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Proem

When first diagnosed with Multiple Sclerosis, my neurologist told me he was expert in treating groups of people (populations) with MS, but he didn't know crap about me. His job was to learn about me, and my job was to learn about MS. I shared what was important to me in my life, and he taught me about MS and treatments. We slowly learned what worked for me in care and treatment and what didn't and re-examine year after year.

In last week's podcast episode, we chatted with Duane Reynolds from the [Just Health Collaborative](#). He guides health systems in creating cultures of belonging, enabling a **fair and just** opportunity for everyone to achieve optimal health. I wonder what worked and what didn't among the interventions his clients tried?

When I worked at Boston Children's Hospital, I was fascinated by their Cardiology Department's [Standardized Clinical Assessment And Management Plans \(SCAMPs\)](#) to promote, not require, care standardization. SCAMPs "offered a clinician-designed approach to promoting care standardization that accommodates patients' individual differences, respects providers' clinical acumen, and keeps pace with the rapid growth of medical knowledge." In lay terms, that was similar to my neurologist. People are different. Understand them, their preferences, stay up to date with research, make a treatment/care choice, and document what worked and what didn't. Re-examine. Continually learn.

These three stories, my doctor and me, equity in health systems, care of children with severe heart problems, all contain a problem desperately needing fixing, choices – some based as research, others not – some action taken or no action. How can we continually learn from experience, share that cumulative experience to inform future choice-making and action?

Underwhelming response to brilliance 03:41

I have introduced this idea of continuously studying the impact of choices made by systems, clinicians, and individuals in many flavors and contexts for more than 20 years. Continuously studying the impact of choices made seems like such a no-brainer to me—the most basic of basic. In self-absorbed moments, I even think it's brilliant. However, the responses have been underwhelming, ranging from 'of course, great idea,' to a pat on the head, to nothing. Anecdotally, I've found that people who identify as a patient or caregiver almost always think it's a great idea. My friend [Melissa Reynolds in New Zealand](#), a



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Maypole for people with Fibromyalgia and Chronic Fatigue, teaches continual systematic learning of what works and what doesn't for pain management and everyday parent functioning for individuals and then shares that out to her virtual communities. And round and round it goes. Many, but not most clinicians, say yes, "that's how you can manage cook-book medicine." Researchers and measure developers mostly have no response. It flies right by. Why? Is it the packaging, the audience, the methodology, inertia? Clearly, I'm missing something. What?

Pitches, no home runs 05:26

I've tried various pitches. Here's one: Sometimes I can look to science to say that if I take this medicine, have that procedure, change these habits, take those vaccines, I'm likely to feel better, function easier, prevent something bad, accomplish a goal in my life. But it might not. The studies tell me about populations, groups of people, not me specifically. I'm an individual with specific goals in life with a family, religious, ethnic, regional history. I make medical and health choices or don't (a choice in itself). I want to know how my choices impact my outlook, health, function, and well-being? Was it as expected by the science or not? Wouldn't rolling up that individual information inform us differently and continuously about value and where we should spend our tens or trillions of healthcare dollars and hours?

Here's a different pitch: Many of us care deeply about health equity. Health equity is a puzzle of systemic, hyper-local, and individual issues and circumstances. How can we study the impact of interventions we experiment with to reduce inequities on individuals rolled up into communities, delivery systems, and regions? How can we answer the questions: Do systemic interventions really affect individual choices and circumstances? Could we shine a different light on value to society and people by continuously studying the impact of choices made?

Yet another pitch I've tried. Patients, caregivers, and their clinician partners make medical and treatment decisions every day. Some choose A, others choose B, C, D, E, F, and others don't choose (itself a choice). Then what happens? What was the outcome? How did they fare? Did they get better? Did their function improve? Did their outlook lighten? Who made which decision, in what circumstances, conditions, and physical environment, living with which systems? What questions could we ask of a data set that included the choices we made?

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Invoke curiosity without commitment 8:47

I asked my friend and podcast guest, [Amy Price](#), a researcher from Sanford and an editor of the British Medical Journal, about this.



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**Health Hats:** I have two questions for you. One is, am I onto something? And number two is what's step one.

**Amy Price:** Okay. I think you're onto something, and I think it is a huge unspoken need. All right. I understand why you're not getting traction. And I think the first step is to invoke curiosity without commitment.

**Health Hats:** Yes. I totally resonate with that. Yes.

**Amy Price:** Okay. So that, to me, that will be step one.

**Health Hats:** Okay. All right. And to me, the way I do that is to tell stories. And then see who thinks that's a good story and then join with them to figure out what's step two.

**Amy Price:** Because if they have an investment in the steps, then they will go farther.

**Health Hats:** Brilliant.

**Amy Price:** And then by having an investment in the steps, they have an investment in you. I find it's helpful if I say I'm going somewhere. I'll explain where that somewhere is. And then I say to people that are a little bit interested, do you want to come with me? Yeah. And then if I say, do you want to come with me, how much do they want to build? How much are they capable of building? And if they're just coming with me, that leaves them the dignity, just to watch and support from the background. But if they have ideas, it leaves them, leaves doors open for them to bring innovations. I never really thought of that. It is the whole co-production. This is a prime question for co-production.

#### Reflection 11:00

Invoke curiosity without commitment. Certainly doable, small, repeatable, iterative. What else can I learn? I'm scheduled to speak with [Matthew Hudson](#) about embedded researchers this week, and Talya Miron-Shatz, an Israeli researcher and author of *Your Life Depends on It. What you can do to make better choices about your health* in December. I will take the opportunity to speak to them about this idea. Perhaps I can corral my friend, previous guest, and informaticist, [Laura Marcial](#), to muse with me as well. Stay tuned. Share your thoughts. Keep the faith.

