

REFORMER THOUGHTS

REFORM



Blockchain in the NHS

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5-6 St Matthew Street
London, SW1P 2JT
020 7799 6699

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Foreword

In my report "Distributed Ledger Technology for Public Good", published November 2017, I urged the Government to explore the possibility that distributed ledger technology (of which blockchain is one example) could offer solutions to some of the most intractable public policy challenges faced by the UK. Healthcare is just one example but one in which the UK, as home of the NHS, is uniquely positioned to benefit from.

The particular properties of distributed ledger technology (DLT) - immutability, anonymity and decentralised control - could transform the NHS in areas such as health assurance, patient record management, drug safety and treatment accountability. This excellent collection of writings on the topic of blockchain in the NHS provides an invaluable overview of the opportunities and challenges offered by this technology and underlines yet again that although we must not shoehorn a solution into a problem, the prize - should we get this right - would be great indeed. I am heartened by increased public awareness and the improved quality of debate on this topic as demonstrated by this collection, particularly timely as the bitcoin bubble loses its bounce.

One area of enthusiastic agreement is in the central role of data. Data is a significant asset to the NHS, as the medical data of over 65 million people is, collectively, a dataset with incredible potential. Yet, there are currently significant practical issues with data sharing. A lack of interoperability, that is the fact that NHS systems and devices cannot easily exchange and interpret that shared data, is rightly identified as a barrier.

Understandably, there are also huge concerns over privacy and trust. There are technical, legal, cultural and ethical issues around data that must all be considered and addressed. In one article Sophie Sheldon and Lydia Torne outline how GDPR requirements such as the need for a defined data controller and data processor,

the jurisdiction of data transfers and data subjects right to erase data appear difficult to reconcile with key characteristics of DLT - anonymity and immutability. I considered some of these questions in a progress update to my report. The collaborative and cross-disciplinary discussions facilitated by DLT working groups have enabled an assessment of issues, identification of viable workarounds, and management of risk. It reinforces my belief in the need for leadership, collaboration and innovation and my support for the working groups as well as many of the recommendations of the CryptoAssets Taskforce regarding DLT.

A number of interesting applications and initiatives are referenced throughout the collection ranging from Mediledger, which offers tamper free supply chains in drug manufacturing to Medicalchains, which is a kind of health passport. An area of clear potential but raising many questions is the possibility of trusted, immutable patient records - can this be introduced in a way that puts the patient in charge of their own records and is truly beneficial to patient and clinician? 70 per cent of hospital executives are optimistic about the potential of blockchain for data sharing and I believe the UK is well-placed to include DLT as a key component in its digital strategy. If we get it right, the NHS can continue to be the greatest healthcare system in the world, and in addition can become the greatest example of the deployment of DLT for the public good.



**Lord Holmes of
Richmond MBE**

*"Although we must not
shoehorn a solution into
a problem, the prize –
should we get this right
– would be great"*

Introduction

Can blockchain deliver patient-centred care?

The NHS is not a single organisation. In England alone, this includes 7,494 GP practices, 234 NHS foundation trusts and NHS trusts and 207 commissioning groups. Together, they serve over 1 million patients every 36 hours. Effective information sharing across this vast and complex system is vital if the NHS is to achieve its vision to deliver joined-up, high-quality healthcare.

This ambition is no mean feat. In debates around healthcare data, technical concerns around the type and accuracy of data being collected are compounded by cultural, ethical and legal considerations around confidentiality and consent. How to ensure only the 'right people' have access to a person's most sensitive data? And how to decide who are the 'right people'? Surveys show people are worried about their data being used for commercial purposes, and just 36 per cent of people trust the NHS to use their data appropriately.

Putting individuals, rather than the Government, in control of data about them is key to alleviating some of these concerns. By enabling citizens to become the controller of their own personal healthcare records, blockchain technology promises to make this shift possible.

WHAT IS BLOCKCHAIN?

In reality, blockchain is just one type of distributed ledger technology (DLT) but has gradually become a catch-all term. DLT are databases that offer a way of decentralising information without compromising security or integrity i.e. the accuracy of the data. Distributed ledgers can either be unpermissioned or permissioned; unpermissioned ledgers, like the bitcoin model, are open for anyone to access, while permissioned ledgers require authorisation for users to hold a copy.

While traditional databases are stored on a central server, information on DLT is stored across a network of computers that all hold identical copies of the database. Those making changes to the ledger are identified and, crucially, when a piece of information is added, it cannot be changed or deleted. In healthcare, this could mean a permanent record of who has accessed someone's medical data.

A permissioned ledger for medical data, which patients could control, has the potential to transform the relationship patients have with their healthcare data. Individuals would have access to their personal health records and could grant or deny permission for others to access it, whether they be clinicians, researchers or even commercial organisations.

WHAT DOES THIS MEAN FOR HEALTHCARE?

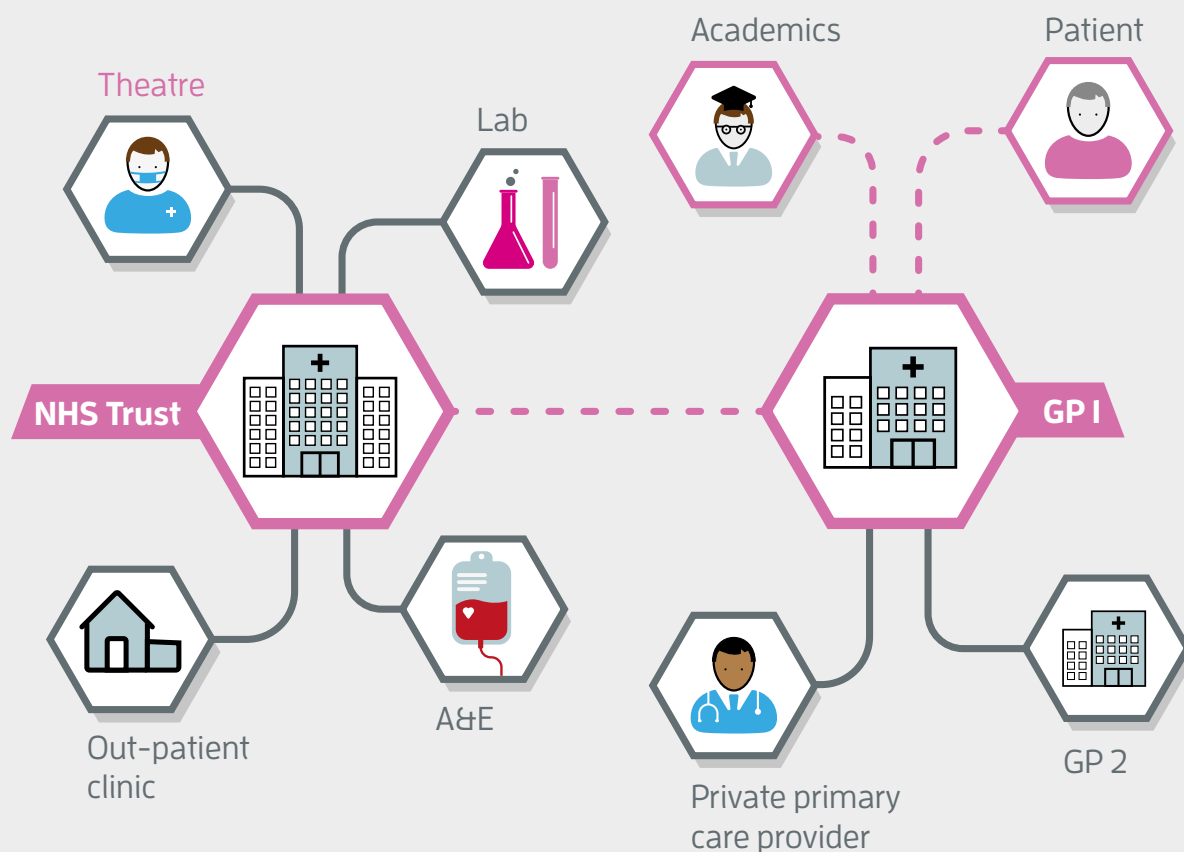
This *Reformer Thoughts* brings together optimists and sceptics to discuss the potential for DLT in healthcare. DLT may not be a cure-all for the epidemic of data fragmentation across the NHS but, if used effectively, opens up opportunities to expand our knowledge of human biology, give doctors a fuller picture of a patient's condition, and empower patients to make decisions about their healthcare.



Imogen Farhan
Researcher at Reform

"A permissioned ledger for medical data, which patients could control, has the potential to transform the relationship patients have with their healthcare data."

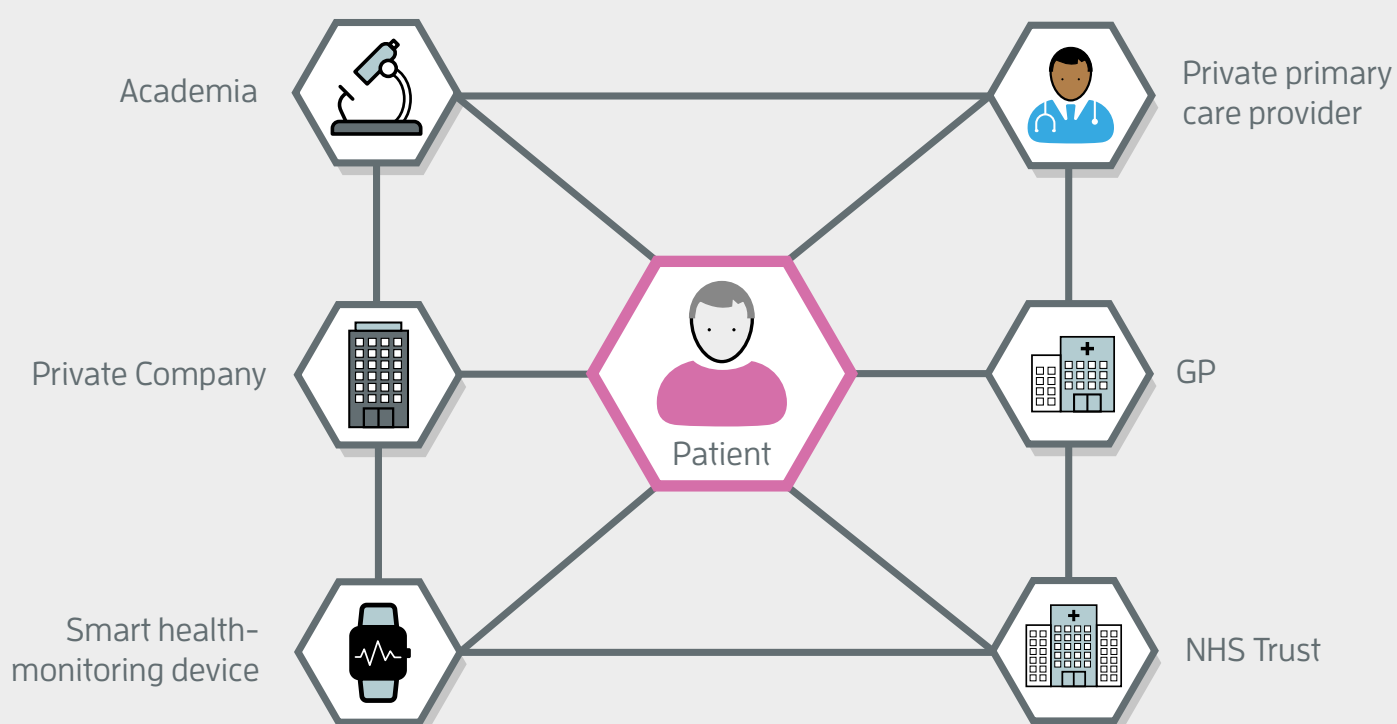
Now: A decentralised data-sharing landscape



The blockchain model: A permissioned ledger for medical data which patients can control

— Always share information

- - - Sometimes share information





Implementation Challenges and Considerations

Blockchain & Health Records: Challenges from both sides

When talking about blockchain and healthcare, one of the applications that receives the most hype is the creation of decentralized patient-controlled health records.

The idea here is that the patient owns their health record as a single source of truth. He or she grants or revokes access to clinicians or researchers, preventing unauthorized access, data leakage (the resale of data on to third parties) and tampering. The idea is that this single record offers a solution to the perennial challenge of interoperability.

There are a number of problems with this idea, relating to blockchain technology itself and the way health data has historically been created and stored.

The first of these problems relates to privacy and scalability issues with blockchain technology. Data on the blockchain is accessible by anyone and storing and computing data on the blockchain is slow and expensive.

One solution that could allow blockchain to be used for health records is the Enigma Project. This is an off-chain network, which serves as an extension to conventional blockchain platforms. It allows code to be processed both publicly on the blockchain, maintaining a public ledger of a transaction, and on Enigma's off-chain network where the data is encrypted. By processing data off-network, the Enigma network can process intensive computations that still remain publicly verifiable on the blockchain.

But there are tougher challenges to solve relating to how health data is created and stored. Over the years, each Electronic Health Record (EHR) company has built their own unique data model to represent the data in a patient record. The complexity of medicine creates ample opportunity for variation between one data model and the next. Despite efforts to standardize nomenclature through projects such as SNOMED, or data structures through the FHIR consortium, combining even just two medical records about the same patient remains a challenge.

Added to this, the way medical records are created by clinicians means that even with identical data structures there are inconsistencies in the content. Individual clinicians document and create their own version of events, examinations and diagnoses. For clinicians, the patient record acts as a medicolegal defense record and a note to the next clinician about what was done and what needs to be done next. Reconciling each clinician's opinion about the same patient is hard to do within a single organization, let alone across organizational records.

There are cultural and business challenges too. Part of the reason why health records are siloed is for medico-legal and billing reasons. Providers and payers like to have ownership of the data that is created. As an example, consider allergy information. Certain antibiotics given to a patient with a penicillin allergy can be fatal. A clinician administering such a drug needs to be sure of the veracity of the information on which they are acting. There is likely to be resistance, and companies building blockchain technology need to focus on educating clinicians and healthcare managers.

With the excitement surrounding this new technology it is important to avoid "tech-push": "attempts to shoe-horn a solution into a problem. The technical challenges will be overcome but blockchain will not be adopted in health care unless it can truly solve a need. In addition, the application adopted most quickly will be influenced by those that pay for the technology and may not necessarily benefit the patient or the clinician. This is where government involvement, regulation and careful consideration of the applications will be important.



Cosima Gretton

Clinical Product Manager,
Mindstrong Health and
Teaching Fellow, University
College London

*"The complexity of
medicine creates ample
opportunity for variation
between one data
model and the next."*

The potential for blockchain for healthcare – the hype and the reality

Blockchain technology can profoundly transform healthcare IT for the better. Unfortunately, with the current hype, blockchain is used and abused as a panacea for many issues of modern healthcare IT, namely interoperability and secure storage. Blockchain will not solve those issues and expecting it to is setting ourselves for failure and disappointment.

INTEROPERABILITY

Interoperability “describes the extent to which systems and devices can exchange data, and interpret that shared data. For two systems to be interoperable, they must be able to exchange data and subsequently present that data such that it can be understood by a user.”

While blockchain technology could potentially provide the foundational interoperability (allowing data exchange from one IT system to another), it does not provide structural (the structure or format of data exchange such that the purpose and meaning of data is preserved and unaltered) or semantic (the ability of two or more systems to exchange information and to use the information that has been exchanged) interoperability, which is what we need to achieve in healthcare IT.

Let's look at digital photographs for comparison. If every smartphone would use its own standard for storing and displaying digital images, the photos we take would never be able to leave our phones and be shared with our family and friends. For that reason, phone softwares have adopted common standards for digital images and that makes exchanging digital photographs quick and effortless.

In a similar fashion, healthcare IT interoperability can only be achieved by standardised data formats and interfaces for data exchange. Blockchain cannot solve this problem.

This means healthcare IT vendors must stop their practices of rent-seeking through vendor lock-in by using proprietary standards and adopt open standards such as OpenEHR for electronic health records data format and OpenAPI for data exchange.

SECURE STORAGE OF DATA

There are two issues when using blockchain as a secure storage of health data:

Inefficiency – Blockchain is a network of thousands of nodes and a piece of information added to the blockchain is stored on each and every single node of the network, replicating it thousands of times. This makes storage incredibly expensive and inefficient. To prevent data loss, replicating it a few times is enough and we do not need blockchain to do this.

Openness – All data stored on the blockchain is publicly accessible. We do not want to or are legally allowed to make personal health data available to everyone. Often a proposed solution for this is to encrypt the data before storing it on blockchain. That is a dangerous proposition as we must keep in mind that while blockchain is eternal, encryption is not. Encryption that cannot be cracked today, could be cracked in the future, especially when quantum computing becomes a reality, making all that information wide open for everyone to see.



Vasja Bočko
Chief Executive Officer
and co-founder, Iryo

THE TRUE VALUE

At Iryo, we believe that the true power of blockchain technology is providing a never-before-seen degree of immutability of data stored on it. In healthcare, that should be harnessed in two ways:

1. Providing a method for detecting data tampering.
2. Providing a fully decentralized access control list.

When a new piece of information is added to a person's health record, by using a hashing algorithm we can generate a digital fingerprint of that data and store it on the blockchain. If that data is subsequently tampered with the digital fingerprint will change and we can easily detect the change by comparing the new fingerprint to the fingerprint that was stored on the blockchain.

Blockchain can be used to store information on who has permission to access a certain piece of data. Patients are able to decide who they will give these permissions to and such grants are written on the blockchain. In centralized systems, such lists are controlled by a system administrator, meaning that there is a single point of failure. Access rights can be changed by a rogue administrator or an attacker that gains administrator rights. With blockchain, that cannot happen.

Lastly, we at Iryo believe that blockchain technology is opening up a crucial public debate on the need for decentralisation of certain systems. In healthcare that means empowering patients so that they become the true owners of their health records and other health data and get to decide who they share it with.



healthcare IT interoperability can only be achieved by standardised data formats and interfaces for data exchange. Blockchain cannot solve this problem.



GDPR and Blockchain

Interest in blockchain does not seem to be going anywhere anytime soon. Increasingly, it is being proposed (in a variety of contexts) as a potential solution for the storage of patient health data.

Much of the excitement about blockchain's potential stems from blockchain's features of immutability, anonymity, and decentralised control, which are particular benefits for the healthcare and life sciences sector. But, unless the personal data stored on the blockchain is truly anonymised (which, in practice, is very difficult to achieve), the storage and processing of that data will need to comply with the EU General Data Protection Regulation 2016/679 (GDPR). However, these very features make it very difficult for blockchain technology to comply with the GDPR.

FOR EXAMPLE:

- To understand how the GDPR applies to any arrangement, it is necessary to know who is acting as a 'data controller' and who is acting as a 'data processor'. However, in a public blockchain model, it is often difficult to confirm the identity of all nodes, the activities each node performs, and under whose direction a node is processing the data. Indeed, the concept of a node acting as a data processor (simply treating data as it is directed to do so by the data controller) arguably goes against some of the fundamental concepts of blockchain. Without this understanding, it may be very difficult to ensure the participants' compliance with GDPR.
- In the context of a public blockchain, nodes might be located anywhere in the world such that personal data is sent outside the EEA without the data controller knowing where/when such transfers takes place. Data controllers may, therefore, struggle to comply with the GDPR's requirement for the required legal arrangements (such as data transfer agreements between EU-based data exporters and non-EEA based data importers) to be in place in respect of such transfers.

- A key right under the GDPR is that a data subject may request to have data held about them erased; however, this may be impossible given the immutable nature of blockchain. Even if each node could rely on an exception under the GDPR (and it remains to be seen whether such an exemption would permit the retention of personal data indefinitely in any event), the retention of personal data in this way is still likely to breach the GDPR's data minimisation and storage limitation principles.

Many of these issues can be mitigated, but the result may be a solution which does not resemble a 'true' blockchain. For example, a private permission based blockchain, would allow a controlling entity to identify all participants, categorise their activities as a controller or processor, limit the risk of transfer of data outside the EEA and paper the participants' obligations appropriately. Furthermore, "work arounds" such as storing most of the personal data "off chain" and being able to remove all access to the blockchain may alleviate some of the issues around erasure, data minimisation and storage limitation.

The EU Commission has expressly stated its interest in looking into opportunities offered by blockchain, including launching initiatives such as the EU Blockchain Observatory and Forum and the EU Blockchain Infrastructure (EuroChain) which aim to make the EU a knowledge hub and leader in the application of blockchain. As a result, the EU Commission may come to appreciate the difficulties posed by GDPR for certain blockchain applications and might adopt a progressive approach, providing guidance which endorses certain "work arounds" as GDPR compliant.



Sophie Sheldon
Supervising Associate,
Simmons & Simmons



Lydia Torne
Managing Associate,
Simmons & Simmons

The Opportunities for Blockchain in Healthcare

Blockchain: providing privacy audits for healthcare data

Healthcare data is one of the most important assets owned by the NHS. As our understanding of gene therapies and other technologies progress, this rich data trove containing decades of medical records could help unlock cures for even the most intractable diseases.

Leaving aside the question of ownership of this data (does it belong to the NHS? Or to the patients whose information it concerns?), it seems that one of the most pressing concerns of NHS users is data privacy.

Their fears are well-founded. A recent data breach following an unnoticed bug in the SystmOne application used by GPs resulted in the records of 150,000 people being shared with researchers, even after they had explicitly opted out of such sharing. And the WannaCry attack in 2017 heightened general concerns over the ability of the NHS infrastructure to withstand hacks.

Broadly, it seems the British public trust the NHS with our health data. A survey earlier this year showed that the majority of people believe their medical records will be safe.

However, the same survey showed that more than half of people questioned were concerned about how their data might be used – and this is where blockchain technology could potentially help.

Much has already been written about the potential of blockchain technology within healthcare. Shared ledgers could mean benefits such as: cost reductions; easy ways to prove the authenticity of pharmaceuticals; and medical professionals easily being able to access high-availability data with one single source of truth.

It may seem inherently contradictory to talk about transparent, distributed systems such as blockchains providing solutions for privacy. As the common argument goes, if data breaches cannot be prevented even when data is stored at one location, how is distributing this data widely across many different locations going to make it more secure?

Let us first look at why health records are so sensitive. Quite apart from not wanting other people to know about potentially embarrassing conditions, people may wish to restrict access to prevent insurers or employers finding out about underlying conditions they do not want to reveal. For example, most private health insurers do not currently take genetic data into consideration, but this would presumably change if these tests were done as standard.

It is therefore important to be able to reassure people that their data is safe. Merely telling them that it is encrypted is unlikely to reassure most people. And this is where the immutable nature of blockchains comes in.

Imagine, as a patient, that you want to make your data available to research programmes which could help people with the same condition as you. But you do not want the same data to be sold to a health insurance company who may use it for marketing research that will augment their balance sheet without providing any benefit for people. Or imagine that you would be prepared to consider the second option – but only for some kind of payment.

The ability to see instantly who has accessed your data and how it has been used, and to assign and unassign access privileges without having to request this data or trust that it is a complete and accurate list for which blockchain technology is perfect.

A trusted, immutable, timestamped list of who has seen your medical records, and for what purpose? It may sound too good to be true, but I would bet that this will be one of the first blockchain benefits to be realised within the British healthcare system.



Rhian Lewis
Tech Consultant and
Blockchain Specialist

"The ability to see instantly who has accessed your data and how it has been used, and to assign and unassign access privileges without having to request this data or trust that it is a complete and accurate list is something for which blockchain technology is perfect."

Moving Beyond the Hype? Blockchain in healthcare

Health and Social Care Secretary, Matt Hancock, has said that technology could achieve the 'holy trinity' of healthcare. That is, better care for patients, easier service provision for clinicians and lower costs for the taxpayer.

Some technology, such as AI, has been adopted by many in the health service to solve specific challenges. In comparison, other technologies have not been used widely but could arguably have a similar impact.

Blockchain has a number of other unique attributes – highly secure, tamper-proof and transparent – making it a reliable and efficient storage of data. These benefits have led to much hype around its possible applications in public services, from supply chains to identity management. Hype, however, has not always lived up to reality. People have looked for something to apply blockchain to rather than finding a specific problem the technology can solve.

One problem that blockchain technology could solve in healthcare is technical interoperability that hampers data sharing. In the current system, different organisations each hold data. These, more often than not, are stored in siloes leading to inefficiency and inaccuracy. Siloed data storage can have serious implications for care, such as misdiagnosis, which is estimated at between 10 and 20 per cent. It is also highly inefficient, causing delays in surgical procedures if medical history cannot be verified. Furthermore, this type of data storage is frustrating for professionals. A cancer consultant might have to ask for data from CAT scan labs, radiologists, GPs and pharmacists before they can form an accurate picture of a patient's condition.

There is optimism around the role blockchain could play in addressing this challenge. In practice, this could mean creating a healthcare record on a blockchain. This network could be built across local health areas so that GPs, hospitals and care services could all have access to one, identical version of a patient's medical records. Blockchain's distributed

nature would mean that when one organisation updated data about a patient this would automatically update all other records held on that patient. A permissioned network could be used with only authorised parties granted access, which patients could control. This, along with encryption, would keep health records secure, answering one of the biggest concerns when it comes to sharing healthcare data.

In Matt Hancock's holy trinity, patient care could be significantly improved. All professionals would have access to the same information and because of blockchain's immutability (once something is added to the blockchain it cannot be changed or removed) patients could trust that professionals know their whole health history. For clinicians, some blockchain-enabled apps for data sharing are showing how much easier service provision could be. Doctors could securely share information with patients, and manage electronic orders and referrals on their phone.

Arguably, blockchain technology use is nascent in the NHS because the NHS is not digitally ready. The previous health secretary's ambition to move the NHS to paperless by this year has now moved back to 2023 and electronic health records are not in place in many hospitals. Evidently, the NHS has catching up to do before it can utilise the benefits of such a transformative technology. This does not mean, however, that the Government should not be considering the role this technology could play in their long-term plan for the NHS or start trialling the technology to understand the problems it could solve.

The Health Secretary has rightly argued that technology presents significant opportunities for improving healthcare. Although in its infancy, blockchain could be one of those technologies.



Maisie Borrows
Research Manager
at Reform

"Blockchain's distributed nature would mean that when one organisation updated data about a patient this would automatically update all other records held on that patient."

Decentralised Electronic Health Records with Blockchains

If you saw your doctor tomorrow, what do you think they would see when typing your name into their electronic health record system?

Sadly, regardless of how frequently you see them, your doctor will never have access to your complete medical history.

Today, patients still have to recite their entire story each time they see a healthcare professional due to problems of record transfer across GPs and hospitals. As a result, it is extremely difficult to maintain a single copy of any medical record that you, or your doctor, can be certain is valid. Doctors are forced to deal with incomplete information when making critical clinical decisions, and patients feel out of the loop of their care. These issues are in no way trivial. Yet, no alternative way to store sensitive patient records has been successfully implemented that may rid us of these problems. Until now.

Blockchain and associated technologies provide the opportunity to review and redesign the UK's healthcare data systems. Blockchain technology has the potential to empower patients with full access and control over their healthcare records. In contrast to storing healthcare records on a centralised cloud-based system, blockchain allows data to be securely decentralised. This means that every patient could safely hold their electronic healthcare records and share them immediately with any doctor in the world.

Imagine travelling abroad and accessing your complete UK electronic health record just like being able to withdraw UK money at any ATM. Blockchain companies are already making this future world of healthcare a reality.

For example, by using blockchain technology to offer a secure, accurate version of an individual's electronic health records, Medicalchain's health 'passport' enables patients to share the right data, with the right professional, at the right time. Secondly, the company's online consultation service MyClinic.com connects patients with a network of some of the world's best healthcare practitioners and providers. Empowering patients with better access and control over their healthcare is evidenced to result in significant health benefits.

The desire to create a single electronic record to aid in such benefits is advocated by the Government. However, public initiatives in Britain are patchy, and rely on older technologies. Policymakers should look to countries such as Canada, France and Switzerland which are actively incentivising blockchain companies to operate there with offers of technical hubs and accelerators. Similar support for the nascent industry is required in Britain. Looking forward, there is no reason why blockchain should not be a key feature of the Government's industrial tech strategy.

By engaging in discussions about blockchain technology now, policymakers and industry alike can ensure that the transformation of healthcare offers patients real control over their data, improving communication between healthcare professionals and the efficiency of the NHS.



Dr Philip Xiu
Chief Medical Officer,
Medicalchain

"every patient could safely hold their electronic healthcare records and share them immediately with any doctor in the world."

The blockchain broker for multi-omic data

In today's data-driven economy, data is king; companies like Facebook and Google monetize your digital-data footprint. The genomics space is rapidly evolving in an unsurprisingly similar fashion, not without controversy.

Personalised genomics companies such as 23&Me charge their users (~100\$ per SNP test, not whole genome sequencing) and provide information on their predisposition to disease.

This information stored by 23&Me; both clinical and biological, is valuable for pharmaceutical companies as it can aid in understanding the underlying biological mechanisms causing disease. Healthcare is progressively becoming a data-hungry industry as classical data-companies such as Google's parent company Alphabet, Amazon and Alibaba are entering this space. As these companies begin to tackle complex diseases, they will want access to large scale datasets to train machine learning algorithms.

This need for data means that companies are prepared to pay a premium for access to such rich genotypic information. Recently, GSK invested \$300 Million in 23&Me for an exclusive license to their informational database and previously 23&Me inked a \$60 Million deal with Genentech. The race is now on to gather large biological and clinical datasets with China and the UK sequencing significant cohorts in their population.

With the convergence of cheap genome sequencing, and high demand for multi-omic information associated with phenotypic data, there is a market for multiple companies like 23&Me to be data brokers (extensive list here of available services), with ever increasing concerns around genetic discrimination and privacy breaches.

In order to address the lack of data and increasing privacy concerns, there are companies that allow users to share and monetise their personal genomic information (Heterogenous, LunaDNA). These companies serve as an intermediary for trading your personal information.

As with other data-sharing industries, the DLT (Distributed Ledger Technology) offers an interesting opportunity to use blockchain as a safe data broker for multi-omic data. The emergence of companies such as Nebula, Shivom, Longgenesis, DNAtix and Genecoin demonstrates an appetite within the industry for a decentralized repository for multi-omic data. (Read more about the companies in this space in this article)

What is the value of the distributed ledger technology to sharing genetic data? As opposed to a normal database, blockchain offers a couple of unique offerings beyond a basic data aggregator.

In order to better understand disease, biologists are looking to gather information across a range of diverse populations and need lower barriers to accessing previously inaccessible biological information. DLT offers a global solution for genomic data banking, by allowing for easier storage of genomic information and better methods for compliance to health-data sharing standards.

Secondly, data-as-a-marketplace on the distributed ledger is being used by other industries. Using this business model for the genomic industry can allow users to only share information with researchers or companies they are interested in, but also allow global payments, avoiding challenges with the classical payment infrastructure. Leveraging cryptocurrency, it will be possible to build a truly international genomics database without any global restrictions.

Blockchain offers a method to allow people all over the world to share their valuable healthcare data at lower cost in a fashion that they can control. This in turn means better access to richer, powerful healthcare data (both clinical and genetic) for companies to truly make an impact on the challenges in medicine today.



Rabia Khan PHD, MBA
Founder, Stealth Mode

"In order to address the lack of data and increasing privacy concerns, there are companies that allow users to share and monetise their personal genomic information".

Conclusion: Unlocking the value of NHS Data

Data has always been key to innovation in healthcare; Dr John Snow used data to identify the source of cholera, and Florence Nightingale used data to transform hospital hygiene.

The NHS now collects an astounding volume of data on a daily basis, but its potential to transform healthcare is held back by fragmentation. DLT technology provides new opportunities to overcome this.

The vision of DLT in healthcare has been boldly set out by the authors in this collection. For patients, blockchain technology has the potential to put them in control of their own healthcare records, lending weight to the NHS's goal to deliver "patient-centred healthcare". For doctors, a user-stored healthcare record could provide a fuller picture of a patient's medical history, enabling them to make better informed decisions and improve patient outcomes. For researchers, DLT opens up opportunities for large-scale data collection by enabling patients to choose when to share, and even monetise, their personal healthcare data.

For an organisation that remains the world's largest purchaser of fax machines, the adoption of DLT in the NHS may seem like science-fiction. But changes are already underway. Working with the NHS, organisations such as Patient's Know Best are already using blockchain to enable diabetic patients to securely share data from smart health-monitoring devices with their healthcare professionals.

Yet there are still some important questions to be answered when considering the potential of this nascent technology. Concerning the technology itself, the encryption used to secure blockchain may not guarantee privacy forever, while replicating data across a potentially large network of computers raises questions

around efficiency - although not everyone advocates storing data directly on a blockchain. To put this in context, a single ultrasound scan of the heart generates about two gigabytes of data - the same storage needed for roughly two feature-length films. With 1.2 million ultrasound scans performed each year, the cost of storing data on a blockchain could be considerable.

Putting aside concerns about the technology itself, the authors of this collection have demonstrated that the challenges of data fragmentation in the NHS cannot be met by blockchain alone. The interoperability of medical records and data remains a barrier, that blockchain alone cannot overcome by itself. To ensure data exchanges between two systems are understandable and meaningful, we need to talk first about standardising data formats.

What blockchain does well is present a way forward to transform the relationship patients have with their healthcare data. To achieve this, standardising how healthcare data is formatted to facilitate meaningful interoperability between systems would be a good place to start.

"what blockchain does well is present a way forward to transform the relationship patients have with their healthcare data."

Imogen Farhan
Researcher at Reform

Related content

Reform's report, [The future of public service identity: blockchain](#), demonstrates how blockchain technology could be used for identity management, shifting the ownership of personal data from government to citizens.