Notes from the Village

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

TrustMyOwn.Health 013: Nobody's Data Is Complete

Last week, a Villager asked me a question I've been mulling over. What happens when a vault owner leaves something out? For example, a lab value that keeps coming back wrong, a diagnosis that turned out to be false, or something private about behavioral health you'd rather not repeat at every visit. Does the doctor on the other end have a right to know something's missing? Is there liability in that? Could a clinician even refuse a record because it isn't complete?

While writing draft after draft of this newsletter, I had an unexpected realization: no health record has ever been complete. Not mine, not yours, not the one your doctor is looking at right now.

My own EHR doesn't include my Health Hats podcast, the three specialists I saw before switching insurance, or the times I decided not to take something and didn't mention it. My doctor doesn't have all of it either. She sees only what the systems that talk to hers send her. Even within a single hospital, one department often can't see what another recorded. Completeness was never the standard. It just felt that way because nobody said otherwise.

So, when a vault owner chooses what leaves their vault, they're not making the record incomplete. It already was. What they're doing is deciding, on purpose, what a chosen recipient sees and when. That's exactly what the Data Sovereignty Covenant protects: you decide who sees what.

What matters more, I think, is what happens to the choice itself. Every piece of data in your vault carries a label (metadata): where it came from, when, and whether anything's been flagged or disputed. If I tell the vault, "I'm not taking this one med," that note travels with the record. A doctor reading it later doesn't just see the prescription. She sees that I flagged it and when. She's not being told the record is complete. She's being told exactly what's here, what isn't, and who decided.

Marianne, who practices internal medicine, put it plainly: the ER runs on incomplete information constantly — patients in distress, decisions made fast.

If a specialist needs a test I left out, they'll likely re-run it. That's a real cost. But it beats a record that lies to you by pretending it's whole.

Onward,
Danny Health Hats