
It's your data.
Take it back.
Unlocking your health data with blockchain.
tieto

# It’s your data.
# Take it back.

Unlocking your health data with blockchain.

# The current hype surrounding blockchain

The current hype surrounding blockchain should make any reasonable person sceptical: It's revolutionary. It's disruptive. It's ground-breaking. It's going to transform economies, tear down bloated institutions and herald a new age of information. Or so we hear.

**Well, scepticism is a healthy reaction, but scepticism shouldn't lead to dismissiveness, a sin as great as gullibility.**

Blockchain is genuinely interesting but it's only a technology, and on their own, technologies accomplish very little. It's that killer application based on the technology that has the power to radically transform.

Case in point: HTTP was an interesting technology; but it took the World Wide Web sitting on top of it to shake the world. HTTP was foundational, the Web was disruptive. In a similar fashion, blockchain or Distributed Ledger technology is foundational and the disruptor is… not here yet. But if history is anything to go by, when it does finally come a lot of business will struggle to adapt, some will thrive and a select elite will dominate.

**So, what's the true promise of blockchain? What kind of application does it enable?**

In the Healthcare domain at least, one of the most interesting uses of a technology which cryptographically secures the transfer of data, is in controlling access to and usage of one's own medical records. In fact, blockchain is all about maximizing the value of data, by making it flow more freely, making sure it's super secure and only allowing the right people access to it when they need it.

Such a technology in Healthcare can enable the creation of care systems where data flows securely and seamlessly from care provider to care provider, around the patient. Interestingly though, blockchain or the absence of it, isn't the biggest hurdle towards realising that vision. But when the other hurdles are removed, then blockchain is going to be fundamental. To explore this, let's imagine some alternate worlds…

# Wait, you say, don't I already own my data?

**Well, how you answer this depends on how you define ownership, what you consider data and where you live.**

For instance, the European Commission mentions "insufficient legal certainty" with regard to data ownership as one of the obstacles to free flow of data and lists the clarification of ownership as a key goal.

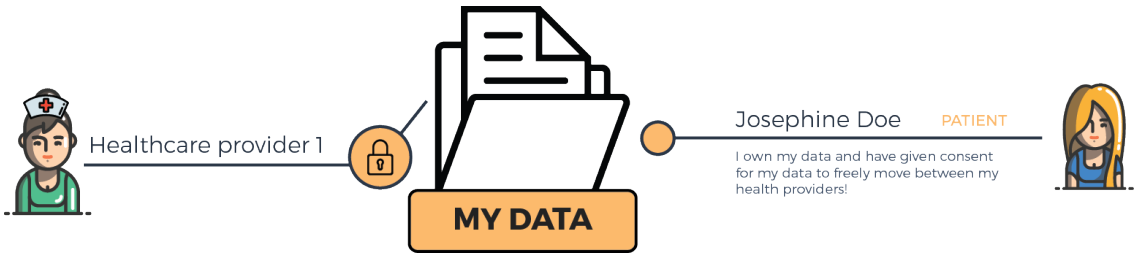
So the concept of owning is harder to nail down that you would have thought. The situation isn't helped by the fact that paradigms and mental models from the physical world are troublesome when it comes to digital assets.

For example, digital assets don't dissipate when they are 'used' like physical assets, and they lend themselves to being duplicated indefinitely. Also the real world concept of ownership is quite nuanced in itself. I might own my car, but so too does the bank which paid for the majority of it. I might own my pet hamster, but I cannot mistreat him. I might own the right to use public amenities such as my local park or the water supply (paid for by tax revenues), but that doesn't mean I can control it or restrict others' access to it.

**And in addition to the fuzzy notion of ownership, there's also the fact that most of my data is of very little practical value to me,** not until it's combined with other data and consumed by someone who knows what they are looking for and/or software which can interpret it.

For example, at the lowest level, my latest MRI scan is a long string of bits. This is the raw data. It's completely useless on it's own. But this raw data, when interpreted by viewing software, rendered on a high resolution screen and studied by trained medical professionals, can save my life. It becomes extremely valuable. In a similar way, my full health record is valuable to me and my doctor, but it's even more valuable when combined with millions of other health records and analysed for statistically significant trends in treatment outcomes, early warning indicators etc. Indeed the true value of my data might not be to me at all, but someone else who's taking part in a trial of a new preventative drug. So, should I be able to own my data in such a way as to prevent someone else receiving life-saving treatment? Is that ethical ownership?

And that's a whole other can of worms we can label 'Usage and Control'. So, let's push all these uncomfortable ownership definitions to one side and focus on the issues of usage and control.



# Usage and control of your data

Owning your data gives you the right to deny parties from using it in a certain way. It allows you to build a roadblock. But it doesn't give you the right to demand how it will be used, or even if it will be used at all. It doesn't give you a right to build a bridge.

For example, you can block a market research organisation from selling your data to commercial entities, but you cannot force a doctor to accept the heart-rate data you collected on your Fitbit.

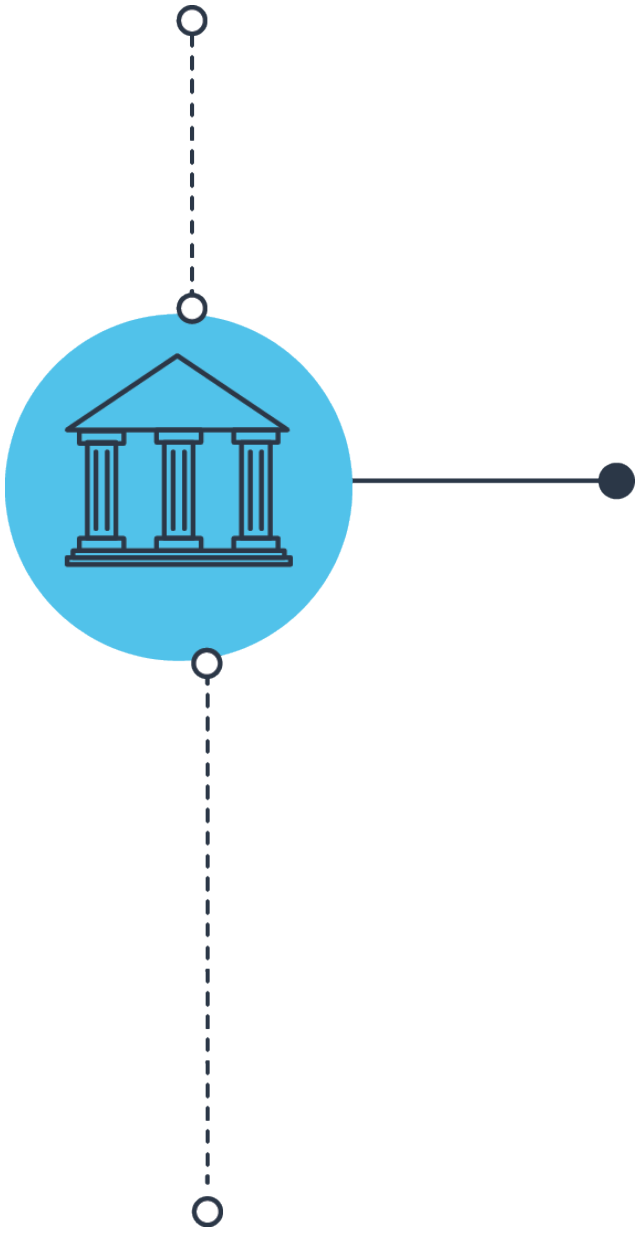
Similarly, you can demand access to the data a hospital has on you (effectively a copy of your patient journal), but you have no right to demand how that access should be realised. A hospital can choose to print out a hard-copy, burn it on DVD, or even transcribe the whole thing by hand. They are not obligated to pass the data electronically to you and more critically they are not obliged to pass it electronically to another hospital. In short, your ownership of your data does not predicate the flow of your data seamlessly between authorized parties. Ownership and control are different things entirely, and each presents its own challenges to our vision of patient centred care systems. But let's continue this thought experiment by imagining that you own your own data and owning your data does mean you can control how it is used. Now you can demand that your different care providers can share information about you. So we're there… right?

## Legislation

Given that in our new world, moving your data freely between your health providers has your consent, why isn't it likely to happen? Well, here things get a little more nuanced. There are four obstacles to the free movement of your health data: legislation, technology, competition, governance. The good news is that these obstacles are being eroded one by one.

Each Nordic country is battling the first obstacle (legislation) through slightly different (but similar) visions for a national health IT backbone, as well as removing the legal obstacles to the movement of your data along such a backbone. Outside the Nordics, the European Commission

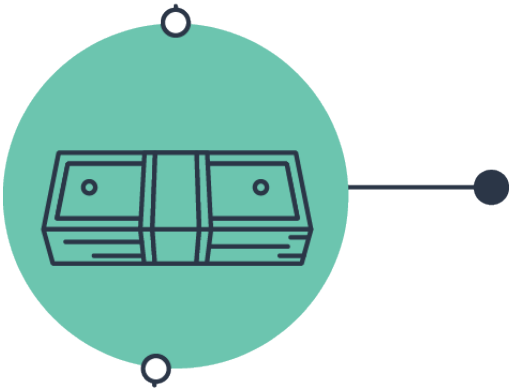
is working to regulate the ownership, use and flow of a citizen's data (see GDPR and the previously mentioned "EU Free Flow of Data Initiative"). On top of this the MyData Alliance is a great start at "crowd sourcing" the ethics of personal data movement. Expect more things here as this movement gains momentum.



Each Nordic country is battling this barrier through slightly different (but similar) visions for a national health IT backbone, as well as removing the legal barriers to the movement of your data along such a backbone.

### Technology

Technological obstacles to the free movement data have largely vanished as cloud computing becomes ever more robust and affordable and as interconnectivity standards such as HL7 FHIR and Journal standards such as OpenEHR become more prevalent. Yes, there still are some small bumps along the way (discussed later) but, generally speaking, connecting two disparate journal systems is not a technical issue. That's two down. here as this movement gains momentum.



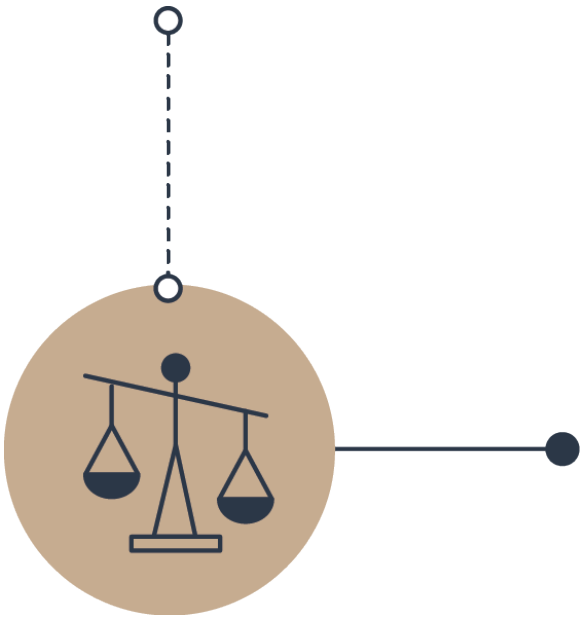
### Competition

The Competition obstacle is really only relevant in a private healthcare market where there is little incentive to share patient data with competing health providers. In a functioning Welfare State (such as the Nordics) with well-funded public healthcare services this isn't really a factor. Your care providers don't greedily hold onto your data for fear of loosing you to another care provider (although interestingly the new Finnish SOTE reform includes a vision for "customer-oriented freedom of choice", which is one to watch). So that's three of the obstacles to free movement of your health data gone.

## Governance

All that's remaining then is governance. If disparate systems can legally talk to each other about you, are incentivised to do so, have your consent and there is no technical obstacle… then what's the problem? [Spoiler Alert: here comes blockchain]

Well, who would you trust to run this sharing-is-caring network? The Government, perhaps (via the national Healthcare Authorities)? Certainly this would be the natural choice as a broker between all the care providers who sit on some of your data. But even if you trust the government not to act maliciously (to not use your data for nefarious purposes), do you trust them to be efficient and effective? Do you trust them not to be influenced by political ambition or corporate pressure? Do you trust their solution to be secure?



If disparate systems can legally talk to each other, have your consent, are incentivised to do so and there is no technical barrier then…

**Who will govern the flow of data?**

There is a growing libertarian movement which most certainly does not. Libertarians come in many shapes and sizes, from the extreme to the moderate. But an innate distrust of large organisations (be it governmental or corporate) is part of what unites libertarians, as well as a vision of a society which obviates the need for some or all of these organisations.

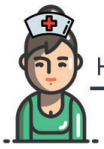
# The libertarian ideal

The Bitcoin movement was born out of a libertarian ideal to remove the dependency on fiat (government backed) currencies. It's peer-to-peer, semi-anonymous network (a blockchain, actually) which has at its heart a clever consent mechanism, is useful in an ecosystem where all parties naturally distrust one another.

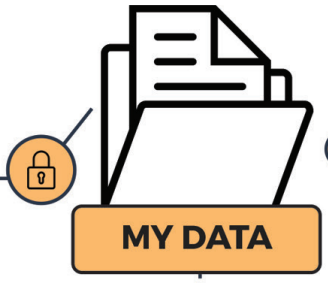
Bitcoin works (for now) because the consent mechanism cannot be compromised without spending more money that you would gain. But a digital currency like Bitcoin is only one use for a peer-to-peer blockchain. A blockchain is a cryptographically secure mechanism for sharing and storing state, any state. It is incorruptible, immutable, and fully auditable. But what you store on a blockchain can be almost anything you like. Blockchain relies on algorithms rather than corporations and people to secure data. Even the company who provides the blockchain solution can not themselves compromise the blockchain network. This is the beauty of blockchain for libertarians. But you don't need to be a libertarian to be interested in the free movement of your personal data. If blockchain can be leveraged to independently store and securely transfer your data then…

Libertarian or not, this is a great vision, and blockchain looks like it has an important role to play here.

We're not yet ready for a Global Health Record stored on blockchain but coupled with such technologies as as IPFS and Storj, and incorporating such features as Smart Contracts (not part of Bitcoin, already part of Ethereum and soon Hyperledger Fabric), blockchain brings us very close. So close that Google has just announced that their DeepMind Health team will develop "verifiable data audits" powered by blockchain.



Healthcare provider 1




Josephine Doe PATIENT

I own my data and have given consent for my data to freely move between my health providers!

OBSTACLE 1 LEGISLATION

Each Nordic country is battling this barrier through slightly different (but similar) visions for a national health IT backbone, as well as removing the legal barriers to the movement of your data along such a backbone.

TECHNOLOGY OBSTACLE 2

Technological barriers to the free movement data have largely vanished as cloud computing becomes ever more robust and affordable and as interconnectivity standards have become more prevalent.

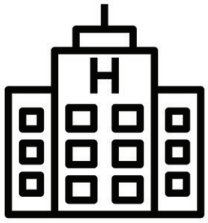
OBSTACLE 3 COMPETITION

The Competition barrier is really only relevant in a private healthcare market where there is little incentive to share patient data with competing health providers.

GOVERNANCE OBSTACLE 4

If disparate systems can legally talk to each other, have your consent, are incentivised to do so and there is no technical barrier then...

**Who will govern the flow of data?**




Healthcare provider 2

# California-based startup Gem

**What's interesting (especially in light of the quest for the Killer App) is the approach taken by companies such as California-based startup Gem. Instead of focusing on the low level blockchain, Gem is interested in what sort of infrastructure can be built on top.**

They ask the question what a technology such as Distributed Ledgers enables. Their offering is an application platform for Enterprises to build their own data exchange networks ('GemOS'). Since Tieto has large offering portfolios in industries as diverse as Finance, Healthcare, Welfare and Education what interests us about GemOS is that such a network is useful for more than one industry AND these networks have the potential to be plugged together across industries. GemOS hints at a future where a super-secure, peer-to-peer data exchange network allows you to shuffle your own personal data between your bank, your real estate agent, your social care caseworker, the planning permission office, your doctor and your kid's teacher. Smart Contracts enable automatic triggering of rules (expiration, auto-deletion, or more nuanced business rules etc.) and fine-grained access management allows you to control who can see what and for how long. Voila! A multi-party record-keeping system with an immutable audit trail, organized around unique, global identities. As well as putting you in control such a network would have tremendous value for applications focused on patient-centric record management, IoT wellness networks, emergency responsiveness, cost and care transparency or population health management.

Which brings us all very close to that killer app for Healthcare IT. For anyone working in this area one approach is to sit back and wait for it to appear, then hope that you recognise it when it does, and can act on it. The lesson from history however, is that you probably won't recognise it. In the early 1990s very few companies recognised the impact of the World Wide Web. Blockbuster certainly didn't. It was offered a small company called Netflix for 50M USD. Blockbuster declined. It's now long gone and Netflix is worth about 15B USD.

So, instead of sitting and waiting, we should be actively preparing ourselves for the inevitable disruption, which is nipping at our heels.. Healthcare organisations, vendors, technology companies, and patient groups, we all need to move now!

For more information on Gem and their approach to healthcare, visit https://gem.co/health.

# We all need to move now!

- We need to be better at explaining why secure and seamless data flow is important, to patients, to physicians, to care organisations, to vendors.
- We need to be crystal clear about data ownership, control and use. Who, what, when and how.
- We need to be putting more investments into ironing out the remaining bumps in blockchain, as well as harmonising the different blockchain technologies. Ethereum, Bitcoin, Hyperledger are only the first wave. New arrivals include Iota and soon K-Chains, "for quantum transactions." They are all incompatible.
- We need to be working together with patient groups to build a framework for consent, and make this as frictionless as possible. The MyData movement is critical here.
- We need to be debating and defining the ethics of data transfer (not just the legislation). What is ethical "secondary use" of your data for example? Should it be opt-out or opt-in?
- More than anything, we all need to have our heads out of the sand and be looking ahead. If you are an IT vendor acting as a custodian for patient data, then your business in ten years will not look like your business today (presuming you still are in business in ten years).
- If we put more effort in now, then there's no reason we can't all benefit from an exciting technology such as blockchain and make the care process more integrated and seamless. The only remaining roadblock preventing us from living in a world where our health data flows around us is lack of imagination.

Tieto aims to capture the significant opportunities of the data-driven world and turn them into lifelong value for people, business and society. We aim to be customers' first choice for business renewal by combining our software and services capabilities with a strong drive for co-innovation and ecosystems.

**www.tieto.com**

tieto