When laying the foundation for a robust interoperable healthcare system, we need to start at the protocol level and design new infrastructure that is owned and controlled by no one and everyone. We need identity and digital value protocol layers and we need immutable health records controlled by their rightful owners. Due to regional data protection regulations, like GDPR, privacy sensitive information, like health records, must be guaranteed to stay within specific geographic jurisdictions. This is why public chain deployment is not yet an option. Together with The Enterprise Ethereum Alliance, we want to contribute to the development of required tooling and policy frameworks to run permissioned blockchains as critical infrastructure. Leveraging the decentralized computing platform, we are reinventing data management for the entire healthcare system. We are forming a consortium, CareChain, to deploy Trusted Infrastructure, starting in Sweden and the European Union and progressively in other jurisdictions.

From the press release when CareChain joined the Enterprise Ethereum Alliance

CareChain is an initiative and a consortium that aims to create interoperable national blockchains for health data. A blockchain makes it possible for the first time to give individuals ownership and control over their own health information.

It is no longer just technology enthusiasts who collect data about themselves via their own sensors (wearables). A study from 2016 shows that 32 percent of the population in Sweden registers their weight and that 26 percent registered their training data. Twenty percent have shared self-generated data with care practitioners. The number of individuals engaging in their own health and care is rapidly increasing, with the technological development of wearables and sensors instrumenting the human body moving at amazing rates. Healthcare and research professionals are showing an accelerating interest in supplementing journal and research data with large amounts of self-generated data. Such a wealth of data allows them to extract key insights by running analyses across the entire data and full history, including each measurement, journal entry, diagnosis, drug intake, surgical procedures as well as environmental and lifestyle factors that contribute to health and disease risk.

This raises the question of who actually owns the information and under what conditions others can be permitted access, and for what purposes. Here we can see an attitude shift that, in combination with new legislation such as PSD2 and the European Data Protection Regulation (GDPR), enhances the rights of individuals to their own data. Additionally, recently both the

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2 https://en.wikipedia.org/wiki/Payment_Services_Directive#Revised_Directive_on_Payment_Services_(PSD2)
governments of the Netherlands and Finland turned it into law that individuals have an absolute right to their health records.

We envision individuals themselves possessing and managing the rapidly increasing amount of health data and thus gain the opportunity to actively engage in their healthcare as consumers rather than merely as patients. Additionally, they become empowered to offer both healthcare professionals and researchers access to their entire health history as well as to directly purchase services in a global marketplace to improve their health.

To unlock this potential, a number of challenges must be addressed.

1. **A universal digital ID.** All health data must be rooted in a universal digital identity owned and controlled by the individual. It is a cornerstone in each system designed to put the individual at the centre.
2. **Guaranteed, Integrated Information Integrity.** The system must in its basic structure ensure that the information is authentic and cannot be manipulated.
3. **Built-in policy guarantees with traceability.** All actors must be able to verify that sharing, analysis and other handling and use of the information has been done based on the owner's, ie the individual's intentions and in accordance with applicable laws, regulations and processes. All events must be verifiable and traceable to all actors.

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**The Blockchain - part of the new internet**

The research in cryptography and decentralised systems that allowed the crypto exchange Bitcoin has produced technology in the form of new communication protocols that enable fully decentralised systems to be built in which all actors can act based on a common definition of truth. This truth is forever enrolled in a digital ledger accessible by all actors and which cannot be manipulated. It is a common misconception that this means that posted events cannot be changed. Of course, that is not the case. The information can be updated in the same way that you can register a verification to correct an error in the bookkeeping. However, history is always left untampered.

For a crypto-currency such as Bitcoin, the ledger contains all transfers of Bitcoins (transactions) ever made on the network, so that all stakeholders can know who owns specific bitcoins and ensure they can not be used more than once. Bitcoin has been followed by several further developments of the concept, such as the highly acclaimed Ethereum³, to support business relations and processes being run on the same integrity-assured basic technology, as well as other related protocols for decentralised messaging and data storage. Hereafter, we refer to all of these technologies as the Blockchain (or Web 3.0) in the absence of established terminology. While Bitcoin's ledger handles the latest balance, ie. which identity controls what bitcoins, Ethereum generalises the concept to keep track of the state of a program, ie the current value of input and output variables. This type of program is called *Smart Contract.*

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³ [https://ethereum.org](https://ethereum.org)
Decentralised Systems

A decentralised system consists of a number of parties acting individually to achieve the overall function of the system. The actors in a decentralised system can organise themselves, identify each other, as well as protect communication between themselves. There is no central authority that can make decisions on behalf of other actors, all are equal, so-called "peers".

This means, for example, that there is no "cloud" or any other central server in the system.

Using the Blockchain, we can construct systems of information, processes and apps that are rooted in a digital ID owned and controlled by the individual. The applications in such a system are called Decentralised Apps and communicate with other dApps and other players in the system directly peer-to-peer, ie without going through any central server.

The information is stored encrypted in common by all actors on the network, such that only the information owner can compile and unlock the complete information.

Information in existing systems can be cryptographically linked to the digital identity and thus signed into the blockchain and thereby, during a transition period, remain in the original system while retaining the same authenticity guarantees.

Self-Sovereign Identity

Currently, in Sweden, we do not have a system for National Digital Identity. We only have a solution for the Digital Identifier Personal Identification Number ("personnummer"). This means that all other aspects of our identities are dispersed and stored in thousands of different databases of the service providers. Our solution is different. We allow the individual to manage and control all aspects of identity in the form of Verified Claims, ie attributes and data digitally signed by an issuer. It could be the clinic administrating a vaccination providing a digital certificate.

DIGITAL IDENTIFIER ≠ DIGITAL IDENTITY

© CareChain AB
This means that we will re-architect our systems so that data in the form of Verified Claims will reside with its rightful owner while the computation or query will have to come to the data. A particular application is Distributed Machine Learning where the millions of parameters of a Deep Learning Neural Network are set by training on-device and data providers are re-numerated, in crypto-tokens, according to how much they improve the quality of the model.4

A true Digital Identity application needs to not only manage the collection of Verified Claims from all different data sources but also allow for Self-Generated Claims aka Patient Reported Data. This data will be essential to Precision & Predictive Health as it provides the only clues before an episode of disease.

This has massive implications. This is Privacy-by-Design and to a large extent makes Data Protection Regulations obsolete. Business models will also have to be redesigned for this new reality.

The advantages of a consortium

A consortium can establish a blockchain to which everyone can connect, but where only members, independent organisations who enjoy public trust, are jointly responsible for the computers (nodes) that verify the transactions. In other words, the nodes managed by the consortium members guarantee network integrity. To falsify the information in a consortium chain such as CareChain would require an attacker to break in to a majority of consortium members, which in practice would be nearly impossible, or that more than half of the organisations would agree to rewrite history and thus individually risk their public trust.

4 This can be used to subsidise health insurance; the sicker you are the more impact on the model and more value.
In contrast, today’s public blockchains use a model for verifying transactions based on the so-called mining nodes individually solving calculation-intensive problems, known as proof-of-work. This model limits the chain capacity and can introduce a latency which is inappropriate for the transaction volumes that CareChain will handle. Additionally, use of today’s public blockchain offers no way to ensure that the information on the Blockchain stays in a particular geographical region.

The CareChain consortium requires no mining, as members trust each other and can be held legally responsible for deviations from this agreement. The capacity to handle large transaction volumes is thereby dramatically increased and the unfortunate ecological side effect in terms of significant energy usage, as required by proof-of-work verifications is also avoided.

Intraplanetary Roadmap

Although the data protection legislation is now being harmonised with GDPR the Patient Data Laws are still different in each jurisdiction why we propose national interoperable CareChains. Standard interchain protocols will however allow for the exchange of identities and data across the Internet of CareChains to realise the vision for global healthcare inclusion as a sustainable development goal. The different chains do not even have to be running the same software, what matters is that they all conform to the DID\(^5\) identity standard.

![NETWORK OF CARECHAINS](https://decentralized.id)

Scaling Healthcare - a first Use Case

It is already clear that hospital care does not scale. Limiting scalability is not only hospital beds but also access to scarce medical expertise; only so many doctors can be educated and deployed.

In a joint innovation project CareChain and Karolinska University Hospital are now looking towards blockchain technology to tackle some of the fundamental challenges involved in achieving a truly scalable solution.

\(^5\) [https://decentralized.id](https://decentralized.id)
When designing a scalability strategy the most natural approach would be to aim for more of a **self-service** approach; having the patients monitor themselves in their own beds at home. The main challenge to overcome here is that of being able to **trust** the data monitoring and to be able to **efficiently communicate** on a higher semantic level to reduce the risk of error. Can Blockchain help here?

But we do not stop here, once the platform for caregivers has been studied we move onto the more general challenge involved in data management for clinical research and a reinvented healthcare ecosystem. The ultimate goal of the CareChain initiative is really to **enable population scale machine learning** to re-program disease and **debug health**.

**Platform**

An absolute requirement of any non-trivial blockchain solution is that all the actors involved are able to manage **self-sovereign identities** and sign transactions. The most natural choice here is the standard proposed by the [Decentralized Identity Foundation](https://www.decentralized-identity.org/) in collaboration with the United Nations **id2020.org** project. The particular implementation used is **uPort** running on [Enterprise Ethereum Alliance](https://www.enterprisedistributedledger.org/) permissioned network.

Last mile connectivity, in this particular implementation, is provided by **Intel Health Application Platform** and their secure multi-protocol domestic gateway.

**Decentralised Hospital Care**

The scenario is this:

1. A patient has been admitted to hospital care and the condition is no longer critical. In addition, in the case of a deteriorating condition, emergency intervention is required sooner than 30 minutes (the maximum time to get back to the hospital by ambulance).
2. A patient is relatively stable but suffers from a chronic condition that requires constant surveillance.

If this is the case we can prescribe **ASIH - Advanced Hospital Care in the Home** - and send the patient home with the CareConnect App and appropriate medical grade monitoring equipment.

**Continuous Asynchronous Care**

Human medical expertise can either be substituted for, or at least augmented by, machine intelligence or more efficiently distributed by an asynchronous deployment rather than synchronously on a patient by patient basis.

Each doctor can manage a large number of patients using social networking mechanisms such as even feeds, chat and video. Using an advanced decision support system we can demand full attention, by sending a notification alert, only when needed.
Semantic Communication

In addition to the inherently semantic data provided by medical devices and analytics we also introduce the concept of Smart Regimes. They are interactive tasks that can be prescribed and deployed to the patient app to for instance track Mood, Cognition or determine resting pulse after exercise and much more. Standardised Care Plans will be composed from a set of mandatory Smart Regimes customised to fit the monitoring needs for a certain condition.

This way we collect the kind of structured data that is essential for machine intelligence while at the same time we providing immutable data lineage and provenance. Semantics and the inherent data provenance is what sets our solution apart from other prevalent simplistic telemedicine solutions. These Care Plans can obviously also be generalised to prescribing the data collection requirements in a clinical trial setting.

Collaborative Care

Where the solution really excels is in being able to cross the trust boundaries of multiple organisations enabling collaboration between hospital specialists, primary care doctors as well home care personell.

Also, since the Health Records are Personal and Self-Sovereign patients can, at their own discretion decide to include world expertise for a second opinion or informal caregivers from the family in the thread.

The alternative would be a point to point backend integration between every party involved in the patient
journey or dictating that every caregiver use the same standardised and centralised system. This is simply not a viable strategy in an international context.

Health-as-a-Service, Research and the Future

The study is not yet completed but we can already see that Blockchain is indeed crucial for this application. It is the only way to realise the Self-Sovereign Personal Health Record and gives us trusted data provenance as well as a natural integration point across organisations where no other integration exists.

We believe that in the future we will buy (or be provided with) Health-as-a-Service combining the best of breed of specialists from a worldwide market. This kind of platform will be fundamental to realising this vision. Intermittently it is interesting that the public health insurance systems compensates care givers per event, per patient contact. This opens up for a free subscription model where the platform would generate more revenue the more care is being provided while at the same time providing real world evidence to power the marketplace.

Once individuals are in control of their data we have the perfect network in which to deploy large scale clinical trials and research studies. We can broadcast invitations to the network and depending on eligibility offers for participation can be made.

To conclude with the bigger picture, here is our prophecy for the future of health management:

1. Pharmaceutical companies will become data companies. Having access to the best data will be the main competitive differentiator.
2. Pharma will, just as logistics, media and social networking before be driven by network effects
3. We will see the rise of a new type of company as the hybrid between pharma, care provider and insurance. All disciplines that can profit from data to manage cost or boost profit.
4. Patient **privacy and control** will be crucial. Patients will be able to leverage the value of their data both financially and healthwise.
5. From the current inflection point in drug (and other preventive remedies) development efficiency we will see **exponential gains** in outcomes and life expectancy.

This is clearly not a zero sum game. The values **unleashed and created** by this platform will be enormous, dwarfing that of all preceding platforms and enterprises regardless of vertical. Ultimately, we believe all value is created around marketplaces and want to create markets for data, training of and trained machine learning models.

**Roadmap**

Our three phased approach starts with developing the Self-Sovereign Personal Health Record platform for users who are either prescribed the app by their doctors or are highly motivated by chronic disease requiring careful monitoring. We will collect real time evidence and patient reported outcomes and experiences.

The next step is all about distribution and standardisation. We are already working with key industrial stakeholders to establish the infrastructure consortium and patient organisations including a strategic partnership with WarOnCancer⁶, a social community for cancer warriors, to distribute the patient app in order to become the de-facto standard for real world evidence. In the last phase our network of data owners will be invited to make their data available to research while preserving their privacy using distributed machine learning and cryptographic techniques such as zero-knowledge proofs and homomorphic encryption.

**Concluding**

CareChain is the only consortium of its kind in the world. It represents a completely new decentralised data platform for health data that is **not owned or controlled by any individual**

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organisation but which puts the individual at the center and addressable by identity not location. By being completely open and politically neutral, both the major system suppliers to healthcare as well as app developers can experiment with the new protocols in a public-private partnership. Philosophically the ownership and governance structure is similar to that of the Internet and the World Wide Web where each participant contributes to the network effect. We believe this is an absolutely crucial success factor and CareChain consortium participation generates strong network effects in more rapidly developing a new architecture that integrates individual and health-generated data under the control of individuals and in harmony with GDPR and similar international legislations. At the same time, the opportunity to create benefits for other actors is opened by sharing health data, in plain text or anonymised in social groups for analysis or investing data in clinical research pro-bono or for token profits.

We are now actively soliciting

1. More organisational members and nation states to join us, to contribute mining nodes, integrations and distribution - legislation mandatory would help here!
2. Real world use cases proving the concept will also need to be worked on why we invite collaborators in this area too.
4. National support to establish a Testbed and the Innovation Platform

"You never change things by fighting the existing reality. To change something, build a new model that makes the existing model obsolete."
– R. Buckminster Fuller

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7 https://www.government.nl/topics/ehealth/government-encouraging-use-of-ehealth