# **Vana Academy – Week 4 Submission**

**Due Date**: July 4th, 2025 – 11:59 PM

### **1. Project Title**

HealthDataSov – Establishing “The Patient” as Owner & Proprietor of their EMR Data

### **2. One-Liner Description**

HealthDataSov will establish “The Patient” as a legitimate financial stakeholder within the booming medical record information ecosystem by establishing patient-consented access to medical information in a context not currently available to the Artificial Intelligence data models of the healthcare industry corporations.

### **3. Team Information**

* **Team Lead**: [Josh Fanning](https://www.linkedin.com/in/joshfanning/) – Venture direction and ethos; resource acquisition (technology and personnel); partner, investor and customer outreach; project management; business administration.
* **Business Advisor:** [Scott Filiault](https://www.linkedin.com/in/scott-filiault-5311361/) – Advisor in all things business and business development; personnel resource acquisition; partner, investor & customer outreach.
* **EMR Information S.M.E. and Advisor** : [Carrie Denny](https://www.linkedin.com/in/carriedenny/) – Subject Matter Expert (beyond my advanced knowledge) lead responsible for producing concepts, specifications and requirements on EMR data most valuable to the DAO. Also contact generator for the EMR Data Technical lead.
* **Blockchain Technical Lead**: [Shin Jiro](https://shinjirohara.vercel.app/home/) - Development of all blockchain technology-side prototype software.
* **EMR Data Technical Lead**: TBD – Development of all EMR data software development prototype software.

**Team Notes:**I worked alongside Scott Filiault and Carrie Denny from 2015 through 2019 as key employees at Pulse8 (acquired by Allscripts/Veradigm in 2019). Together, and with a band of talented, hardworking group of 15 other core employees, we helped to make Pulse8 a leading Medicare Advantage data analytics warehousing and software venture. Pulse8 achieved success by embracing a strong “all-for-one / one-for-all” ethos in the pursuit of a Big Hairy Audacious Goal (the BHAG) as outlined Verne Harnish’s book, ‘Mastering the Rockefeller Habits’.

Shin Jiro, the blockchain tech lead is on a short trial retainer and was recruited within the Vana Discord server.

I had approached another blockchain developer I have come to know through my crypto hobbyist circle. His X handle is Proteus (<https://x.com/proteanx_>). I know Proteus as the co-founder and chief developer of Ord-X (<https://www.ord-x.com/>) a Bitcoin Ordinals collectible platform. Proteus immediately “got it” when I presented him with the HealthDatSov concept and had legitimate excitement for the project, however, his current workload was too great to commit to any substantial work hours in the near term.

With regard to the unfilled ‘EMR Data Technical Lead’ post, I had considered approaching several of my contacts and received a lead from Carrie Denny, however, I decided to keep the role unfilled and to not act too quickly on filling this post – it’s a critical role for the successful lift-off of the project and therefore cannot be a rushed decision. Among the combined contacts of Scott, Carrie and myself I am confident a “rockstar” healthcare data dev can be brought onboard if the project moves forward.

**Project Artifact Links**

[HealthDataSov Google Drive](https://drive.google.com/drive/u/0/folders/0AB50OrSFpSglUk9PVA): Repo of PDF MS Office artifacts acquired or developed for this submission, as itemized below:

* Vana EMR Data DAO High Level Schematic.pdf*- The schematic first shown to Anna K. at M.I.T.*
* HealthDataSov Vana Data DAO One Page DRAFT v4.docx
* PubMed WP A Patient Controlled EHI.PDF – *Public domain outline of how to build patient-access-to EMR file software.*
* CMS Health Technology RFI May 2025.PDF *– Trump administration Request for Information on all things EMR / Healthcare data initiatives – Trump himself is very much in favor removing regulations around data access for patients.*

### **4. Problem Statement, Solution & Pain Points**

The Solution

One of the major milestones of the 21st Century Cures Act (2016) has come to fruition: EMR file download access for The Patient has been a reality since December 2023! Disconcertingly, however, there has yet to be mainstream application development enabling the individual to become “owner and proprietor” of their digital medical record files. With the skyrocketing demand for Artificial Intelligence (AI) model training data, the resultant opportunity costs of this missing technology are now too great to ignore.

The Solution

HealthDataSov will fill the void by establishing an EMR API engagement software process (and eventual technology platform) enabling individuals to securely take digital ownership of their medical files. Moreover, HealthDataSov will empower “The Patient” to safely exchange de-identified data and information extracts from their EMR file vault for direct financial disbursements via cryptocurrency payment rails connected to the Vana blockchain enterprise.

Pain Points and Roadblocks

The implementation of the HealthDataSov concept will necessitate considerable resources for operational security as EMR data contains both Personal Identity Information (PII) and Personal Health Information (PHI) both of which are highly regulated and protected by federal and state law. As a result, there is considerable liability attached to any enterprise seeking to integrate PII / PHI data into their business workflow – this will require sizable financial investment into legally-arranged indemnity insurance.

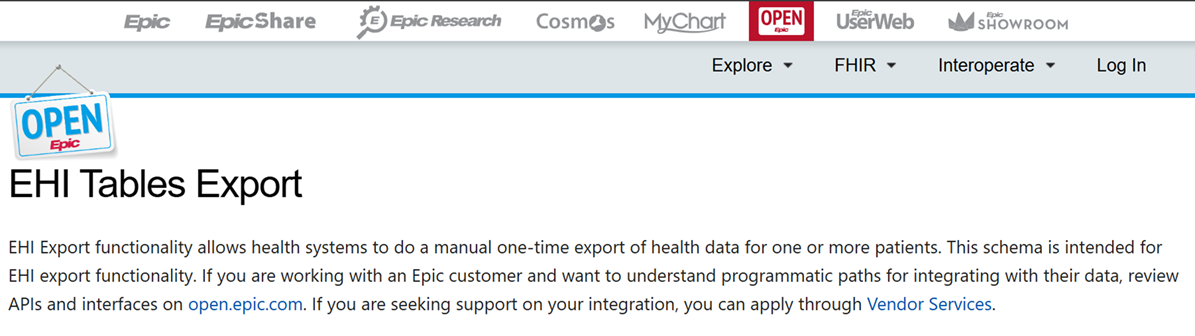
### **5. Dataset Description**

Electronic Medical Record (EMR) data comprises a comprehensive, digital collection of a patient's health information within a single healthcare practice. This data is fundamentally categorized into two main types: structured and unstructured.

* Structured data consists of standardized, easily searchable information such as patient demographics (name, date of birth, address), vital signs (blood pressure, heart rate, temperature), laboratory results, medication lists, allergies, and immunization records. This format allows for efficient data retrieval and analysis.
* In contrast, unstructured data includes free-text information like physician's progress notes, consultation reports, and discharge summaries, which provide crucial context and narrative detail about the patient's condition and care.

The data extracted from EMR software systems (both structured and unstructured) is collectively known as Electronic Health Information (EHI) data.

As the Cures Act did not specify a mandatory standard for EHI data extract files, each EMR software vendor has designed its own EHI specification. As Epic is the EMR vendor market share leader\*, the HealthDataSov project will initially focus on implementing the Epic EHI data file standard. *\*Epic Systems continues to be the dominant player in the EMR/EHR market, particularly within U.S. acute care hospitals. According to KLAS Research's latest reports (published in April/May 2025 based on 2024 data).*

Furthermore, Epic has devoted considerable resources toward their EHI data standard and patient access technology. See <https://open.epic.com/EHITables/>. (Screenshot below)

**Data Type & Format:**Epic EHI Data is sourced through TSV (Tab Separated Values) exports across ~1000 tables as documented here: <https://open.epic.com/EHITables/GetTable/_index.htm>.

On 7/1/2025 [Josh Mandel, MD](https://www.linkedin.com/in/josh-mandel/) a leading developer/partisan / policy wonk in the EMR data liberation movement released and made available for public use an interactive website that acts as both reference manual and data set training tool: <https://joshuamandel.com/ehi-living-manual/>. ***This is an important and rather incredible windfall for the HealthDataSov project*.** There is lot of data noise in the sprawling set of EHI tables, this tool will enable our team to quickly and thoroughly hone-in on the critical tables and fields of high AI training model value.

**Data Volume & Frequency:**EHI data is generated by every patient-provider encounter: voice, virtual or face-to-face. The availability of historical encounters will vary by patient encounter frequency and provider organization EMR encounter data “publishing” cycle.

**Acquisition & Retention Strategy:**TBD. To be completely transparent, user outreach, sign-on and participation engagement are completely outside of my skillset and not significantly present among my contacts.

**Value Proposition & Use Cases:**The data, text and images that comprise EMR/EHI data and information sets have boundless intrinsic value to both the business of healthcare and to the humanitarian obligation of attaining the most effective and wide-reaching healthcare delivery system.

Focusing on the business of healthcare: EMR/EHI data has always been in high demand to the manufacturing corporations within the industry – the large biotechnology / pharmaceutical companies absolutely must have data for treatment procedure and diagnosing technology development. Due to the moral obligations of macro-healthcare, the individual patient has never been allowed to “opt-out” of EMR data sharing, allowing provider organizations to freely license de-identified, demographic-level patient EHI data for financial gains. Naturally EMR data brokerage firms have been established, see [datavant](https://www.datavant.com/), [HealthVerity](https://healthverity.com/), [LexisNexis](https://risk.lexisnexis.com/?trmid=CMCXRKEV.corporate.gateway.WS3P-1086803), [IQVIA](https://www.iqvia.com/), [Optum Life Sciences](https://business.optum.com/en/data-analytics/life-sciences.html) and my current employer [Veradigm](https://veradigm.com/life-science-solutions/).

HealthDataSov will technologically enable individual patients to collectively invoke their Cures Act rights and take ownership of their EMR EHI data files for contribution to a decentralized, blockchain-based pooled data system to rival the process established by provider organizations and their brokers. The immediate value proposition to the purchasing parties (biotech and pharma corporations) is access to the same datasets at a significantly lower cost. Looking forward, HealthDataSov could offer, for user patients willing to engage in paid participation – direct interface with healthcare manufacturers. Another future development for HealthDataSov would be the infusion of other user/patient-suppled data (e.g., shopping, survey or social app) for enhanced analytics.

**Why It Matters:**Upon financially incentivized widespread patient ownership of and involvement with EMR data, “self-health” application development and engagement levels heretofore unattainable will be realized. In this way HealthDataSov aims to “do well by doing good”.

### **6. MVP/Prototype Status**

MVP build has yet to commence, however synthetic EMR/EHI data has been procured and is ready, see: [HealthDataSov Google Drive - Synthetic EHI Data](https://drive.google.com/drive/u/0/folders/1cumtjofCD-8UNKbe5vxzq3FNJfeIkEz0/)

### **7. Token Launch Experience**

Not applicable for any of the team members, however, I have been a crypto/Web3 “enthusiast” and have participated as a user in sever Token Generation Event projects.

### **8. Support Requirements**

* **Vana blockchain DEV/advisor for MVP build**
* **Vana advisor and crypto S.M.E. for Tokenonmics design and TGE planning / implementation.**
* **Retail user outreach, marketing, engagement and legal compliance**
* **Investor engagement**
* **Blockchain DEV recruitment**