Notes from the Village

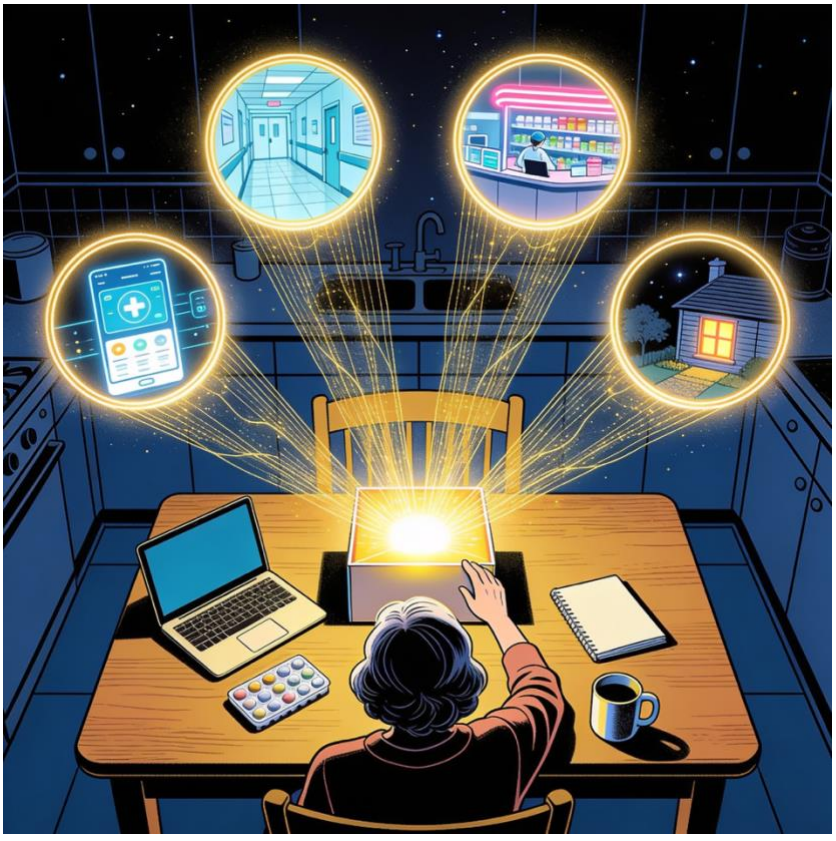
Building the trust network around your health data, one update at a time.

TMOH Newsletter 18: Space Between Portals

I attended PCORI's Annual Meeting last week. I stopped at tables to greet people. When asked, "What are you up to?" I naturally shared TMOH. People perked up at a few things: owning your own data, tracing any number in your summary back to its source, adding data from apps you trust, and working with researchers as a partner rather than a subject.

After a caregiving session, as I rolled by, I overheard frustration: difficulty using health data apps and portals, with little or no help when needed. Heads nodded. I stopped. "What do you want to use the data to accomplish?" Coordinate care for my father-in-law three states away. Track medication changes. Track symptoms and interventions. Understand the plan and the bill.

Those caregivers didn't ask for a better portal. They asked to coordinate care from miles away, track medication changes, connect symptoms to what was tried, and make sense of the plan and the bill. None of that lives in any single portal. It lives in the space between them, in the kitchen-table work that starts after the appointment ends. That's the space we're building PHDB for: a vault you own that pulls the pieces together, lets you bring in the people you trust (a sibling two states away, a parent's aide), and lets you decide exactly what each of them can see.



If you care for someone: what would you want your vault to help you do first?

Let me know whether "Data Sovereignty Covenant" makes sense to you; I'll share what I hear next week.

Onward, Danny Health Hats