PatientDirected.io
The Platform of the Patient

Whitepaper

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LEGAL DISCLAIMER:

As the healthcare system evolves towards a more efficient and patient centric model of care, there are several necessary fundamental infrastructure transformations required. One of these critical transformations is the unfettered exchange of patient medical records between systems and providers, known as data interoperability. This issue is a well-recognized barrier to timely and efficient data access, which drives up costs and negatively impacts patient outcomes though several mechanisms.

Given the current increasing costs of care and relatively poor patient outcomes within the US healthcare system, consumer awareness is growing and pressure is mounting to drive meaningful changes and significantly improve the health care system to improve outcomes and lower costs.

An effort to address these problems via improved interoperability has not resulted in meaningful change or measurable improvements, though the costs are measurable and have resulted in the loss of valuable time, billions of tax payer dollars and a number of patient lives through medical errors and poor care coordination.

Past and present efforts to solve the problem of interoperability have been unsuccessful. The root cause of failure is linked to the fact that the stakeholders that are relied upon to drive change are incented to in-fact resist change. There exists no central business case to drive compliance within the industry. Furthermore the stakeholders that control and store the many silos of centralized patient data are not threatened by the current regulatory environment so as to act in any meaningful way. It is also important to note that even if the current proposed approach to interoperability were actually adopted and deployed, an unmanageable network of loosely connected private data nodes would do little to achieve the many benefits that could only be derived from an open distributed network. Patient control, trust and universal access can only be ensured by a distributed open data store, one that can be achieved today by leveraging technologies such as blockchain and secure IPFS.

Imagine a world where precious healthcare data is liberated from the many private data silos and placed in a secure distributed data network. A network where frictionless data exchange is guaranteed, as is each patient's full

control over access, utilization and monetization of their personal health information.

At this point in time it is a question of will not skill, the technology exists to solve one of the most important problems within healthcare, but is there the will? Can the consumer drive this transformation unassisted by the current stakeholders, who see decentralized data as a threat to their businesses? In response, I propose a solution that allows all parties to benefit form a shift to distributed data, one that can improve patient outcomes, reduce healthcare costs and accelerate innovation and breakthroughs within medical science.

My proposed solution is to create a blockchain and IPFS based platform, known as PatientDirected.io, that acts as a distributed secure store for patient data, with an intrinsic coin ledger. The system operates on a set of very simple rules: 1) a minimum data set of patient information as directed by the patient via PatientDirected.io, is required to be deposited electronically into PatientDirected.io from all relevant electronic medical record systems on a continuous basis via current adopted standards; 2) the patient and or their legal guardians and delegates, will have full control and governance of this data as reflected by their preference and settings within PatientDirected.io; 3) requests to access a patient's data will operate against each patient's governance policies and rules.

 By leveraging the open ledger and smart contract properties of the blockchain, entities requesting access to a patient's data will have visibility into the options available for access and any token fees payable to the patient that are required. Each request can be managed by the inherent smart contract for frictionless data exchange and any related financial transactions.

With the introduction of the PatientDirected.io platform patients can exercise their HIPAA rights, take control of their precious medical information and dramatically and swiftly solve the interoperability problem that has plagued healthcare for years. In doing so the patient benefits in several ways: 1) complete and personalized governance of their personal medical information, 2) an ability to ensure their accurate and timely medical data is available to any provider at any time to further their care, and set guidelines to allow their data to be used to advance the state of medicine and innovation through aggregate analysis and advanced data science research, 3) reduce the cost of health care system wide through efficient data exchange, and reduce their personal health care costs through the monetization of their data via stakeholders that request access,

including pharmaceutical, insurance, biotech, medical device and clinical research organizations.

The benefits to the patient are obvious as they can receive better care coordination, reduced medical errors, reduced medical bills and better health outcomes. Health care providers can benefit from immediate and complete information at their fingertips and truly realize the gains offered by their legacy EHR investments. Healthcare IT vendors can build upon a rich data set of clinical information and provide new insights and clinical guidance based on big data analytics. The PatientDirected.io platform does not contend to displace or supplant the legacy vendor footprint or solution; rather it reinforces its value and sustainability.

It is my belief that only the patient/consumer can drive the needed change as it relates to healthcare data interoperability, and that by empowering the patient through a solution like PatientDirected.io, real change will occur rapidly and with significant long-term benefit for the patient, the health care system and medical science.

Economics

One of the most significant and unique concepts inherent in the PatientDirected.io platform is the economic incentive framework. By offering consumers an opportunity to significantly lower their healthcare costs through data monetization, the consumer is incented to act, and this mass action will lead to the desired industry transformation. Despite the historic resistance of many stakeholders to interoperability, PatientDirected.io will provide long-term economic benefits to these stakeholders in the form of reduced waste, improved efficiencies, and ultimately better patient outcomes, which is a key financial objective under value based care.

The operational and infrastructure costs associated with the PatientDirected.io platform will require appropriate resources. This is a critical point as history has shown that past attempts and interoperability via CHINs, RIOs and HIEs have all failed in part due to the lack of a sustainable economic model. To maintain the viability of the platform, a small transaction fee is retained by the platform (1%) for each non-zero value transaction.

Architecture

The PatientDirected.io platform is based on a several complementary open-source technology systems, in addition to a novel security and privacy framework that addresses the unique challenges of healthcare information exchange.

PatientDirected.io utilizes the Ethereum blockchain-based distributed computing platform featuring smart contract functionality. Ethereum's role in the architecture is to record all patient data events and limited metadata in the form of Secure IPFS (Inter-Planetary File System) pointers. No personal health information (PHI) will be stored in the Ehtereum blockchain. Based on the event type, the appropriate Ethereum smart contract will manage any associated PatientDirected.io token (PTDIR) and required downline token transactions. All smart contract transactions will debit third party accounts and credit the patient's account adjusted for network tolling and mining fees. All smart contract transaction events are considered patient data events and as such are stored in the Ethereum blockchain.

Patient data events tracked in the immutable Ethereum ledger offer a timeline of events that can be reinforced by associated timestamps to create a patient's longitudinal history. These patient data events may have one to many associated clinical data assets, in the form of structured or unstructured text, binary or mixed data. These digital assets and related metadata are stored on the PatientDirected.io secure IPFS. Once entered into the IPFS a unique handle/hash is returned and placed in to the parent patient data event block as a pointer.

The process of accepting or importing data on to the platform will be facilitated by leveraging several industry networks, transport protocols and data exchange standards. A partial list related to existing healthcare enterprises include HL7 (v2, v3, CCDA), Blue Button, FHIR, NCPDP, Direct Trust, DICOM, CareEquality and Commonwell Alliance.   Consumer driven data sources include wearable and remote monitoring data from Apple (Healthkit), Google, Valadic/Human API, and others. As mentioned above PatientDirected.io facilitates patient requests directly to their providers, and acts as the digital conduit for this information transfer on behalf of the patient, using protocols that all EHRs are required to utilize and consumer APIs are capable of transmitting.

The initial minimum data set requested and transferred by healthcare enterprises will consist structured summary data and common data formats. The initial goal is to acquire recent and critical longitudinal data essential for medical decision making, improving outcomes and reducing costs. Secondary goals include expanding the data set to elements that are critical to medical research and innovation.

Given the IPFS is an immutable, distributed and public swarm or network of nodes, several layers of security and data governance technology must be added to enable the secure fine grain control inherent to the PatientDirected.io platform. Our approach to this problem is to create a virtual private network around the PatientDirected.io network nodes, versus allowing these nodes to exist in the unsecured public IPFS network. This approach preserves the distributed immutable and public trust properties of the IPFS, though it partitions a secure subnet within IPFS that is managed by the policies set forth by the patient members of the PatientDirected.io platform. Thus the membership is in control of the network, and does not delegate this trust to any third party. The membership determines which organizations are appropriate node hosts for the PatientDirected.io network, and generally would include trusted healthcare organizations such as NIH, CMS, CDC, independent Biobanks, non-profits and large provider networks. A network of at least 1000 network hosts is desired to ensure verifiable immutability and trust.

By leveraging a technology known as HyperVPN which encapsulates the PatientDirected.io IPFS, all network traffic is is managed and monitored. Sophisticated data governance polices are managed by the HyperVPN with respect to network and asset access. The degree of patient control includes who has access to what assets, under what conditions and for how long. In addition to the external access control offered by the HyperVPN, all data is encrypted within the store by leveraging an IPFS specific encryption technology such as that offered by Perrgos.

Project Team

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- Rock Health Top 50 Digital Health Innovator 2018

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Advisory Panel

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- Associate Professor in the Virginia Modeling, Analysis and Simulation Center at Old Dominion University
- http://www.healthcareitnews.com/video/blockchain-cybersecurity-what-its-potential-what-are-its-limitations

Jens Megers - https://www.linkedin.com/in/jensmeggers/

- Current CEO HyperVPN – next generation cloud security
- Former SVP and General Manager for Cloud Collaboration at Cisco

The PatientDirected.io ICO

The timeline for the ICO is as follows:

Jan 2018 – develop whitepaper and establish core team

Feb 2018 – Build website and project roadmap

Deploy Ethereum wallets and smart contracts for ICO

Build prototype solution on test Ehterum and IPFS

March 2018 – Press Release and Open pre-ICO sale of PatientDirected.io Token

April 2018 - ICO open sale of tokens

June 2018 – Close ICO

ICO Allocations:

40% ICO Investors

20% Patients

20% Team

10% Coin Miners

10% Reserved