

Recently, I asked my neurologist, "Why am I receiving $100,000-a-dose infusions for my multiple sclerosis?" "What if I don't take this ridiculously expensive drug?" I'm a nurse, so I have a health background. He explained it well for me. Well enough that I understood most of the pieces of what he told me, but I didn't understand all of it together. I Googled the infusion once, but haven't retained much of what I read. I trust him. I'll take the next dose. I'm sort of learning and I'm sort of deciding. Am I leading?

As CEO of our health teams, we manage, we lead, we learn, and we decide. I'm on a mission to explore the nuances of this way of thinking about self-engagement in our healthcare.

I'm delighted to be speaking with my friend and colleague, Jan Oldenburg. Jan is a nationally recognized thought leader on personal health engagement focused on transforming healthcare and the physician-patient relationship through digital tools. Jan has been editor and author of several books about personal engagement. Please find a list with links in the show notes. Jan was Co-Chair of the HIMSS (Health Information Management Systems Society) Connected Health Committee were we met in 2012. Jan introduced me to the Society of Participatory Medicine (SPM) where she is now a Board Member. She and I collaborate on the SPM governance committee.
I hoped to further explore with Jan the decision-making aspect of being CEO of your health. I started this chat with Jan several weeks ago when I asked for her thoughts about some work I'm doing funded by the Agency for Healthcare Research and Quality, a federal agency. I'm serving as a patient expert on a project to help patients and clinicians make better decisions together. Much of what I do is translating academic and bureaucratic-ese into language I can understand and share with interested lay people in my network - like you. Jan responded with thoughts about a summary I sent out on Twitter, Facebook,

and LinkedIn. Several times in this chat I will break in to explain stuff that I had to look up. We started by talking about citizen expertise and professional expertise.

The Language of Goals and Preferences? 03:55

Health Hats: How is it that people make good choices about their health care? Let's not say good choices. How about informed choices that work for them? And that they make good use of experts and helpful people around them?

Jan Oldenburg: And that they know how to tell who's really an expert, right? I'm in a Facebook discussion with an old friend from high school who is totally on this anti-vaxxer kick. And about what's delivered together in the MMR and that it should be separated and that Wakefield is perfectly credible but misunderstood. And then of course, she's got other people who then pile on. I seem, so far, to be the lone person saying no. And this is somebody who's actually very bright.

More in the show notes about Wakefield and the anti-vaccination movement. Wakefield was a discredited research study claiming to show a link between vaccination and autism.

Health Hats: I think that what you're describing is emotion versus facts. I think that they're very different frames and I don't think that we are very good at bridging those frames of thinking about stuff.

Jan Oldenburg: There was a tweet chat for physicians the other week. One of the things that came up and is evident in my interactions is that these are people who think they're basing it on research. So they are bringing up all of these sources that disprove or prove Wakefield. So they think that they are using facts and data and logic. But it started in the wrong place, and they end up there in the forest.

Health Hats: So this is not beside the point at all, because I think that people make choices either from inertia - It's what I've done, this is what I'll keep doing - not necessarily mindfully. But they also make choices based on so many different things. And when I listen to people talking, they talk about people's preferences. They talk about people's goals. I think that all of those things go into how people make choices. The choices that they make with their clinicians are probably only a very small proportion of the choices that they make, even about their medical care.

Jan Oldenburg: I totally agree with you. We talk the language of choices and goals but don't really process the reality. I often find myself saying, "you can't dismiss people's health choices as irrational, because they're rational to them. You don't know what context they're making them in." So I might be somebody who prefers non-pharmaceutical options. Actually, I am. We're okay with that, unless it interferes with the treatment we think you should get. We tend to frame the person's goals as our goals for them as opposed to the person's goals for him or herself.

Situational leadership: Right style, right time 08:43

Health Hats: So, I think in this initiative that the goal for AHRQ is that people collaboratively make decisions about medical care with their clinician based on the best evidence. So they're looking at what are the tools that are available and when they think about tools, I think they think a lot about electronic tools. My drumbeat is the most used tools are paper and pencil, and the next most used tool that I'm

aware of is Excel, and that's also pretty rare. Then I think the next tool that's prevalent, which is probably more than Excel, and maybe even more than paper and pencil, is social networking.

Jan Oldenburg: It's early for many. Or as Susannah Fox talks about there's also the waistband tool, do my favorite jeans fit anymore? Clues you get about where you are from how your body is in the world.

Health Hats: There are two areas that I'm interested in talking about with you. The first is, how do you recognize a good tool? And the second is, how do people learn about their health? You and I are unusual. We are the CEO of our health. That's just the way it is. And the kind of help we get is from people helping us be the CEO. And then on the other end of the spectrum there are people who never go to the doctor and never try to engage. Then people who say, "just give me a pill, tell me what to do." And everything in between. And there's probably the same range for clinicians. And there are different ages and different power dynamics. Just so many things and so it seems to me that even though I'm saying those as two different things, they're intertwined.

Jan Oldenburg: Yeah, I think that's true. I had this revelation when I was writing Participatory Healthcare. I interviewed a woman who is a friend of mine as one of the patient stories. She had the experience of getting Guillain-Barre. Not as a result of anything clear. I think it was probably a respiratory infection.

Health Hats: Okay. I'm sorry. She got what?

Jan Oldenburg: Guillain-Barre, you know the paralysis thing often associated with flu vaccines.

Guillain-Barré syndrome (GBS) is a rare neurological disorder in which the body's immune system mistakenly attacks part of its peripheral nervous system—the network of nerves located outside of the brain and spinal cord. GBS can range from a very mild case with brief weakness to nearly devastating paralysis, leaving the person unable to breathe independently.

She wasn't a terrible diagnosis story. Her doctor recognized it right away. Sent her immediately to a neurologist who immediately diagnosed it and told her, "you're going to need to be in the hospital. You need to be hospitalized." And she said something on the order of, "I can't, my husband's out of town. I've got a two-year-old." This is a very take-charge person. Probably one of the most take-charge people I know - about everything. He said, "well, okay, but you know, this is going to happen. You're going to end up in the hospital." And so she left, and she went home, and that night she couldn't even get her two-year-old to bed. She couldn't carry him up the steps, and she ended up going to the hospital in the middle of the night. And it was one of those occasions when, as she talked about it, it became clear that even this most take-charge of humans at that point needed her doctor to be more take-charge than he was. And she couldn't convey that. But he needed to be able to figure that out, by either providing more information that would help her make a better decision or giving her scenarios about things that could happen. I always think about that in terms of what I would write about how I would want to be dealt with, might not be the case in every situation, if you asked me to write it down. So, there's always situational leadership that has to be kind of operative in these settings as well.

Health Hats: I think that's interesting. One of the reasons I like to think about CEO of my health is I feel like it's a leadership dilemma. I've spent part of my career as a boss, and I'm a student of organizations,

and I'm a student of leadership, and I'm a student of health. And so it's easy for me to think about those things together. I was at the neurologist today. We have a very good relationship, and I see him as an important subcontractor for me. But I do leave a lot of decisions to him. I just have no idea. We had a talk about the infusions I'm taking that costs a hundred thousand dollars a dose. Twice a year I have this infusion and what if I didn't take it? We were exploring that, and he explained everything very well. But I'm making the decision to leave the decision to him.

Jan Oldenburg: Right as opposed to him just assuming that it's his decision.

Health Hats: The only tool that I use with him is the portal. Otherwise, it's we talk. When I see him, we talk. Otherwise, I have a relationship with him that when I have questions, I ping him and ask my question and he answers them. That's sufficient. Even though I've had gigs to help develop clinical decision support tools for the treatment of multiple sclerosis. I actually cannot imagine he and I using it. And I'm there because I have a patient perspective and I'm a clinician. That's why I'm an advisor to this project, but I actually can't imagine using it.

Jan Oldenburg: And why is that?

Health Hats: Cuz we just have the conversation and - I don't know. The part that I try to influence is that the tool would theoretically help me before I go to his office so that I'm more intelligent and have thought about those things that might inform the decision. Decisions that we have to make about disease-modifying treatment.

Data is Noise, Make Me a Story 17:42

Jan is showing me some spreadsheets and graphics that I will include in the show notes.

Jan Oldenburg: I want to share some of my data for a second and tell you how I used it. This is old data, right, because I don't actually need to track this anymore to this degree. But when I first developed asthma, I had very non-standard asthma and I was trying to figure out what the hell it correlated to. So this is a year's worth of data - actually taken three times a day. So this is Peak Flow data, and the yellow is all the time I was on prednisone. What I was trying to figure out was why sometimes I would get to my yellow zone and fall off the map and just go down the hill and sometimes I wouldn't. So I did this for three years. And then I tracked my average prednisone by year, the days on prednisone by year, the total prednisone I took by year, my peak flows across those years, and the fact that after I had sinus surgery everything got better. From there on that's the yellow after sinus surgery. I have a new pulmonologist at BCU. He's a great guy. I was talking about how I had done this because I think there should be a tool in there. He was just like, "oh my God, you actually have data that tells a story. Most of the time when people track their data, I just get slips of paper or entries. I don't get it in any form that allows me to understand what the story is telling me." It's both the patient and the doctor that need visualization, the correlations. They need things that are suggestive of what's going on rather than that it's just data points. And most people don't know what would be useful and most doctors don't know how to describe what would be useful.

Health Hats: So are you telling me this story because the opportunity for electronic tools might be to anticipate the kinds of data that are important to use to tell a story. So that a person could collect data about themselves or their devices could collect and then there's an algorithm to turn that into a story.

Jan Oldenburg: Yeah, that helps you tell the story and the other part, I think is that most of the time when you're using an app the only thing it does is nag you about recording your data.

Health Hats: They're all important, but limited feature.

Jan Oldenburg: Totally limited and I think we all respond to nagging about as well as we did when our mothers did it and we were 13.

Health Hats: Or our spouses.

Jan Oldenburg: But the power of it potentially is to suggest correlations and possible actions, i.e., I noticed that your peak flow is always lower when the humidity is above 90%. Or perhaps there's some action you can take or yes, your asthma symptoms - your lowered peak flow - correlates to pine pollen, but not to grasses.

Health Hats: We're a long way away from that.

A button'll do it – contextual education 21:50

Jan Oldenburg: Oh, we're so far away. But it is the potential. What technology does best find those hidden patterns that you can't see? It was one of the things it does well, and some of them may be just noise in the system. It may be noise that the temperature or the humidity has an impact. But maybe not. So it's suggestive. It's not determinative but suggestive. But one more thing and I did put some notes in your document, by the way, but the other thing that I think is easy and we missed the boat on so much. It so drives me crazy that it's not a portal requirement. They required the info button for clinicians inside of EHRs, but they didn't do the info button for patients. And providing contextual education when I am looking at my lab result or even the conditions I'm named with or the procedure. Give me, in that moment, something to educate me about whatever data I'm looking at.

Jan is referring to an InfoButton, formally described by the HL7 standards as:
The Context-Aware Knowledge Retrieval (Infobutton) specifications provide a standard mechanism for clinical information systems to request context-specific clinical knowledge from online resources. In English, you click the button with an I on it to open a window with further information important to you. The record may say "MMR vaccine" and the button returns, "Measles, Mumps, and Rubella vaccine given to children in doses during the first years of life."

Health Hats: I think patients have the same dilemma that clinicians do, which is they're drinking dirty water of information with a fire hose. Even with my neurologist who I love dearly who uses Open Notes. And I've had to have this conversation with him that his notes don't help me a bit because I can't figure out by looking at his notes, am I better or worse? Am I progressing or aren't I?

Jan Oldenburg: Critical question.

Health Hats: Critical question, and that's not in there. I have said that to him, and then he said, "oh look right here, and there's this scale. See over the years I've seen you've gone from this to this to this. That's progression." But I had no idea, and I'm a nurse, and I'm an informaticist, and it was just a bunch of noise.

Jan Oldenburg: Wow, that's a great example.

And now a quick break to hear about our sponsor, Abridge. I see many clinicians on a regular basis, way too many. I'm appalled at how little I can remember when I get home. My wife asks, what did she say? What about this medication or that test? I'm happy to remember half of it. To help me remember everything, I downloaded a new smartphone app called Abridge.

Now, when I go to the doctor, I ask if it's okay to record our conversation. Nobody has said no yet. I push a big pink button to record, and after I'm done, the transcript from our audio appears -- not the whole thing that's too much, but sections around medical keywords like fatigue, pain, tests, exercise meds. Now when I'm done, I can share my visit with my wife, and she can listen to exactly what the doctor said. Abridge was created by patients, doctors, and caregivers. Check out the app at abridge.com -- a b r i d g e .com or download it on the Apple App Store or Google Play Store. Record your health care conversations. Let me know how it went!

Health Hats: What are the key pieces that were talking about? So you've said, just-in-time information that tells a story within the context of either my life or my medical condition, with the opportunity to ask questions. Either way.

Drinking from both ends of a firehouse? 27:22

Jan Oldenburg: Yes. I also had the sense that many of the things in that document. It was trying to be two-way, trying to both give the patient an opportunity to learn and share, but it was also trying to get information right from that patient. I'm not completely sure that you can serve two masters here.

Health Hats: Say more about that!

Jan Oldenburg: I'm not sure you can't. I at least have the fear that in focusing so much of the attention on being a part of the fire hose, it continues the approach, perspective, etc. that is what we do to patients, which is all about a kind of one-way transmission. This is all the stuff you need to know. This is all the stuff we want you to know. Here it is consolidated - maybe. But it's still sort of from us to you. I have this picture, possibly completely unrealistic, that we could do care planning truly collaboratively. That it's not just, "okay, we're going to assemble all the care plans from your different doctors." But we're going to give you a way of constructing your own out of all this noise. You touch on it, but it's a minimum standard. You put care plans in from everybody. Highlight where there are conflicts. Highlight where Dr. A is saying X and Dr. B is saying Y.

Health Hats: Or it costs a hundred thousand dollars a dose and I don't have insurance. Yes, exactly different kind of conflict.

Jan Oldenburg: When we first did cost estimation at Kaiser, because Oregon required it, the mantra from leadership was, " okay, that's fine if we have to do this for patients. But for God's sake, keep it away from the doctors - they don't have to know this, and they don't want to know this." And within three weeks of our launch, the doctors were screaming saying, "you have to give me access to the same tool you give to my patients. Because they walk in here with this data I don't know, and I don't know where they got it, and they're asking me for advice based on the cost, and I have no clue." So, we can focus on what patients want and need. I'm not sure that the things we think they should want and need are the same.

Health Hats: I'm co-chair of a workgroup that's looking at the critical features of a patient-facing app focusing on pain management. My influence as co-chair as a patient: if I could have four features. The list that I shared with you, that you've been commenting on is the let's include everything. Which I find overwhelming.

Jan Oldenburg: Everything but the kitchen sink.

Health Hats: That's okay. It's good to have an inventory. But I'm a practical person, and my brain can handle everything. Hence, I'm interested in what whatever group of experts that I'm working with, what do we think is a bottom-line four things that are key? You've already talked about one, that's a feature that turns data into a story. Whether that's a dashboard or something. We've talked about vetting what we think is evidence. Not that you've said those are the most important things.

Jan Oldenburg: But contextual education. Which is so simple and should be required.

Health Hats: Of what we've talked about, that's clearly the easiest.

Jan Oldenburg: Oh my God, exactly. So falling off a log easy. No excuse. We've also talked about this whole concept of it really is my care plan. Not the one you want me to have. If we really understood how to do that and how to understand my values in a different way than we currently do and get to them? We'd really get some of the things that end up being barriers. Which is either that I worry so much about the expense of the medications or I hate putting this foreign stuff in my body, Or I hate x side effect or …

Health Hats: You can't mess with my sleep or you can't mess with my pathological optimism.

Noise again, story again 32:31

Jan Oldenburg: Yes, exactly. My husband had a heart attack at 46. I'm an educated consumer, and I'm so friggin' confused at this point about what we should be eating. Really? I am. Is it low-fat is it high fat? I mean I get eliminating sugar except for the wine, should I, can It eat bread or is it low carb or is it high natural carb?

Health Hats: That makes a plan. A plan is what do I do next? Who's my team?

Jan Oldenburg: And let me be able to say, okay, how much evidence is there behind this fad? And how do I interpret it? No, like what's going on with keto or you know, what's going on with whatever else. Anyway something that gives me information but doesn't do the assessment for me and give me the answer. But gives me resources to the degree I say I want them. To sort through noise, You and I might be asking very good questions

Health Hats: Sorting through noise. That's a sound bite that works. There is so much noise.

Jan Oldenburg: So much noise and half the time, you know people assume I know nothing about asthma, say. And so they want to give me the basics. No, I friggin' don't need the basics. I want to ask sophisticated questions and get sophisticated answers but on some new thing I get diagnosed with I may be at a neophyte stage and I really want the basics there

Health Hats: Or today I'm in pain, and I can't hear anything. I need to record this for when I go home to my wife I can share it with her and then listen when I'm not in pain and think about what did the doctor say?

Jan Oldenburg: Yes, and what does this mean?

Health Hats: Mean to us? And what are our questions now that I don't feel like crap and I have somebody with me who I trust

Jan Oldenburg: and I actually can re-listen outside the stress of the visit.

Questions? Answers when I need them 35:30

Health Hats: So maybe that's another one. The one thing that I've been plugging is this idea of 24/7 being able to get answers to questions. My first neurologist, right away he said, "You're going to have a ton of questions. I'm signing you up for the portal. Any time that you have a question, I want you to ping me and send me your question.

Jan Oldenburg: What a gift.

Health Hats: And he said I will probably get back to you within a few hours unless you sent it at one in the morning, but you should still send it at one in the morning. And then he had his he had three stock answers. Oh get over it. If it's still there tomorrow, let me know. Or we need to talk right now. I've told people that they go. Oh he's so rude oh get over it, but I loved it. Because I'm a worrywart and I just all these things were happening. Is this the MS? Am I having a relapse? it was 90%, Oh get over it, and then I just got over it, and then it was a few times it was let me know if you still feel it tomorrow. And mostly I didn't, and one time it was we need to talk, and I had to go get steroids. I think that 90% of people's questions are predictable. So why not have a frequently asked question algorithm as part of the website, the portal, whatever.

Jan Oldenburg: Do you know what they've done with Health Loop? Are you familiar with Health Loop? My information is probably a couple of years out of date, in terms of they probably gotten better at this. But and they started out with post-surgery and have extended from there. They basically said, okay, first of all, we need information to know how somebody's doing, and we don't want to have to call them everyday. So we have just a couple questions to ask you. But what they did also was they fed people with an email, "Here's what happens to many people on the third day after surgery." X, y, and z. Please respond with just two, three questions answered to us, and it's signed by their doctor. Because it fed them this, here's what's predictable, It helped them understand which things were to be expected, and which things they need help with.

Health Hats: I really liked that. It was push instead of pull exactly. That's cool. See now. I didn't even think about that. Wow,

Jan Oldenburg: The other part is we spend all this money trying to call people to get answers to questions like "is your wound red" or they don't come in at the right times? And anyway, so there is something to be said there for exactly that. What are the things that you might expect to be asking and what I what does it mean and what can you do about it if anything?

Reinventing search 39:10

Health Hats: I've got a few more minutes. I want to talk briefly about this idea of how people learn. I am not a fan of curricula. Too much. Because I think that people learn best whether they're three or 90 when they want to know something. And they're looking for answers to their questions. And I don't think we're good at that anywhere.

Jan Oldenburg: So think about reinventing search, right? I'm going to say things that I know that we hate it when Google actually does it, right. But if instead of spitting back to me the entire frigging universe, let me tell you a little bit about what data sources I'm interested in, or learn from the ones I actually spend time with.

Health Hats: That's what Sarah Krug is doing with Cancer 101 where they look at how do people take in information. Are they readers? Are they listeners? Are they watchers? Yes, which to me is like sort of the floor. Yes, I know it's feels really revolutionary to me that she does that.

Jan Oldenburg: It's still the floor. I mean I work with women in Pittsburgh who's got a company called MetaRespond. They're based off of a patent with Carnegie Mellon. Their most successful one is educating about open heart surgery, to-date I should say. They worked with a couple of surgeons on what are all the things you want people to know, what people ask, the concerns, the things you get questions about. And created this whole library of snippets of video with an actor answering those questions. Then they have a language model that maps kinds of questions to kinds of answers. And so you can now go in if you're having open heart surgery and just start talking to your device and it brings back the right snippets of information. And so it feels like you're having a conversation about it. People have spent like 90 minutes. It's called MedRespond. The Allegheny Health Network, I think did a study on this, clinical study, people spend an average of 90 minutes working with the open-heart surgery model and the people who did it cost 30% less than the people who didn't.

Health Hats: Oh my goodness, that's monster. Both of those are monster. I mean, I'm delighted when somebody looks at my website for more than 30 seconds. 90 minutes is amazing.

Jan Oldenburg: 90 minutes is huge. Granted they're having surgery. They're worried. They're concerned. They're interested.

Learning at the time of need 42:31

Health Hats: We homeschooled. And I understand the idea of learning about what my kid is interested in. Frankly since I'm a selfish person, I looked at what we were both interested in. Yeah. Yeah that we went for that. We designed our learning experience about a mutual interest. Like right now. I see my son and my grandson taking a course in designing video games. He's 11. They've been doing this for a couple years and he's just learning so much. Finding that, that's the art.

Jan Oldenburg: Yes, as opposed to cramming everything down somebody's throat because you're newly diagnosed as a diabetic, you need to know all this stuff.

Health Hats: Well, we are just so not designed for that kind of thinking and I don't know if it's even reasonable to expect. Because the skills for that all around. I don't know that patients or professionals are really good at that. What do you think of that?

Jan Oldenburg: I'm the kind of learner, I'm the kind of obnoxious person who's always asking all the questions in class. Because when I need to know something I actually need to know it then. Or it distracts me from the rest. And I don't think I'm actually that unusual, except that I actually say it.

Health Hats: The story that's going on in your head takes our attention.

Jan Oldenburg: I've been looking for this stat. So if you happen to know what it is, I would love it. But it's I'm sure there's a stat out there about how few people understand which drugs they're taking for which conditions and what things they're supposed to do.

Health Hats: You're right, there's a stat.

Jan Oldenburg: There's a stat. If you find it, I'm looking for it. Why are you on this medication? Well he's having some pain issues at that point, but my asthma was also acting up. Is this a diabetes drug or is it a heart drug? And yes, they both probably affect it. So just the simple thing of when you get a prescription even does it say in the prescription bottle why you're taking it? It might say for pain, doesn't say for diabetes? So, you know simple things like that about reinforcing things that help people understand their story, too.

Here's that stat Jan was looking for. Forty-four percent of patients believed they were receiving a medication in the hospital that was not actually prescribed. A patient who normally receives a blood pressure medicine, for example, may have thought the medicine was continued when, in fact, it was not. Ninety-six percent of patients failed to recall one or more of the medicines that they had been prescribed during their stay, according to the study, which is published Dec. 10, 2009 in the Journal of Hospital Medicine. Thanks to Liz Boehm at Vocera.

A collaborative care plan in our lifetime 46:15

Health Hats: I think we're going to have to schedule another session.

Jan Oldenburg: I'd actually like that because the daunting thing about a collaborative care plan is medical professional time and whose responsibility and the medical staff side is to actually reconcile all these different things and how do I when things are coming from all of my docs? Do I have to go to each of them individually and say, "hey these two things don't seem like they fit together" or is there some way that we can design for that to be done for all of us?

Health Hats: And I might not have the bandwidth or the time or the money or however you wanted to define the bandwidth to do more than four the things on this care plan. So there can't be 30. Right or there could be 30, but there's four on top and these are the ones. You got to do these.

Jan Oldenburg: Things loom and recede, like my interest level right? And so it's got to be able to be responsive. Yeah. I was worried about that last month. Don't keep giving me that stuff back. That's resolved. I've dealt with that. Now I'm curious about whatever. The watchword in some fashion is responsive. To who I am and what I actually need at this moment in time.

Health Hats: I don't know that we've actually solved anything

Jan Oldenburg: Sadly. No, we've asked we raised more issues.

Health Hats: Well what this does to me is first of all, you've introduced a couple of new things to me, thank you. And I feel like when that happens, then I start seeing things differently. Thanks for that.

No place in the EMR for a story 48:14

Jan Oldenburg: One more quick thing, is that my husband again, he's got heart disease. He's an intelligent guy. I'm not his caregiver because he can care for himself. But when he found a new doctor, a new cardiologist here, he went in with his story written down. As well as his meds that said here's my history. So you've got it in my own words. Who I've seen, what they did, what happened, and his doctor was like, "oh my god. I've never had a patient write their story before. And there's no place for it in the medical record."

Health Hats: That's powerful both of them. Those things are powerful writing the story and there's no place for it. One of my first national informatics efforts after we met at HIMMS. It was when I was I was on a panel, Blue Button Plus. I was on this panel that met weekly for 18 months and I advocated for three things. One was that the data set needed to include family caregivers. Which I was successful at because it was the operational definition of a field. there were two other things that were critical. One was what works for me when I'm scared and what works for me when I'm in pain. And in 18 months of weekly meetings I got nowhere. I could not figure out the hook. In my work, it was clear that those are the two most important things to people when they go to an unfamiliar medical place like any ER

Jan Oldenburg: or when I am when I'm in an asthma bout. I can't talk. I can't tell my story right? I'm coughing too hard.

Health Hats: know what works for you, right,

Jan Oldenburg: But I can't convey it. Yeah, and my husband's pretty good at it but he's not he's not me, right? Yeah, okay.

All right. I gotta go.

Yeah me too this is fun, though. Thanks for inviting me. Talk to you soon. Yeah. Take care. Bye. Bye.

Reflections 52:28

Before this chat with Jan Oldenburg I thought about learning as learning to be CEO. Now I'm realizing that leaders learn on the job and keep learning. Decision-making takes learning - studying options, seeking advice, taking action or not taking action. We often say that decision-making takes data, learning takes data. But data can often be noise, cacophony, a firehose. The art is taking a disorganized or overwhelming stream and turn that into a story that motivates actionable information. Jan took spreadsheets of data related to her asthma, analyzed it, and told a visual, actionable story for herself and her physician. Her husband did it differently. They both found out that there's no place in the health record for those stories. What??

Leading also means sharing information with the team. Team members come with different backgrounds, skills, and experience and may come to different conclusions when reviewing data and information. The CEO makes those decisions that are hers to make or delegates the decisions to her team members. We ended with a discussion about truly collaborative, fluid, up-to-date care planning for you and me. We have so much work to do. We have the right jobs, though - CEO of our health. Thankfully, the rewards can be outstanding.