



Health Data Interest Group @P10

Health data mapping and diverging trends in health data protection

21 September 2017, 9:00-10:30

Edwin Morley-Fletcher

research data sharing without barriers
rd-alliance.org

AGENDA

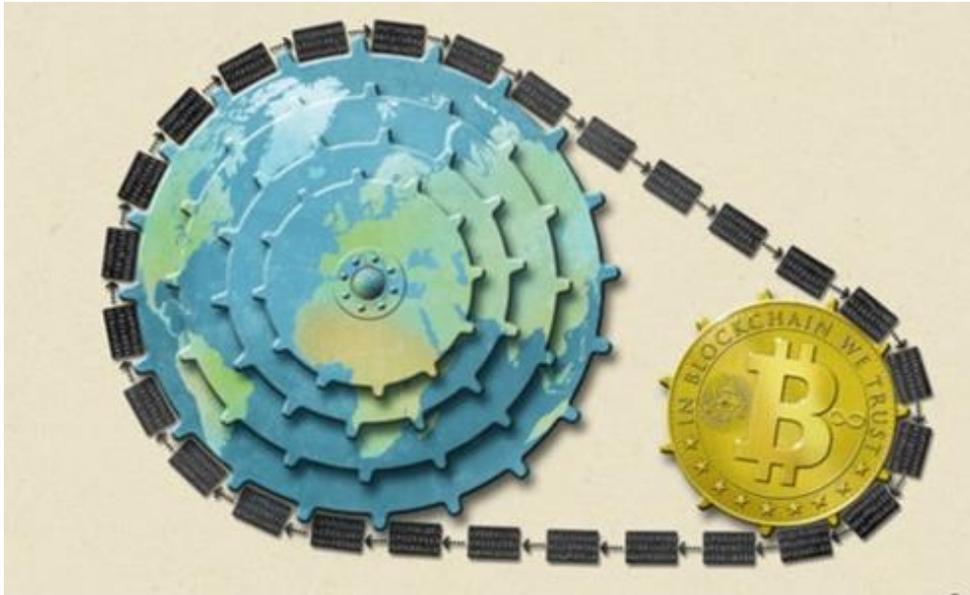
- 1. Presentation of the idea behind this BoF [20']**, Edwin Morley-Fletcher, Lynkeus.
- 2. An example of Blockchain system** (still under construction) **applied to health**, David Manset, CEO of gnúbila and Head of R&I Almetry;) [20']
- 3. Specification of the objectives of a Blockchain in health WG** (discussion, all participants) [30']
- 4. Identification of other potential group members** (all participants) [10']
- 5. Summary of the results, actions, and identification of contributions of the group members** (Edwin Morley-Fletcher, David Manset) [10']

BOF @RDA P9 in Barcelona

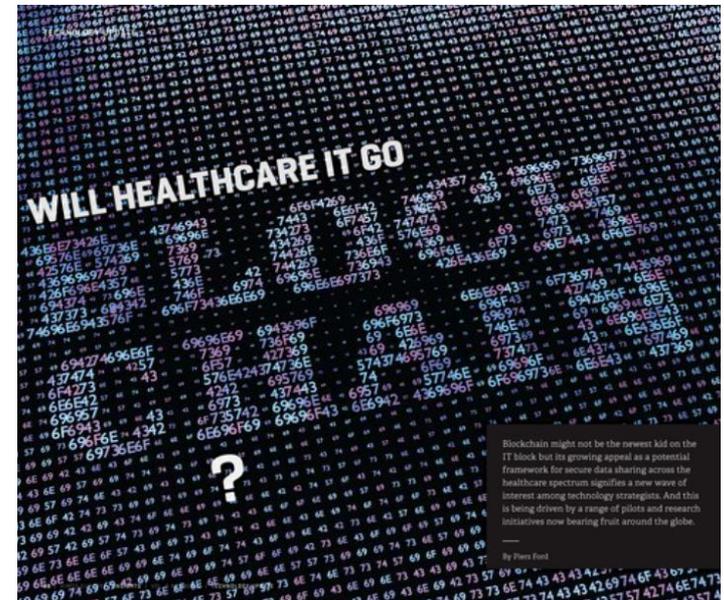
- In Barcelona we had a packed BoF on making use of Blockchain technologies in health data.
- There we stated that the HD-IG was sponsoring the idea of establishing a WG focusing on Blockchain with the aim of debating in depth the potential of such a system:
 - Whether the blockchain can ensure compliance with advanced data protection requirements (such as those defined by the EU General Data Protection Regulation – GDPR),
 - Whether it can operate seamlessly and efficiently, at scale.
- Due to its scope, that first preliminary BoF meeting ideally had the goal of fostering relations to a number of RDA WGs and IGs willing to contribute with their results to, or benefit from, the proposed future WG's activities.

- In Barcelona we had a stimulating presentation by Prof Aggelos Kiayias (Universities of Edinburgh and of Athens)
- Based on the metaphor of the Book and the scribes wanting to add pages to it
- Being allowed to do so only when they could achieve a double six by playing dice (proof of work)
- A telling metaphor, if we refer to the “Religions of the Book”, and to the problem of allowing for the “evolution of dogma”

Blockchain Hype ?



The Economist (2015), "The promise of the blockchain: The trust machine", October 31st



HiMSS Europe

- The Economist went so far as to state that:
 - at first sight, “the notion of shared public ledgers may not sound revolutionary or sexy. Neither did double-entry book-keeping or joint-stock companies. Yet, like them, the blockchain is an apparently mundane process that has the potential to transform how people and businesses cooperate”.
 - “A realisation that systems without centralised record-keeping can be just as trustworthy as those that have them may bring radical change. [...] A world with record-keeping mathematically immune to manipulation would have many benefits.”

Blockchain Hype ? IBM

- “Blockchain promises to put privacy and control of data back in the hands of citizens. Trust and integrity will be established without reliance on third-party intermediaries. IBM believes blockchain is an extraordinarily important phenomenon with the potential to transform industries and upend business models”.
- “In healthcare, new research is seeking to apply blockchain’s distributed ledger and decentralized database solutions to the critical issues of interoperability, security, record universality, and more. Intriguing uses in other industries are being extended to healthcare, such as extending blockchain’s smart contracts to provider network management or connecting myriad medical devices through common, blockchain-enabled systems of information relationships. While technical consensus on a distributed ledger for healthcare has yet to emerge, with debate ongoing regarding scalability, security, and regulatory compliance, blockchain technology and encryption *will* drive innovation in healthcare services and administration”

IBM Global Business Services Public Sector Team (2016), *Use of Blockchain in Health IT and Health-related Research*, proposal submitted on August 8, 2016, to the Ideation Challenge launched by the Office of the National Coordinator for Health Information Technology in the USA.

- Healthcare pain points and potential blockchain solutions were similarly indicated by IBM as well as by Deloitte, in whose White Paper, however, they appeared to be more conveniently summarised as shown in the next table, taken from:

Deloitte (2016), *Blockchain: Opportunities for Health Care*, White Paper developed in response to the Department of Health and Human Services' Office of the National Coordinator for Health Information Technology (ONC) ideation challenge on "The Use of Blockchain in Health IT and Health-Related Research".

Blockchain Value Propositions for Healthcare

	Health Information Exchange (HIE) Pain Points	Blockchain Opportunities
	Establishing a Trust Network depends on the HIE as an intermediary to establish point-to-point sharing and “book-keeping” of what data was exchanged.	Disintermediation of Trust likely would not require an HIE operator because all participants would have access to the distributed ledger to maintain a secure exchange without complex brokered trust.
	Cost Per Transaction , given low transaction volumes, reduces the business case for central systems or new edge networks for participating groups.	Reduced Transaction Costs due to disintermediation, as well as near-real time processing, would make the system more efficient.
	Master Patient Index (MPI) challenges arise from the need to synchronize multiple patient identifiers between systems while securing patient privacy.	Distributed framework for patient digital identities , which uses private and public identifiers secured through cryptography, creates a singular, more secure method of protecting patient identity.
	Varying Data Standards reduce interoperability because records are not compatible between systems.	Shared data enables near real-time updates across the network to all parties.
	Limited Access to Population Health Data , as HIE is one of the few sources of integrated records.	Distributed, secure access to patient longitudinal health data across the distributed ledger.
	Inconsistent Rules and Permissions inhibit the right health organization from accessing the right patient data at the right time.	Smart Contracts create a consistent, rule-based method for accessing patient data that can be permissioned to selected health organizations.

Who is Ronald Coase ?



- Ronald Coase (1910-2013)
- Nobel Laureate for Economics on 1991, more than 50 years after his disruptive *The Nature of the Firm* (1937), and 30 years after *The Problem of Social Costs* (1960).
 - Why clusters of individuals operate under the direction of hierarchies and not purely under the guidance of market prices? He famously answered that using the price system is costly (in terms of 'transaction costs').
 - According to the Coase Theorem, in the absence of transaction costs, the allocation of resources is independent of the distribution of property rights.
- It is now possible to reverse Ronald Coase's Transaction Costs.
- What Internet did to transaction costs regarding information, blockchain can do regarding trust.

- Public and private initiatives, both in Europe and in the US, are currently addressing the potential of applying the blockchain approach to health data.
- This is related to great general expectations (“what Internet did to transaction costs regarding information, blockchain can do regarding trust”) and to the assumption that what is needed for health data is a Distributed Empowerment system, providing secure access from anywhere on any device.
- There is the need to develop new mechanisms of trust and of direct, value-based relationships between people, hospitals, research centres, and businesses, leading to an open biomedical information network centred on the connection between organisations and the individual.

- A Distributed Empowerment system having the Blockchain ledger as secure, non-editable record, where all transactions are confirmed by the network as entries forming blocks of transactions, and the whole network monitors the legitimacy of each transaction, guaranteeing distributed control.
- A distributed system which can technologically replicate and even overcome the network efficiency of a single monopoly, and where:
 - Instead of “googling” for everything, we can perform the equivalent action by verifying that any digital ownership is certified by a blockchain.
 - Information access is not enough anymore. Truth access was a missing piece of the information revolution, which the blockchain fixes.
 - The old question “Is it in the database?” is being replaced by “Is it on the blockchain?”

- A blockchain can be based on portfolios of Smart Contracts.
- Smart Contracts are the executable pieces of code, stored on the blockchain for future execution.
- These bind people and transactions to specific actions and outcomes and require no further direct human involvement after the smart contract has been made a part of the distributed ledger (which is what makes these contracts "smart" or self-enacting).
- Smart Contracts are the new form of legal contracts, which both formalizes and enforces their terms, without requiring a third-party acting as trusted authority.

A long historical journey

- From having recourse to a Fair Independent Third Party (Common Law)
- To the Law Codification process (From Justinian to Napoleon, and beyond)
- To having again “the contract among the parties is law”
- In a self-enacting digital codification, which allows for the maximum personalisation

- Applying the blockchain approach to health data guarantees secure access from anywhere on any device
- The Blockchain ledger is the secure, non-editable record where:
 - All transactions are confirmed by the network as entries forming blocks of transactions
 - The whole network monitors the legitimacy of each transaction, guaranteeing a distributed control system
- Each stakeholder can enact anonymous transactions through the ledger:
 - Employing public key encryption for identifying owners in the ledger, recording one half of the public key pair
 - Only the person or institution holding the corresponding private key can decide what happens next to their data
- Each stakeholder is equipped with a 'wallet' containing:
 - An encrypted identifier
 - His/her Dynamic Consent translated into Smart Contract
 - His/her Data Access Policy file, translated as well into Smart Contract
- All stakeholders' options are dealt with through Smart Contracts encoding

- Currently, all existing blockchains protocols have the property that every computer in the network must process every transaction
- This property provides extreme degrees of fault tolerance and security
- But at the cost of ensuring that the network's processing power is effectively bounded by the processing power of a single node.
- New approaches move beyond this limitation, achieving the scale needed to support mainstream adoption, for example through sharding, i.e. horizontal scaling, dividing the system over multiple servers, so that while the overall speed or capacity of a single machine may not be high, each machine handles a subset of the overall workload, providing better efficiency than a single high-speed high-capacity server.
- Expanding the capacity of the deployment only requires adding additional servers as needed, which can be a lower overall cost than high-end hardware for a single machine.
- The trade off is increased complexity in infrastructure and maintenance for the deployment.

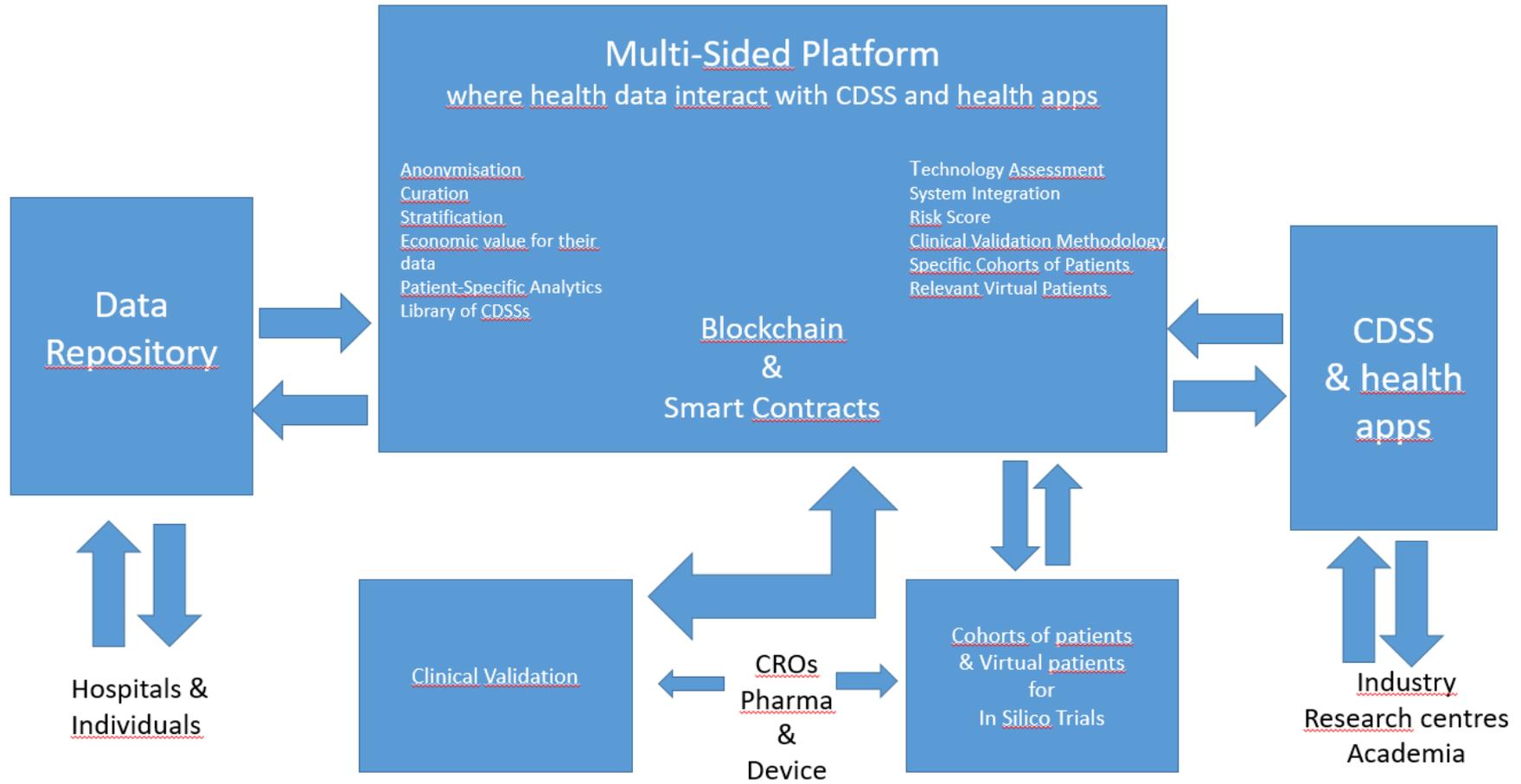
The goal of attaining a Multi-Sided Platform for healthcare



Jean Tirole, Nobel Laureate 2014

- Multi-sided platforms (MSPs) generating strong positive network effects appear to be the organisation model showing the **greatest capacity to scale**, based on the implicit support derived by each of the sides served by the platform.
- Professional service firms are on this basis:
 - Moving away from centralized and vertically integrated models (in which all client services are provided by their employees)
 - Moving towards the decentralized MSP model, in which they enable independent contractors to deal directly with clients, even though often maintaining a significant degree of control over the contractual terms between clients and professionals.
 - The Blockchain and its Smart Contracts complements can strongly contribute to the effectiveness of MSPs

Where health data can interact with CDSS and health Apps with Smart Contracts



The Economist explains (Aug 22nd 2017): What are initial coin offerings?

- An initial coin offering (ICO) is a flotation which is quite different from the similar-sounding “initial public offering”, or IPO, where a startup lists on the stock exchange.
- Whereas investors in shares receive ownership rights, those who put their money in ICOs get crypto-currency, or tokens issued on a blockchain. They are meant to serve as the currency for the project they finance: on Filecoin, for example, subscribers will use the currency to pay for file storage, but can also earn it by contributing storage to the network themselves.
- Most ICOs are unregulated. Instead of providing an audited prospectus, issuers just publish a “white paper” which describes the project’s aspirations in attractive terms.

For further contacts

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