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# I Designed a Blockchain EMR to Protect Patient Data. Then I Open-Sourced It.

Some Ideas Are Too Human to Be Owned. Open-Sourcing Frankly EMR, a Blockchain Electronic Medical Record (EMR) for Patient Data Ownership



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A 75-year-old patient, newly diagnosed with cancer, sits in front of a glowing screen.

The treatment might extend their life. It might also take away their independence. They decide to seek a second opinion. They open their medical portal.

Two futures appear:

## Option A

*Their full medical history is visible. Labs, scans, and clinical notes are all easy to download, review, and share. The data belongs to them.*

## Option B

*They run into a paywall.*

*Basic view access costs \$9.99/month. For \$14.99 /month they can unlock “Premium Access,” which lets them request their own medical images. Each image costs \$29.99.*

*The system doesn’t just sell the data; it charges for the privilege of asking.*



Image generated using AI (ChatGPT + DALL-E by OpenAI). Concept and prompt design by Frankie Aguinot.

Which version feels more likely today? Which one treats the patient with dignity?

This isn't a preview of the future. It's already here, simply hidden under soft colors and smooth UI. We agree to terms we never read. We give away consent without realizing what we've traded. We're told the system is working, but it forgets who it was built to serve.

The real challenge of the advancement of medicine hasn't been solving the science. It's been protecting the people it was meant to help.

## The HeLa Moment

It started with extra credit.

I was in my pre-med program at Creighton University in Omaha, Nebraska. Fresh out of the Navy and still wired to optimize, I showed up for a campus event because it offered a grade bump. I hadn't read the book. I knew exactly zero about the story. The speaker was Rebecca Skloot, on her tour for *The Immortal Life of Henrietta Lacks*. That night changed something.

She didn't describe cells. She told the story of Henrietta Lacks, a Black woman whose cancerous cervical cells were taken without her knowledge during treatment at Johns Hopkins in 1951. What began as a medical procedure became the backbone of thousands of patents, generating billions in profit. But they were taken without her knowledge.

What struck me most was that her treatment wasn't negligent. It was considered, in Skloot's words, "*sort of top of the line.*" ([Fresh Air, February 2, 2010](#))

*There was no villain. Just a doctor trying to cure cancer. Just scientific efficiency that stripped her name from the label and replaced it with HeLa. Just commercial indifference that made blockbuster drugs possible but left her descendants with no medical insurance.*

I walked in a privateer for extra credit, officially sanctioned but with morally grey motives. I walked out a future physician avowed to be vigilant against the disenfranchisement of patients.

Because science isn't the enemy but it sure can lose sight of the human in the excitement of discovery.

**That was the night medical data sovereignty stopped feeling theoretical.**

## **Before Medicine, There Was Accountability**

Before I became a physician, I was trained as a nuclear operator in the U.S. Navy.

In that world, "good enough" doesn't exist. Every component is traced. Every action is logged. Two bolts might look identical, but one is certified down to the exact section of the mine it came from. Not just the mine. Not just the date. The specific geological cut. That level of accountability becomes instinct.

“You don’t trust what you can’t trace.”

You stop designing for what should happen. You design for what can be proven. So when I built my EMR, I didn’t start with software. I started with the full-cycle chain of custody. The system tracks the origin of raw materials, then logs every step: manufacturing, shipping, prescribing, dispensing, dosing, and metabolism.

*Yes — all the way to your pee in a cup.*

That’s not a metaphor. That’s the endpoint. If a pill goes in, the system expects to see it come out. From mine section to urinalysis. Logged. Confirmed. Closed loop. Because that’s what nuclear safety teaches you: You don’t trust what you can’t trace.

That was the perspective I brought to healthcare, and it shaped everything I built.

## The Birth of Frankly EMR

I designed an EMR system architecture and named it **Frankly EMR**.

Not just as a nod to my name (and my dad’s, and my son’s) but because it reflected the straightforward purpose of the system: **give patients control without confusion, and give doctors back time for patient care.**

It was also a quiet counter to the most widely used electronic medical record systems: Epic.

If Epic sounded mythic, Frankly EMR was plainspoken. Like HAL in *2001: A Space Odyssey* was a wink to IBM, **Frankly EMR was a nod to tangled menus.**

The first goal was simple: Give control back to the patient.

But that required a system that could track everything. Every time someone opened a chart, issued a prescription, reviewed an image, or shared a file, it left a record. Each interaction generated an immutable cryptographic hash — **a permanent fingerprint that powers blockchain-based data security systems.** A proof of who did what, when, and why.

**“In Frankly EMR, ethics was no mere design principle but the structural scaffolding.”**

This wasn't about assuming people were untrustworthy. It was about building a system where compliance did not depend on memory, intention, or the number of hours of sleep. **Consent was not a checkbox. It was a smart contract.** Patients could limit, expand, or revoke access at any time, and every change was recorded. This wasn't a facelift on an old system. It was a full rewrite.

It *had* to be built on blockchain.

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Not to sound trendy, but to make records permanent. Once something was recorded, it stayed recorded. No silent edits. No lost trails. No version history buried ten clicks deep. No one could quietly edit away a mistake. No one could delete their way out of a breach.

What stayed with me from the peak of the Non-Fungible Token (NFT) era, when people paid up to millions of dollars for blockchain-verified digital art, wasn't the hype. It was the idea of provenance. *People were trading cartoon monkeys with better traceability than a cancer patient's biopsy.* That wasn't just absurd. **It was infuriating.**



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Frankly EMR enforced that same traceability but for people, not speculation.

Every access was logged. Every role had boundaries. Researchers couldn't quietly scrape data. Government agencies couldn't assume blanket access. Even AI interfaces were limited to what the clinician was allowed to see. No amount of righteous fervor, scientific efficiency, or commercial indifference could override the patient's right to consent. **In Frankly EMR, ethics was no mere design principle but the structural scaffolding.**

The second goal was just as urgent: Doctors needed something that respected their time.

Most EMRs are designed around billing and compliance. Frankly EMR was designed around care. As a physician-designer, I know the best intervention is the one the person will actually use. So instead of more features, I focused on less friction.

The answer was to use AI as the interface.

Frankly EMR would surface what the physician needed before they asked. Frankly EMR pulled the right labs. Frankly EMR presented the pertinent fields. Frankly EMR flagged dosing issues. Frankly EMR highlighted the next clinical step. Frankly EMR told you where to go like you were screen sharing

and reminded you that it was the patient's birthday next week. All for the low, low training price of "Click This Link".

It worked with the doctor, not against them.

**Frankly EMR wasn't built for investors or engagement metrics. It was built for the people who carry the risk when systems fail.**

## The Missed Chance

Following a year of building and a clear signal that the reciprocal pre-seed was never coming, I walked away with my IP.

The pharmaceutical stayed proprietary. The system stayed mine. Frankly EMR remained my original architecture, conceived, designed, and documented entirely before I ever released it.

It didn't get built at scale, but what stays with me isn't the pitch that failed. It's the knowledge that someone else could take my personal oath to do no harm turned digital and build something similar.

Then use it to take more than it gives.

Because the same decentralized technology tools that can return power to patients can also be used to lock them out entirely. Blockchain can empower consent. It can let patients decide who sees their data and for how long. But without safeguards, it can also create vaults no one can open, hidden

contracts no one remembers signing, and access controls that never point back to the person the data came from.

It's no longer about stolen cells from a cervical sample.

It's about full genomes.

Entire medical histories.

Turned into assets.

Bought, sold, and withheld.

*All without the patient's knowledge.*

Frankly (pun fully intended), I did not want to stand on the same vista as Alfred Nobel — along with the countless founders whose tools were later turned to harm — looking over the damage our inventions caused. I built with rigor because I wanted to be accountable, not opportunistic.

**Now Frankly EMR lives in a [GitHub repository](#), open-sourced under a Creative Commons Attribution-NonCommercial 4.0 license. Not as a product. As a warning.**

And the 75-year-old patient who just received a cancer diagnosis? They're still sitting in front of that glowing screen. Their two futures will be shaped by those who create technology.

They still deserve better.

## From Frankly EMR to Promptwell

Promptwell didn't come years later. It started three days after my missed chance. Still grappling with the themes of **trust and technology**, I found myself back with that same patient.

A 75-year-old patient, newly diagnosed with cancer. The treatment might extend their life. It might also take away their independence.

This time, I imagined one more line at the bottom of their chart:

Diagnosis assisted by AI.

**Would they trust it? Or scoff?** I kept coming back to the same answer: it depends on their familiarity with AI. Not the model, not the math. Just whether they understood what it was and how it worked.

**Promptwell started there.**

I wasn't trying to chase the future anymore. I was trying to build something that could help patients and clinicians in the present now. At first, it was just a blank chat window. A quiet space to think. But slowly, it became a way to teach digital intuition. To show people how to interact with technology without fear or helplessness.

## Where Frankly EMR was built to protect data, Promptwell would be built to protect understanding through AI literacy.

Not to replace care. Not to automate empathy. But to build trust before the moment it's needed. Because when you can't build the system, you teach people how to question it. You teach them how to read the line that says "*Diagnosis assisted by AI*" and know what it means.

The mission hasn't changed. The timeline has.

*Author's Note: This essay is part of the public record of the Frankly EMR project. All concepts, architecture descriptions, and design philosophy herein are original to the author and were first released publicly through this publication.*

*Update — November 23, 2025*

This article was updated to clarify the licensing terms for the Frankly EMR project. The intent of the work has not changed: Frankly EMR remains open-source under the Creative Commons Attribution–NonCommercial 4.0 International license. This clarification simply makes explicit that **any commercial use — including sale, licensing, or monetization of the Frankly EMR system — requires the author's written permission**. Transparency and patient protection remain the guiding principles of this project.

This update was made by the original author via the Medium account used for the first publication.

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## Written by **Frankie Aguinot, MD**

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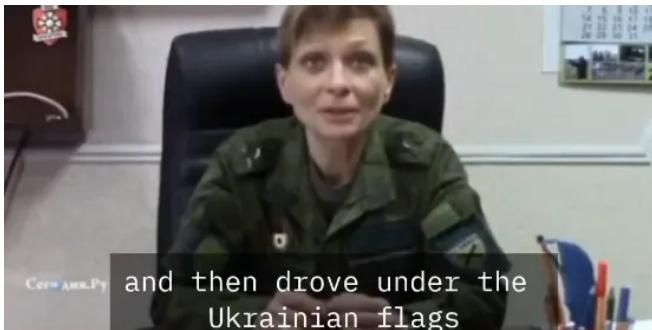


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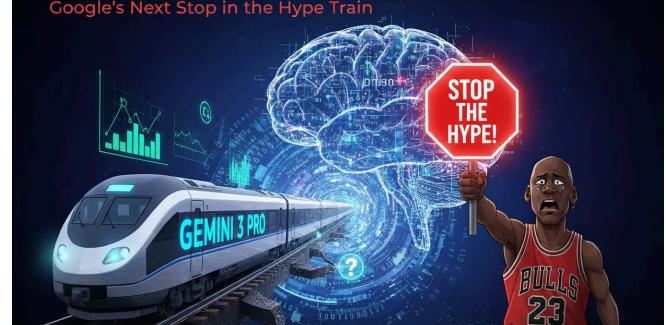
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