Notes from the Village

Building the trust network around your health data, one update at a time.

TrustMyOwn.Health 015: The Other 99%

I presented to a group of nurse executives and informatics leads last week. One thread kept coming back: health data is more than medical data. A vault earns its keep less by storing clinical records and more by holding everyday health data, the stuff of daily life.

The nurses got there before I did. One of them said nurses' notes might be the real story, and it showed up in my dreams that night. Think about what a good nurse writes down: he didn't touch his breakfast, she seemed confused after her nap, his daughter says he hasn't been sleeping. That's everyday health data, noticed by the one professional who's in the room long enough to see it. It's also the part of the record patients and doctors rarely read, and it's shrinking as charting moves to checkboxes and AI. Research suggests patterns in nursing notes can flag a patient in trouble before the vital signs do. Imagine that kind of noticing across a whole life. Most of it happens at home, by us and the people who love us, and right now it goes nowhere.

Here's the math that niggles at me. Researchers estimate that gaps in medical care account for about 10% of early deaths.[i] The rest traces back to how we live, where we live, our genes, and who's around us. Then there's time. People with chronic illness spend a few hours a year with a clinician, out of about 5,000 waking hours.[ii] The rest of the time we're on our own, doing the work of being healthy or sick. I call it the 99% Problem.

Perhaps a bit dramatic, yet clinical care matters enormously when you need it, and I've needed it. But clinical care already has records, systems, and people paid to keep track. The 99% has us.

Most health tools start from the clinic's point of view: gather the records, connect the care team, aim for a cure or tight control. For someone living with a condition, or still searching for a name for it, the goal is different. Best health for where you are, with what you have, right now. Not perfect, not cured. The best I can do.

What Patients Said

To get there, I need my own health data. All of it: what's in my chart and what I know about myself. My circumstances, environment, habits, and how I respond to treatment. Some of that only exists because I noticed it and wrote it down.

With clean, organized data, I want to see patterns over time. Patterns help me walk into an appointment with the right question, tell whether something is working, keep a scattered care team on the same page, and make decisions I can live with.

That's what we're building the vault to do.

What do you know about your own health that's never made it into a chart? Write back and tell me.

Onward, Danny Health Hats

Written by me with brevity, clarity, flow editing, and reference checks by Claude

[i] McGinnis JM, Williams-Russo P, Knickman JR. The Case for More Active Policy Attention to Health Promotion. *Health Affairs*, 2002. https://www.healthaffairs.org/doi/10.1377/hlthaff.21.2.78

[ii] Asch DA, Muller RW, Volpp KG. Automated Hovering in Health Care: Watching Over the 5000 Hours. *NEJM*, 2012. https://www.nejm.org/doi/full/10.1056/NEJMp1203869