Notes from the Village

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

Subject: TrustMyOwn.Health 020 I Fell Flat

I fell flat

On a call this week, I tried to explain participatory governance. I stumbled, lost the thread, and hung up, disappointed in myself.

I talk easily about participatory research (people with lived experience at every stage of a study), governance (who decides and who answers for the results), and shared decision-making (who chooses the treatment plan). So why couldn't I put the three together? Maybe I care too much to say it neatly. Here's my second try, written down.

How we're organized

At TrustMyOwn.Health, our Board of Directors sets the direction. Alongside it, DEQOB, our Data Ethics and Quality Oversight Board, oversees the Data Sovereignty Covenant, the promises that put you in charge of your data.

1. Your data is never sold without your authorization.
2. Every disclosure needs your permission, one at a time.
3. Your privacy protections can never be weakened.
4. You can take everything with you, including anything derived from your data.

For the alpha, we envision four teams: a Technical Committee building the app, an Advisory Panel helping each participant define success, a User Team working with participants day to day, and Finance and Marketing tracking the true cost of support. Participants shape those teams through their goals and daily experience. We also plan to give our trusted network partners seats on DEQOB. No team or investor gets to decide alone what happens to someone else's health data.

Advice is not authority

Reading that back, I caught myself. I'd love to tell you that TMOH is fully participatory. It isn't, not entirely.

In a Health Hats episode last spring, I told three stories from my years in health care leadership. In each, people inside the system changed the outcome. Only in one did they hold real power: a resident on the board. Advisors can shape a decision. They can't stop one. So here's where we are.

Where you advise. A lot. You helped us think through funding the alpha in Issue 11, and alpha participants will show us what works. We'll listen and make changes, but the final call rests with the TMOH Board.

Where nobody decides but you. The four commitments above. We took those decisions off the table for ourselves, once and for all.

Where we're still figuring it out. Everything in between. Our mission model means the mission determines what the company may do, not the other way around. What that looks like as we grow isn't settled, and I won't pretend it is.

Your turn

When have you had a real say in a decision, one where you could see how it was made and trust that your voice would count?

At work, at your kid's school, in your congregation, on an advisory council, or in your own care? What made it feel real? If you can't think of a time, tell me that too. Hit reply.

Best health for where you are, with what you have, right now.

Onward, Danny Health Hats