296 Pages of Data, Zero Bits of Information

07/22/2026

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Proem

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

I met 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 listening to. Usually, I jettison podcasts that do that. I stay with this one because I approach AI in healthcare the way I approach 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 grey that reflect deep understanding. In four of 44+ 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, where 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, more openly than most. So, when Steve later asked me to come on his show and talk about how I use AI, not the theory but the daily grind, I readily agreed, and they let me publish the audio unchanged. This newsletter follows my usual pattern of editing for readability and flow. You can find the verbatim transcript in the show notes.

I struggled to prepare for this conversation. I wanted to wear all my hats but had to narrow my scope 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 the least suffering available to me right now, given what I actually have. Here's the conversation.

The cape unfurls - superpowers

Steve Labkoff, host of Practical AI in Healthcare, asked me how I got my superpowers. As a teen, the Vietnam War draft frightened me. I felt adrift, with no purpose. When I was 16, I sought draft counseling at a church in Detroit. They invited me to become a counselor myself. I learned the craft of changing systems from within. Not a revolutionary, but a what's-the-next-step kind of person. Nursing came almost by accident. At 17, I had to choose between reading water meters and working as an aide at the Detroit Psychiatric Institute. The meter job paid more, but I had to cut my hair. I absolutely refused to

cut my hair, so I took the aide job. The nurses introduced me to the idea of nursing. Voila, nursing school!

After nursing school, my first jobs weren't in acute care. In 1976, I was the first male public health nurse in Western Massachusetts, providing home care and physical rehabilitation. I learned that most healthcare doesn't happen in the medical system. It happens outside it. Over the next two decades, I worked in the emergency department, the ICU, pediatrics, and behavioral health. I then shifted from studying individual health to studying organizational health: performance improvement, electronic health record (EHR, the digital version of a patient's chart) implementations, and a few stints in the C-suite (senior leadership).

Then, in 2009, I was diagnosed with multiple sclerosis and learned I'd had it for 25 years. Every time I'd had an MS episode, I'd undergone a cardiac workup instead. My father died of a heart attack at 45. The pattern had been in my records the whole time. Nobody had connected the dots.

Checked Boxes to Seat at the Table

I call myself Health Hats because I wear a lot of them: patient, caregiver, nurse, advocate, informaticist, podcast host. Wearing that many hats has earned me a seat at many tables: technical expert panels at the Centers for Medicare & Medicaid Services (CMS), the National Academy of Medicine (NAM), the Agency for Healthcare Research and Quality (AHRQ), the National Quality Forum (NQF), and the Patient-Centered Outcomes Research Institute (PCORI). Organizations could check many boxes by engaging me as a patient representative. A safe addition when they tried something new.

Although I learned a great deal, I was never there for a seat, but rather to open seats for people who weren't there yet. An early example was a seat in 2013 on the Office of the National Coordinator (ONC)'s Blue Button Plus initiative. It was a federal effort to standardize how patients could retrieve their health data from clinical systems. I was selected because of my many hats. I spent two years on that project, trying to add a caregiver field to the data set and to get anyone to care about data informing the variability of pain, fear, and cognition. Fear closes your heart. It closes your mind. When you're scared in a clinical encounter, you're not making good decisions. You're just saying yes to end it. And cognition varies. I can absorb better at 10 in the morning on a good day compared to 3:00 in the afternoon when I'm spent.

The caregiver field was added. The pain and fear never gained traction. Wearing my nurse exec hat, I found that my colleagues saw the caregiver field only as something to fill in, not to use. Perhaps if I had been able to add more patient representatives, I would have had more success.

I'm an N of One

I want to be clear that I'm a privileged white old man with MS living in Boston, but I'm an N of one and don't represent other patients, let alone other privileged old white men with MS. I'm representing myself and my perspectives. My health goal is best health, which I define as optimal physical, mental, and spiritual health and function. Not a cure, but best health for where I am and what I have right now. 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, and my habits. Not just my medical history, but my life history and my treatment responses. That's my patient-reported data. Stuff that only exists because I observe it, and sometimes I record it.

Hundreds of Pages, Zero Information

That gap between collecting data and using it followed me into my own care. Six months before this conversation, I decided to gather everything my doctors had on me from 2011 to 2025. Two months later, I got a box: a four-pound box of paper from my primary care practice's records vendor. Not in chronological order. Not digital. An actual box. Hundreds of pages to scan. The health system where many of my specialists practice provided a file of three months of records in fifteen minutes. Eight visits generated 296 pages of redundant, non-searchable PDFs. Fast and useless, which is a different problem than slow and useless, but still not usable. Another health system provided nothing.

Access to data and access to usable data are not the same thing. That's not a complaint about any one health system. It's the whole game. My goal isn't a cure. It's best health, the most function, and the least suffering available to me right now, given what I actually have. Getting there requires my own data: not just what's in a clinician's chart, but what I know about my circumstances, environment, habits, and life history. Most of that exists only because I observe it and occasionally write it down.

As a Nurse, My Job is to Put Myself Out of Business

Here's the nursing angle, which I don't get to use as often as I'd like anymore. My goal as a nurse was always to put myself out of a job. From minute one with a patient and family, I'm planning my exit. That takes maximum face time, real presence, real conversation, not more charting, not more hunting through information I can't find.

That's where I think artificial intelligence (AI) could earn its keep in nursing: pattern recognition across a cohort of patients. When I was an emergency nurse in rural West Virginia, if I'd had more readily available information about my patients and their families, AI could have helped me surface the patterns that already existed. I'd get time back as a nurse. If the nurse gets time back, the patient and family get the nurse's presence instead of her paperwork. That's the trade I'm actually interested in. Unfortunately, my experience with increasing a clinician's productivity results in fewer support staff, which leads to unaccounted-for tasks being added to nurses' work. Less time with patients.

Toolkits and 3 T's 2 Cs

For my own health, I've built toolkits. I have a constellation of symptoms. I'm not MS. I'm not my symptoms. My symptoms loom large. I have pain, anxiety, bladder issues, and mobility challenges. I need a toolbox. I keep spreadsheets, a journal (my podcast), and large language model prompts (LLMs like Claude or ChatGPT) that I feed my data into. I ask, "Do you see a pattern in this?" Sometimes what comes back is almost embarrassingly simple: "Have you thought about seeing a physical therapist?" when I clearly hadn't. Once, it flagged a mood change from a neuropathy medication as a possible side effect before I'd made the connection myself. My neurologist agreed and entered it in my record as an allergy.

My neurologist adds the new visit note at the bottom of a years-long note. I reverse-engineered his notes. I gave Claude ten years of my neurologist's notes and asked how I was actually doing, tracking my progress. Claude identified the specific rating scale he'd been using but never shared with me. I asked my neurologist to put the scale at the top of his note.

None of this makes me trust AI uncritically. My rule is to sleep on anything it gives me and check it again, because the first read is always impressive and the second usually reveals what is underwhelming,

wrong, or missed. That's part of why I argue for keeping a human in the loop, even though there's real research, including Adam Rodman[i]'s work, showing that human-in-the-loop review doesn't always improve the outcome. I don't care what studies say. Keep the humans in the loop anyway.

Over the years, I've built a framework for judging any digital health tool, the Three T's and Two C's (Time, Trust, Talk, Control, Connection). Time (you need it to learn and build trust), trust (it can't be a shortcut), talk (real conversation, which AI can help you prepare for but not replace), control (I decide what goes in and who sees it), and connection (the human lifeline no tool can manufacture, though a good one can make room for it).

Reflection

Looking back, a few threads keep surfacing. The four-pound box of paper and the 300 unsearchable PDFs are the same problem in two costumes: access to data and access to usable data are not the same thing, no matter how fast or slow the system hands it over. My whole career as a nurse was built on trying to hand myself a pink slip, more presence, less charting, and I still think that's where AI could actually earn its keep, if it doesn't just get absorbed into fewer support staff and more unaccounted-for tasks instead.

What I keep learning is that none of this is about the tool being smart. It's about who has the patience to ask the right question twice and who's willing to sit with an answer overnight before trusting it. My toolkit, the spreadsheet, and the ten years of notes I fed to Claude only work because I stay skeptical of it, the same way I stay skeptical of any clinician until I've built some trust. The Three T's and Two C's aren't really about AI at all. They're about how I decide who and what gets access to my attention and my trust, whether machine or human.

So, here's what I ask of you. If you're a patient: use AI, keep using it, but find a buddy to do it with and talk to your clinician about it. Their reaction alone tells you something. If you're comfortable with it, mentor someone who isn't. And if you're building these tools: get patients, caregivers, and practicing clinicians into the room from day one, not after the design is done and you're looking for validation.

See you around the block.

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[i] **"Large Language Model Influence on Diagnostic Reasoning: A Randomized Clinical Trial"** — Ethan Goh, Robert Gallo, Jason Hom, Eric Strong, Yingjie Weng, and colleagues including Adam Rodman, published in *JAMA Network Open*, October 28, 2024.