Contents

Proem

I usually ask the questions. This time I'm the guest.

I met Drs. Steve Labkoff and Leon Rozenblit a couple of years ago at a DCI Network conference. They host Practical AI in Healthcare, a show I've listened to steadily, though it creates more tension for me than any other podcast I keep coming back to. Usually, I jettison podcasts that do that. I stay with this one because I approach AI in healthcare the way I approach best health; I'm an N of one and resist generalizing, while most guests do a fair amount of it. I bristle at most of them, wanting the shades of gray that reflect deep understanding. In four of 33 episodes, the guest has had lived experience: ePatient Dave DeBronkart, Amy Price, Hugo Campos, and me.

I invited Steve and Leon to join my virtual Reckoning group, which I've hosted since 2019. We give podcasters warm critiques of selected episodes: the kind of feedback you give when you've made a hundred mistakes yourself, can spot them quickly in someone else's cut, and have endless thoughts about production, audience, dissemination, and life. They took the critique well. When Steve later asked me to come on his show to talk about how I use AI, not the theory but the daily grind, I readily agreed. They let me publish it here unchanged, apart from this Proem and Reflection.

I struggled to prepare for this conversation. I wanted to wear all my hats, but had to narrow my focus to two. I chose my lived experience and nurse hats.

Underneath it all was the question I keep circling back to. Not a cure. Best health, the most function, and

Hello, and welcome to this week's edition of Practical AI in Healthcare. My name is Dr. Steven Lapcoff, and this week I'm actually on my own because my partner, Dr. Leon Rosenblatt, is actually on spring break with his kids, so I am covering for him and he'll be back in the next week. This week we have a guest who we met at a conference in Boston a few months ago at the Beth Israel at the DCI network.

Steven Labkoff: We have Danny van Leeuwen. Danny is a nurse. He has background in giving actual physical care to patients. He actually runs his own podcast called Health Hats, the Podcast, and he's been using AI in both his personal life and in his professional life very extensively. Also, Danny has a significant medical condition, and I'll let him explain that in the course of the discussion because it's with that lens that we got introduced at our patient-centric AI conference, and that's why we thought it'd be a good idea to have Danny come and have a chat with us.

So welcome to the podcast, Danny. How are you today?

Health Hats: I'm good. Thank you. Thanks for having me. I appreciate it.

Steven Labkoff: So Danny, as you probably have heard because you've helped us with our podcast, and for that I want to say thank you. For those who are listening in, Danny runs actually a group that actually helps folks running podcasts improve their podcasts, and he's had Leon and I on many times to listen to critiques and feedback, and it's been very, very helpful.

Danny, we often start our podcast with asking for folks' origin stories, like how did they get their cape and their superhero tights. What did you do to get you to this point in your life? And just tell us the background of what brought you here.

Health Hats: Oh, thanks. So I'm a child of Holocaust survivors, and my parents-- when I was young, my parents were active in the civil rights and fair housing movement in the '60s.

And when I was 16 and I was thinking about the war in Vietnam and worried about getting drafted, I wanted to learn what I could learn about the draft and how I could protect myself and manage. And I went to a church in downtown Detroit, and I went for a session of draft counseling as, you know, a little precocious at 16, and I found it fascinating, and they found me fascinating, and they encouraged me to become a draft counselor.

And so I, uh, I actually took their course and became a draft counselor, and what I learned is that you change systems from the inside, not the outside. And I learned how the sausage was made, and that, uh, really pointed me in a direction. The way I got into nursing is really because I didn't want to cut my hair I had an opportunity for a job at one point, and I could have read water meters or become an aide at the Detroit Psychiatric Institute.

And reading water meters paid more, but I didn't wanna cut my hair, so I got the job as, as nurse's aide. And while I was there, they introduced me to the idea of going to nursing school, which was amazing.

Steven Labkoff: It was more-- You got paid more to read meters, water meters, than you did-

Health Hats: Yes.

Steven Labkoff: That's unbelievable. Life gives you some real interesting turns and twists, doesn't it?

Health Hats: It does. And I was really fortunate because my first jobs in nursing were in physical rehabilitation and home care. I just happened to be in a place where the Holyoke Visiting Nurses was dying to hire a guy, and I was a brand-new nurse, and they ended up hiring me. And so my first introduction to nursing was not in acute care.

It was in home care, and actually, I was the first male public health nurse in Western Massachusetts in 1976. And really, what I learned there was that most healthcare does not occur in the medical system. It occurs outside the medical system. And so when I ended up getting into medical care, it was always so interesting to me that everybody there thought this is where, you know, health happened, which it doesn't.

So over the 20 years of working as a nurse, I've worked in, other than the rehab and home care, I've worked in the emergency department, I've worked in ICU, I worked in pediatrics, behavioral health. And after about 15, 20 years, I shifted from becoming a student of individual health to a student o- of organizational health.

And what I mean by that is I got into performance improvement. I led a couple of electronic health record implementations. I had a couple of gigs in the C-suite. I did some consulting. Now, in 2009, I was diagnosed with multiple sclerosis, and when I was diagnosed, I learned that I had had it for 25 years.

And since my father died young, he died at 45 when I was 19 of his second heart attack, and so every time I would have some kind of episode, I would get a cardiac workup. And by the time the cardiac workup was done, you know, the episode was over, and this went on two, three, four times a year for a long time.

And there was a pattern there, and nobody was connecting the dots for 25 years. That's very important to me because the pattern of what was going on was in my records for 25 years, but nobody had synthesized it.

Steven Labkoff: Yeah, they may have been biased, right? Because of your family history and having these episodes, you know, as a clinician, you get very biased by family history, and that can actually lead you down roads which may not be correct, and it sounds like that's precisely what happened with you.

Health Hats: So I've-- I wanna bring in the caregiver role because I have been a caregiver for my grandmother, my mother, and a son in their end-of-life journeys. So I've been on many sides of very difficult decisions. As you said, that my shtick is health hats, and I'm health hats because I'm a patient, I'm a caregiver, I'm a nurse, I'm an advocate, I'm an informaticist, I'm a podcast host.

I wear a lot of hats. And wearing many hats has gotten me a seat at many tables because they can check off boxes. When it was really different to be bringing patients o-on board, I was an easy choice. Uh, I was at the table for technical expert panels at CMS, at National Academy of Medicine, at AHRQ, National Quality Forum, PCORI, Patient-Centered Outcomes Research Institute.

But really, I wasn't really there in it for the seat itself. My goal was always to open seats for people who weren't there yet Now let's build the bridge, since this is a podcast about AI, let's build that little bit of that bridge. So my first, like, serious experience with-- Well, I don't know about my first.

I was involved in something that you probably are familiar with, which was the Blue Button Plus program, and my goal in that, I was there both as a patient and as somebody who was working with people with disabilities. I, I was VP of quality for an organization that supported about 40,000 people with disabilities.

And my goal for that couple of years of weekly or every other week, I can't remember, calls was, uh, to add a f- a caregiver field to the data set, and to also introduce the idea that what people needed was information that would be able to say what works for me when I'm in pain and what works for me when I'm afraid, which was an issue for me, and it was an issue for the organization that I was working with at the time.

Now, I have to say that the caregiver field got added, so I felt some success in that. But as a nurse leader in the informatics group I was part of, really they were only interested in putting a name in the field, not doing anything with that information, which

I- Just collecting, so just collecting the data.

Steven Labkoff: They didn't care what the data was used for? Is that what you're saying?

Health Hats: Correct. Yeah. And I couldn't-- got no traction on the pain and fear, which now that I'm older, I understand why, how difficult that is. Nevertheless, it's something that's important to patients and caregivers. So I think I would close this section with that I am both an early adopter of technology and a rapid skeptic, that I'm kinda making this number up, but I've probably tried over 100 health apps, and I would say that I've used five more than three times.

And so I think there's a gap between what's promised with digital technology and what's useful for people. So that's really why I'm here and what's guiding for me in this.

Steven Labkoff: So let's take it to the next step. In our prequel, I didn't even know about your personal background to that degree. Mm-hmm. We can take that one offline later about the Holocaust survivor issues.

We, we have family, I have family in that same situation, frankly. Let's change gears and talk about the challenges that you've seen. You opened the door a little bit on that a few minutes ago- Yeah ... in terms of people wanting to collect data but not necessarily doing much with the data, not being able to understand the true value of the data to some degree.

And you said it yourself, people weren't connecting the dots.

Medical records have always been complicated. They've always been bulky. They've always been full of information, some of which is really relevant, a lot of which is not so relevant, and connecting the dots to making that a, uh, an important information source is not always an obvious task.

So what, what was the particular angle on that challenge that you were trying to gun at?

Health Hats: Well, I think we have to take a step back-

and think about what is-- Well, I'm just gonna speak for myself, okay? I know that I often, you know, as I said, I get asked to sit at the table because people can, you know, check boxes, like is that I'm a patient.

I wanna be clear that I'm a privileged white old man with MS living in Boston, but I'm an N of one, and I don't represent other patients. I'm representing myself here and my perspectives. My goal in terms of

my health is best health, and what I mean by best health is optimal health and function, physical, mental, spiritual.

Not a cure, but best health for where I am, what I have right now. And to get there, I need my own health data, not just what's in my clinician's chart, but what I know about myself, my circumstances, my environment, my history, my habits. Not just my medical history, my life history, my treatment responses. And so that's like patient-reported data, and that's stuff that's only exists because I observe it and sometimes I record it And that's where it falls apart right away.

You were just alluding to some of it, that there's all this medical data and what's useful about that. I think Dave DeBronkart was a guest on your show. And when he launched his Gimme My Damn Data campaign, I responded to him with, "Watch what you wish for. You'll be trying to drink dirty water from a fire hose."

And, and that was years ago, and it's still true. So six months ago, I, I'd been on a mission to gather my medical data, and my-- I'd been with my, uh, primary care practice since 2011, and I wanted all that data from 2011 to 2025. This was, like, in December I started on this crusade of trying to get my data.

And actually, two months later, I got a box, a four-pound box of paper, and it was paper that was not in chronological order. And it's just sitting right here. I've scanned it in. It's not, um- Was it in--

Steven Labkoff: Was it a printout of Epic or something, or was it actual-

Health Hats: It's a computer printout. It seems like it's a vendor that they use to-

Steven Labkoff: It wasn't digital. They sent you, literally sent you a box of paper.

Health Hats: Yeah, it was a box of paper. Oh. And then I use a lot the, the Beth Israel Lahey Mount Auburn system, and I asked for the last three months of my records, and I got 296 pages of redundant, non-searchable PDFs, and I got that in 15 minutes. Uh, I see a lot of doctors, so maybe I had seen Hmm.

I think I had maybe eight or nine visits, and it just happened to be a three-month period that was busy for me, but I got s- 296 pages. And so that really adds to your comment, which is that access to data and access to usable data are really different.

Steven Labkoff: Oh, absolutely. And yeah, I'll tell you, in my world, I think you know that I've worked in the life sciences for many, many years, and we are consumers of healthcare data on many levels.

We consume medical claims, we consume electronic medical records, and one of the hardest things about using medical records for research or for outcome studies and things like that is the very fact you're describing, which is the data tends to be sparse, it tends to be poorly organized. It doesn't always come in an encoded fashion.

Thank God most of what we get these days is at least digital. No boxes of paper for us these days, but it wasn't so long ago that when it was all paper, we couldn't get that data in the first place. It just wasn't even gettable. So at least you've made some progress. And- Yeah ... yeah, I know that you sit on some national level boards, uh, around outcomes, and you can talk about that in a moment.

But those are, you know, those boards are trying very hard to come up with outcome studies and ways of-- Let me back that up. They're coming up with ways of using data to perform outcome studies by harmonizing and, and distilling down to usable forms of this EHR data, which is so challenging.

Health Hats: I think what's key, I-- like I, I think I w- I'd like to focus on my data.

And so what I wanna do is I wanna see patterns. I wanna see patterns that takes my circumstances, my environment, my habits, my treatment over time, and because I think that these patterns are how I formulate the right questions, so the right questions before I go into a clinical encounter. They're how I track when something is actually working, and it helps me to coordinate across care teams that don't talk to each other and make decisions that I can live with that help me attain this goal of best health.

So that's the job, formulate better questions, g- seek better answers, make better decisions. And AI is the tool that I try to use to do it. Now, whether it's up to the task or not is different. I wanna stick in the nursing angle, if you don't mind-

You know, one of the things that I learned the way I got started in nursing is that my goal as a nurse was to put myself out of a job.

Steven Labkoff: So that sounds counterintuitive, but what I mean is from minute one with a patient and family, I'm planning my exit. Like, and to do that, I need maximum face time. I need real present, real conversation, real relationships, not less charting. I was gonna say not charting, not documentation, so that's just ridiculous.

Health Hats: But less, you know. The way you do that, I think, is, you know, less charting, less documentation, you know, not hunting through information you can't find. And that's where nursing, that's a genuine promise. So pattern recognition across specific cohorts of patients. So as a nurse, even though I worked a lot of different places, in each place I worked, there was commonalities.

In-- When I lived in West Virginia and I was an ER nurse in a super rural hospital, if I had had more information about my patients, their families, I could get-- an AI could help me surface those patterns that exist for the people that I'm taking care of, I think I could get time back as a nurse. And if the nurse gets time back, then the patient and family gets the presence of the clinician.

So that's the trade that I'm interested in I wanna go back to that thing about pain and fear. I wanna add what I've learned working on the blue button, plus I wanna add cognition.

So when you think about it, the data almost never captures the variability of pain, fear, and cognition, and those things are really important because pain changes what you can do and what you can decide.

Fear closes your heart. It closes your mind. And so when you're scared in a clinical encounter, you're not making good decisions. You're just saying yes to end it. And cognition is, you know, it varies. Like I can absorb better at 10 in the morning on a good day compared to 3:00 in the afternoon when I'm spent.

You know, you could extrapolate this to other people. They have their own particular patterns and circumstances. But I think What I'm trying to get at in all of this is it isn't first about the data, it's first about what about life and what about the things that are important to people, uh, patients, caregivers, and the clinicians that they partner with, and how can AI help them?

Steven Labkoff: So you've explained to me in the pre-call that you're doing some of this work, so maybe you can unpack a little bit about what it is you're actually doing with it and how it's helping or, in some cases, not helping those efforts.

Health Hats: Well, what have I done? I, I've done different things. One of the things that, that I've done is to try to build my toolkit. You know? So when I say build my toolkit, I'm a, I'm a, a conglomeration of symptoms. I mean, you know, I'm, I'm not MS, I'm not my symptoms, but they're big and they're there, and I feel like I'm trying to, I'm trying to figure out for anything that I have to deal with, whether it's any of the different kinds of pains I have, my, my anxiety, my bladder, you know, my mobility, I have challenges, and I, I need a toolbox.

I need a toolbox, and the way I think is I need at least three things that will work so that when they happen, I got something I can go do, and pretty much the most common thing is drink water. Drink water is by far the most successful intervention across all of my symptoms. It's kind of amazing. It's so cheap, so easy.

It isn't the drugs. Okay, but so how do I do that? Well, for me, I've done that partially just in my head. Partially I've done that by keeping lists. Like, I keep track of the steps I take. I keep track of the amount of time I play music. I keep track of my falls. I keep track of my weight. And so I use digital tools to do that when I can.

Steven Labkoff: I also record my clinician visits because- When you say record, do you mean like audio record or dig-

Health Hats: Yeah. Yeah, audio record, right. And, uh, until recently I used Abridge, which is a company that, um-

Steven Labkoff: How did you get to use Abridge? You-- I thought Abridge was only selling basically into doctor's offices, uh, from the clinician side.

Do you-

Health Hats: So I was before that. Ah. And they started as a patient-facing product, and actually they sponsored my podcast for three years. So I was pre that.

So putting all that together, so I play with, you know, trying to put into Claude There's nothing magic or special. You know, it's me playing, just trying stuff.

You know, some of it, you know, my wife will say, "Hey," she sees a pattern. My kids will see a pattern, or I'll-

Steven Labkoff: Give, give, give us an example of what, of what this looks like. I mean, you're saying you're giving Claude or another LLM- Yeah ... a series of symptoms, or you're giving it a series of, plus your data. Like, unpack it and let us know.

Yeah. What have you did- Okay, so what- ... with the system, and how is it working for you?

Health Hats: I've done a couple of different things. One is, you know, I have a spreadsheet, and I just put the spreadsheet in, you know, as a document or whatever you call it when you have a project and, you know, you load. I load my spreadsheet.

I keep a annual summary, and I keep the year that I'm working on. And I will have fits of journaling. You know, I, this is not something that I am, like, super consistent on, but I'll, especially when I'm struggling with something, if I'm struggling with my blood pressure or I'm struggling with my mood. I have a progressive mobility thing going on, and I'll put that in and I'll prompt.

I'll say, "Can you-- do you see a pattern in this?" You know, and I've gotten, you know,

that there's-

Steven Labkoff: Has it given you some insights? Is it... Like, give me an example of some of the insights it's actually given you that you didn't see yourself.

Health Hats: Well, I've gotten, like, uh, it's kind of humorous. But, but I've gotten, like, you know, "Have you thought about seeing a physical therapist?"

And I, I have. You know, I have a physical therapist, uh, that I don't go to very often. You know, my relationship with her is I go for a tune-up. But they'll-- I, I want-- It'll show, like, I'll do my sort of things are clearly, you know, I'm not walking as far, I've fell on a few times, you know, and I'll get this suggestion, you know.

I also-- What else have I done? Oh, oh, uh, once I had a medication

that I was taking for neuropathy, and I was-- my mood had, like, changed considerably and, you know, I got a thing on that might be a side effect. You know, "Have you talked to your doctor about this?"

Steven Labkoff: And I- And you got that out of the LLM? You fed that to the LLM?

Health Hats: I did. Yeah.

Steven Labkoff: And it suggested it was a side effect, which you didn't figure out.

Health Hats: I didn't. A neurologist said that he thought-- He said, "It sounds like you have an allergy to it." And, you know, he wanted it to be listed as an allergy because he thought it was very possible that he's had people that have had a problem.

Steven Labkoff: When you tell me that you've loaded your data, you give the LLM your signs, your symptoms, you give it your labs, you give it what's in, in the system, and it comes up with a recommendation that you hadn't thought-- Now, you're a clinician. You're a nurse. Yeah. You've been a nurse for many, many decades.

Health Hats: 50 years.

Steven Labkoff: 50 years. And does it surprise you that it comes up with stuff that you didn't see?

Health Hats: No.

Steven Labkoff: Cause I, to be honest with you- I- ... if I, if I did what you just said and it came up with something completely radical that I'd never thought of and it was right-

I would be scratching my head and thinking, "Okay, that's in- that's beyond interesting.

I better pay more attention to this, and maybe I wanna use it differently." Because not, it's not just yous using it. Like, people around everywhere are starting to use it for the same, in the same sim- in the same exact way. So that's the simplification of the medical system, right?

Health Hats: It does. I mean, like when I tell my neurologist, he laughs, and he's like a whatever works kinda guy, you know?

That he feels like he doesn't have all the answers, and that he likes- those stories. I feel like I've learned, I think you know Amy Price, right?

Steven Labkoff: Yeah, very well.

Health Hats: Yeah. We're buddies. And so one of the things that I've learned from her is how to query and how to be skeptical and how to ask questions from different angles, from different perspectives so that you-- And that's why I think that's where the unexpected comes up.

Steven Labkoff: Well, you're describing something that we did at the conference. I don't know if you were in the room in the working group that we did this on, but you're describing, and actually we're submitting a paper on it very shortly, on AI literacy. Yeah. And you, you didn't label it as such, but you're describing yourself as being AI literate and understanding how to use the tools, most importantly, how to be skeptical of the answers, how to interpret the information that's being presented to you.

Health Hats: A- and that, those are all components of literacy, of AI literacy specifically. One of the things I'm finding in my world is that painfully few people are indeed AI literate. Even the folks in IT departments in large life science companies or hospitals who even work in the space and think that they're good at it and are literate sometimes are not.

That has other implications, which are if people are taking on these really impressively powerful tools and they don't quite know how to use them as well as they should, and if they query them incorrectly, to your point earlier about making good queries, the responses that come out may or may not be the point.

And if patients use that information inappropriately because they didn't know how to ask the right questions to start with, that could have deep implications to the healthcare system.

You could say that same thing about doctors.

Steven Labkoff: I will say it about doctors. I

mean, not about AI, about the advice that doctors give.

Health Hats: There's a, a tremendous variation, and it is very different. When I am feeling good enough to be organized and to be directive in the conversation with a clinician, I get a very different output than when I'm not. And I still have to be skeptical of what doctors tell me, and until I build some trust. And, and then I, you know, then there's just too many decisions to make when you're a person with chronic illness.

It's like putting in a kitchen. There's so many decisions to make, and I'm happy for the doctors that I trust to make the decisions for me. But there are certain decisions I don't want to give to the doctor or to AI, like I don't wanna mess with my pathological optimism. I wanna progress as slowly as possible, and I wanna keep playing my horn.

These are really important things to me, and I don't give those decisions that affect that, I don't give up.

But all the rest of it I do, and, and I've worked really hard to build the team that I have that appreciates me and my strangeness and my assertiveness, and, you know, they're not threatened by it.

Steven Labkoff: Is your team AI literate? Do they also use the, these same tools in your care?

Health Hats: Uh, like I don't know. I mean, AI literate is like, is huge. You know? I mean, that's just such a big thing. Do they use AI? Yes. Do I know how they use AI? Well, you know, they use what's attached to Epic. I know that. Uh, I mean, look, my neurologist, who I just love, he thinks like he uses, he uses the portal well because he takes-- he just keeps adding things to the end of the, a note.

Yeah. And so he feels like... Well, I don't find his notes at all useful, and I tell him that. I tell him, "What I really wanna know is, how am I doing? Am I getting better? Am I getting worse? Am I stable? What should I be paying attention to in the next six months till I see you again?" And I can't find that in his note.

That's true. Yeah. Now, on the other hand, I've taken his note and asked Claude and say, "Here's the note. How am I doing? You know, have I progressed? H-how is he measuring it?" Oh, well, then I find he's using this scale, right? And it'll come up with looking through this note, which is like 10 years running, and it'll find, I can't remember the name of it, but there's a scale that he uses.

And then we go back and I'll say to him, "Oh, you're using this scale." And he goes, "Yeah." And I say, "Well, why don't you like put that at the top of your note?" You know, so that I can find it. You know, so we have that kind of conversation- Yeah ... that AI has helped.

Steven Labkoff: Well, that's actually an interesting perspective that AI is helping to reorganize things, 'cause one of the use cases that has been discussed at, at length actually, and it was discussed at our conference, is using AI to digest medical records.

Health Hats: And when I say digest, it's not about like ingesting them, which is slightly different, but digesting, which means find all the different pieces, put them together, come up with a narrative that summarizes perhaps 300 pages of information which may be sparse and may be poorly organized, and bring it all together.

And that's actually a task that AI is actually turning out to be pretty darn good at. And that again changes the nature of the healthcare system and the healthcare journey. You know-

And it does a fair job. You say it's really good at it. So- It's

better than I could do. It's better than I could do. Well,

yes.

Well, you're not-- First of all, that's not your training, and you don't have the time for it. And you still have to review it.

Yeah, of course.

Because I have never used AI that gave me a, "Oh, this is great." I mean, the first time I read it pretty much every time I think it's amazing. And then, you know, my rule is sleep on it and check it again.

And then it's like, oh my God, this, first of all, it either just said nothing very fancy or it got some very basic things wrong. And then I'll say, "Oh, you know, you missed this and you missed that." And it'll go, "Oh, you're right, I did." You know?

Steven Labkoff: Well, that also speaks to the concept of keeping a human in the loop- Yeah

which is something that you espouse and many folks in the healthcare aisle- I do ... espouse. Ironically, you know Adam Rodman, I think. He was at our conference, he spoke. Yeah. Uh, he's done a study which shows actually having a human in the loop in some cases actually makes the conclusions worse, believe it or not.

Ah.

Which is w- a non-intuitive finding. You would think that the two together would be better than either one alone, but so that's, that's now relatively n- well, it's not even that new anymore. That information came out about a year ago. So I, we gotta start wrapping up in a few minutes here. Yeah. You know, we didn't cover the concept around outcomes around your three T's and two C's.

Maybe we can cover that in the last bit here, and then we can get to closing.

Health Hats: Okay. So I feel like one of the questions that you've asked is how AI helped, right? And so what I need to tell you is the framework that I've developed over the years, which I've actually shared in my AI Claude project that's Danny's Health, what I call the three T's and the two C's, and this is like the framework I use to evaluate any digital health technology.

And so they are time, trust, talk, control, and connection. What I mean by that is time is, you know, you need time to learn, to plan, to talk, to build trust. So I say the clock isn't the enemy, it's the, the wrong things filling the time, so the, the time. The second is trust. You know, trust can take a really long time.

It can happen really quickly. Sometimes you never have it, and you know in your gut when you don't have it. And most digital health tools, AI, have a trust deficit, I think, not because they're untru- untrustworthy, which maybe they are, but it's really because the people who use them, use the tools, don't, don't trust them, and I think it's really important.

You c- you can't shortcut trust in the use of any tool. I think talk is really important. It's woven through all of it, real conversation. There is nothing like actual conversation that is making decisions together, which is a lot of what healthcare is about, is making decisions. AI can help you prepare for it, and it can help process it.

And then control. I trust more when I have power in a situation. So if I'm feeling like an ant ready to be crushed, I'm not making good decisions. And finally, I would say connection is, it's the human lifeline. You know, when somebody greets you when you cross a threshold, that's a connection. When someone's been where you're going and they can say, "Oh, that helped me."

AI can extend that connection. They can help people find communities that are available at 3:00 in the morning, but you can't manufacture it. I, I think that connection is really important, so that's where I g- you know, time, talk, trust, control, and connection, and I use that framework when I'm evaluating.

Steven Labkoff: And that framework gives you a better, you know, a how do I say this right? It gives you a, like a rubric, if you will, to go- Yes ... through, uh, the information that's coming out of it. Danny- Yeah ... we're gonna have to wrap up here in a second. Sure. Are there any last comments you wanna make that, that will, you know, help other patients in the, in the space in terms of how they might wanna think about adopting- an AI tool in their world?

Health Hats: I think that I would say use it, use AI, keep using it, experiment with it. That, that i- i- just like anything else, it takes time to learn. It takes time to be comfortable with it. Use it. I would say advocate for humans in the loop. I don't care what the study says. It's about humans.

We are human. Keep it humans in the loop. I would say find a buddy, you know. Do this with somebody else. Find a buddy- That's good advice ... and experiment. I would say, yeah, talk to your clinician about it. It's a good barometer of a physician. If they don't wanna talk or blow you off, that tells you something.

Absolutely right.

And I would say if you're comfortable with it, mentor. You know- That's a good idea ...

be the buddy. And for clinicians and for systems and developers, I would say you need to have patients, caregivers, and practicing partner clinicians in the design. They need to be there from the beginning.

And, you know, so i- it solves the problems people have, not the problems that the developers think are there or the venture capitalists thinks are gonna make money. You know, y- and if you have an opportunity, join, you know, participate.

Steven Labkoff: All good advice. Well, Danny, I wanna thank you very much for your participation in, in today's discussion.

Hopefully that there are other patients out there who listen to the podcast, they'll take something away. For the clinicians out there who are listening, you know, you've heard it straight out from a patient who happens to be a healthcare provider himself, and he's got very strong perspectives on how this can be used in a positive and productive way, and I think the framework that he's put together is very useful.

Danny, I wanna just say thank you for all the help that you've provided helping this podcast get off the ground. That's been really incredibly generous of you and your friends who have helped us a lot, and a lot of the things that have happened on our podcast, uh, for improvement's sake, have come directly from those conversations, so thank you for that.

I wanna thank you for being a guest and sharing your journey and sharing your experiences here. And for the rest of us, I'm gonna say thank you for joining us, and we will see you again next time on another episode of Practical AI in Healthcare. Thank you for listening. Thank you for joining us this week on Practical AI in Healthcare.

If you're ready to go beyond buzzwords and hype and explore how AI is truly transforming healthcare, stay tuned for more conversations that get us to what works. Until next time, stay practical

Reflection

When Steve interviewed me, he didn't know that everything I told him is the origin story of TrustMyOwn.Health. The box of paper. The 296 pages that were technically my data and practically useless. Twenty-five years of a pattern that sat in my chart the whole time, that it took a person, my PCP, a year to put together. Could AI have done it in an afternoon? I got tired of that being the normal experience instead of the exception. [Add: what specifically prompted starting TMOH, and when.]

TMOH starts from a premise I didn't have language for until I said it out loud to Steve: trust isn't a feature you bolt onto a health platform after the engineering is done. It's the whole structure, or the whole thing fails.

The three T's and two C's I use to size up any digital health tool turn out to be close to a design spec. Time, because a vault of your whole health history takes patience to build, not a single import. Trust, built into governance rather than promised in marketing; TMOH's Data Sovereignty Covenant binds the board and investors to the same terms as everyone else, which is the only version of trust I believe in. Talk, because the point was never to replace the conversation with my clinician, it was to walk in more prepared for it. Control, because I decide what goes in the vault and who sees it, the same way I decide which of my own decisions I hand to a doctor or an AI and which ones I keep for myself. Connection, which no vault can manufacture, but a good one can make room for.

I told Steve that AI found a pattern in my chart that twenty-five years of clinicians missed. That's not really a story about AI being smart. It's a story about who owned the data long enough to ask the question. That's the whole bet behind TMOH: put the owner at the center, and let the rest of the ecosystem, the networks, the vendors, the AI, earn its place around that.

See you around the block.