Notes from the Village, Issue 16

TrustMyOwn.Health 016: A talk, with the footnotes turned on

Tenants No More

Hello, Village.

Soon I'll give a two-minute talk on who owns health data at the Camden Coalition's 2026 Putting Care at the Center conference. I've spent much of my career on this subject. Two minutes. Every sentence fights for space.

The talk opens in an apartment you've lived in for fifteen years. You painted the kitchen. You finally got the radiator fixed. Then a notice appears on the door: the building sold. Your key still works, for now. But the place where you built your life was never yours.

A good metaphor for our health data?

The room will be full of clinicians, care managers, and advocates who've spent decades at kitchen tables with patients and families. I'm asking them to carry that advocacy into the server room. You're not that room. You're the village, and you've been watching us build. So, here's the talk with the footnotes turned on, one image at a time.

"The building sold"

You're a tenant in someone else's building.

This is why the Data Sovereignty Covenant forms the foundation of TrustMyOwn.Health. Some decisions are outside the company's authority from the start. They were never ours to make. In plain terms:

- Your data is never sold unless you say yes.
- Every disclosure gets its own yes. One signature doesn't open every door.
- Privacy protections can't be weakened later.
- You can pack up and leave with everything, including what the vault figured out from your data.

Is "can't be weakened later" a guarantee? I'd love to say yes. The truer answer: it's a commitment built into the structure, not house rules a new landlord can take down. A commitment is only as strong as the people holding you to it. That's partly your job now.

"Log into eight portals"

The 21st Century Cures Act gave us the right to see our records, a real win. In practice, that means portal after portal, each with a slice of you. Your vault is where the slices come together: portal records, wearable data, your own notes. One key. Yours.

“The rooms the blueprints leave out”

This is the line I care about most. Handing someone the deed isn’t enough when the blueprints omit the rooms they actually live in. Those rooms hold the symptom diary. The pattern you noticed in March, or the one your care partner identified about your mornings. Officially, none of it exists.

Clinical care shapes about a tenth of our health. The rest happens in the 99% of life outside the clinic, and the official record leaves it out. In the vault, your health journal sits right alongside your clinical record. It’s a room in the house, with the lights on.

“A story no provider can trust”

That line stings because it’s fair. When I hand my new hematologist a tidy summary, why should she believe it? Well, maybe she shouldn’t unless she can see where it came from. That’s her doing her job, not doubting me.

We’re designing the vault, so every fact carries its source. This came from the hospital portal. This came from my journal. This is a summary the vault made, and here’s what it drew on. Trust you can check is the only kind that travels.

When I say vaults like this already exist in prototype, I’ll be thinking of you because your participation helps build it. Alpha is coming soon, and we’re testing rigorously.

Do these metaphors work?

1. Does the tenant-and-landlord picture resonate with you? Or does something trip you up? Maybe “landlord” feels unfair to the clinicians and health systems you trust. Maybe “owning the whole house” sounds like a lot of upkeep you never asked for.
2. What’s in your missing room? What do you know about your own health, or someone you care for, that no portal has ever captured?

Hit reply. I read every one.

The complex care field has spent decades at the kitchen table. Our landlords have had the keys long enough.

Onward,
Danny Health Hats