DONATE YOUR DATA

Product Report

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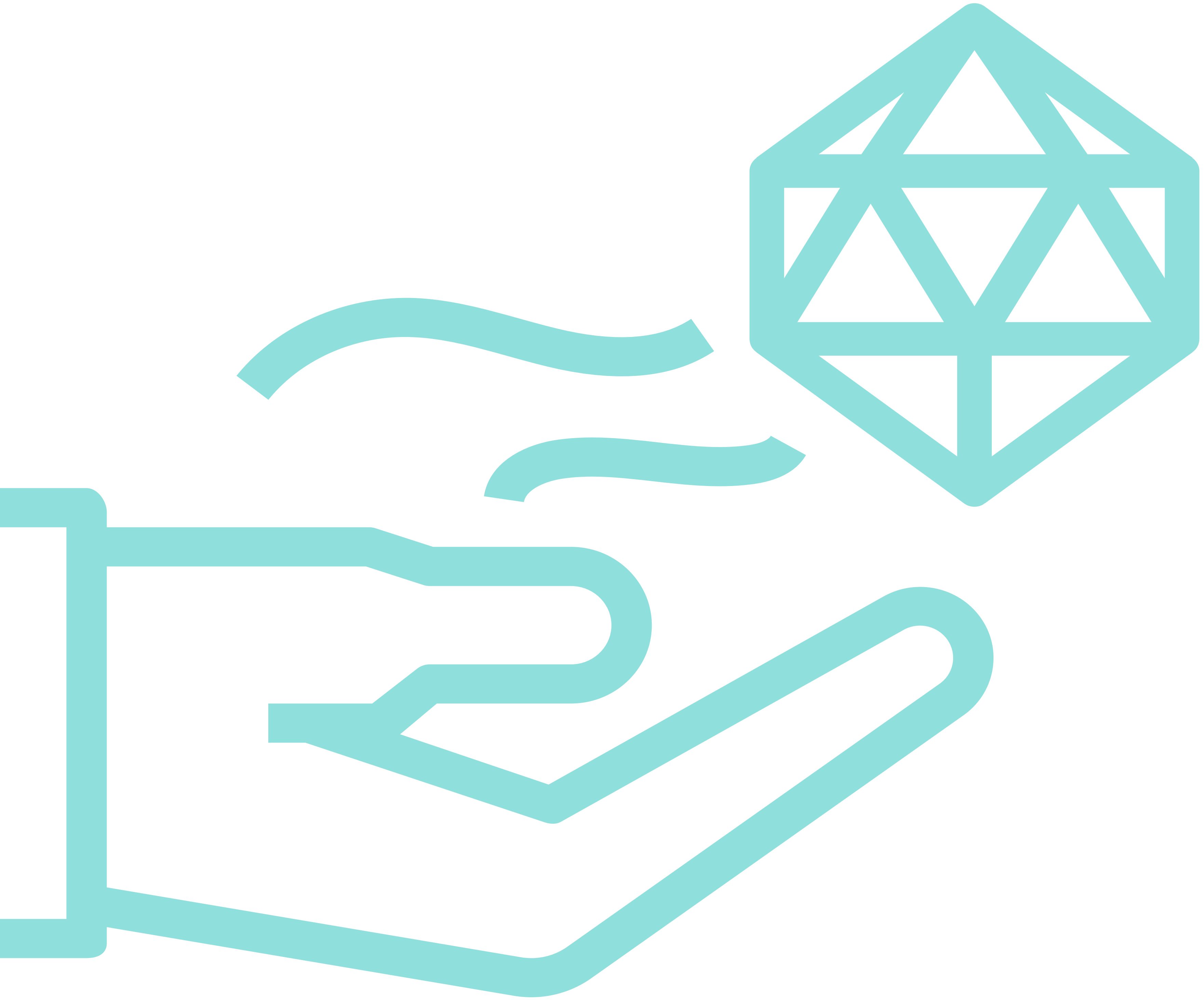

ABSTRACT

Denmark has some of the most well-preserved and public data repositories in the world. Since the 1970s, successive governments have prioritised the development and maintenance of well-structured population datasets, gathering information on all aspects of citizens’ lives.

As society moves deeper into the Information Age, there is a growing discussion on the subject of digital rights and the subject of ownership, in particular. Also at this time, digital health records are becoming a highly valuable source of information for health researchers. However, one of the major obstacles researchers face is the time it takes to apply and receive access to relevant population health data, a process which can take between 12-18 months.

Donate Your Data is a service designed to allow individuals to receive ownership of their personal health data in order to make choices on how to donate their digital information for use in public health research studies. The service offers researchers the opportunity to instantly access digital health information according to the level of pre-consent that is selected by ‘data donors’. Donate Your Data makes it easier for researchers to gain legitimate access to historic and real-time population health data. The system behind the service is designed to handle personal health information in a trustworthy, transparent way by leveraging the power of a distributed ledger mechanism offered by the nascent technology, Blockchain.

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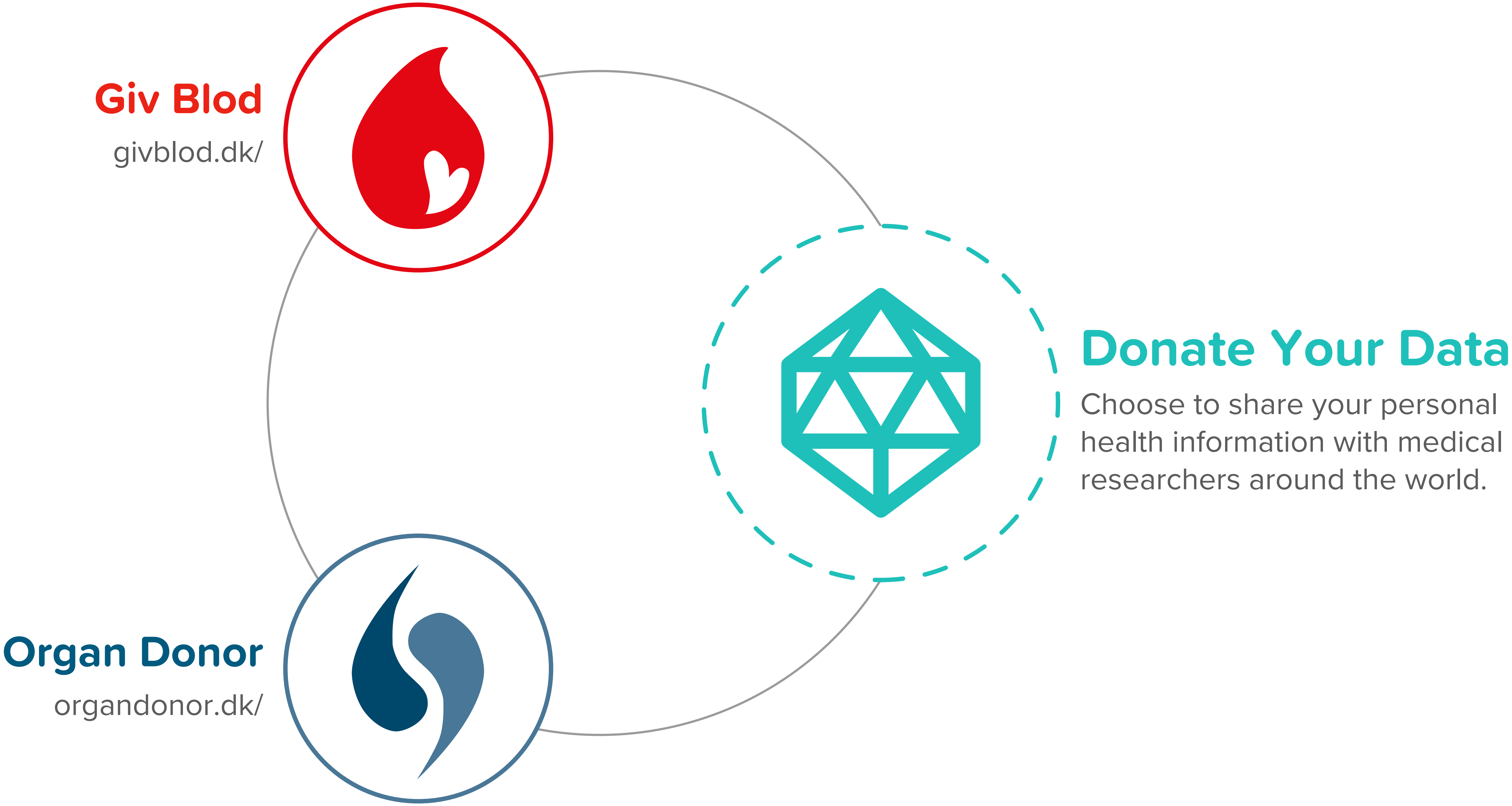


Giv Blod

givblod.dk/

Organ Donor

organdonor.dk/

Donate Your Data

Choose to share your personal health information with medical researchers around the world.

Figure 0.1: Health donation services in Denmark

OVERVIEW

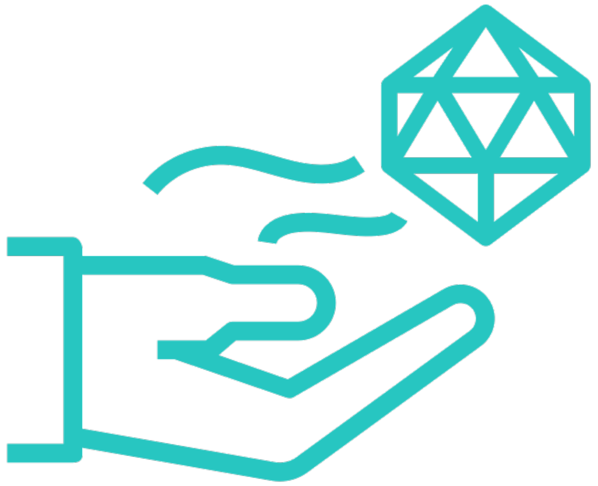
A SERVICE TO ALLOW PEOPLE TO CLAIM AND ACTIVATE THEIR PERSONAL HEALTH CARE DATA VIA A BLOCKCHAIN-SUPPORTED SYSTEM

Donate Your Data provides individuals with the option to activate their personal health data for use in health research studies around the world. It operates according to a peer-to-peer model, allowing information to be directly shared between individuals and researchers without the need for an intermediary.

The primary purpose of the service is to increase the ease in which researchers can be granted legitimate access to relevant, valuable health data, while providing individuals with full transparency and control over how their data is shared and used in health research studies.

Positioned and presented alongside existing health donation services (Figure 0.1), Donate Your Data will be regarded as the primary digital information donation service, offering 'data donors' control over where and when their data is accessed and for what purpose.

Similar to how people today register to donate blood and organs, it will soon be possible to become a “health data donor”, and make a choice over which research institutions are permitted access to your personal health data.



Make a digital donation to health research

DONATE YOUR DATA

1. BACKGROUND

INTRODUCTION

ALLOWING FOR EASIER ACCESS TO POPULATION HEALTH DATA WHILE GIVING INDIVIDUALS CONTROL OF THEIR PERSONAL DATA

Scientific researchers based at public institutions can spend up to eighty percent of their time searching for and requesting access to relevant and appropriate datasets. Typically, this is due to how current legal frameworks are set up to ensure that citizen information is stored securely, providing access only through a formal application process. At the same time, individuals are becoming more aware and concerned about how their personal data is handled by multinational corporations and states.

Digital technology is developing at a rapid pace and, as a result, nations are struggling to adjust their laws to protect the digital rights of their citizens. However, there may be a solution in technology itself. Blockchain has been descibed as having the potential to disrupt the ways in which digital information is structured and stored, with speculation that it could pave the way for individuals to take ownership and control over their personal data. Although the technology is still in its infancy, it has now reached a stage at which it seems possible to start designing and piloting new digital service systems.

> *“Personal data has increasingly significant social, economic, and practical value. According to The World Economic Forum, ”Personal data is becoming a new economic asset class, a valuable resource for the 21st century that will touch all aspects of society”. The wider application and use of personal data, however, is often conflated with negative predictions of a future devoid of individual privacy.”*
>
> POIKOLA ET AL. (2017)

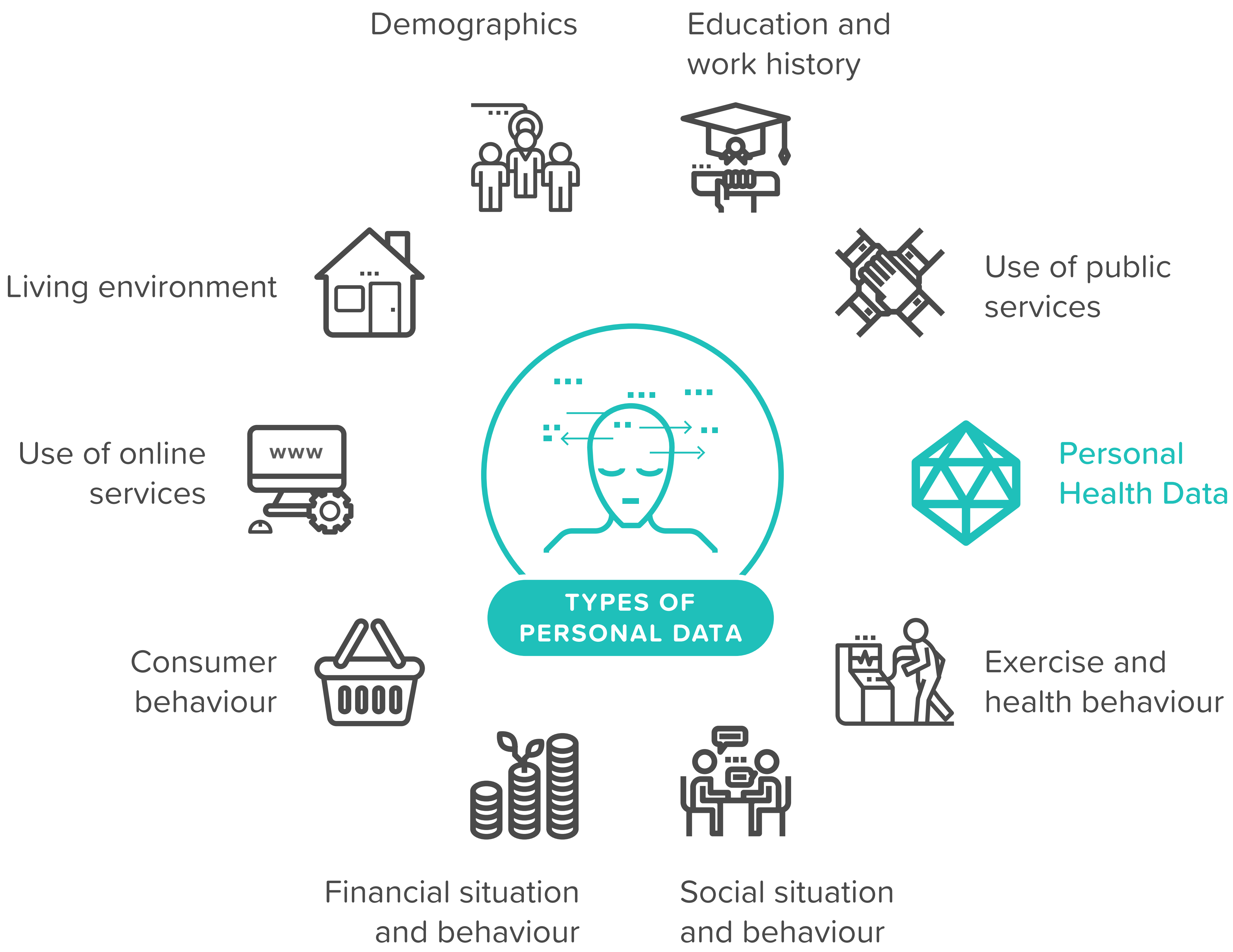


Figure 1.1: Types of personal data

Attributions: Poikola et al. (2015)

PERSONAL DATA

PEOPLE ARE CONTINOUSLY GENERATING INFORMATION THAT IS CAPTURED, DIGITISED AND CONVERTED INTO VALUE BY SERVICE PROVIDERS

In today's digital society, information is created and categorised across hundreds of different activities (Figure 1.1). Every time someone interacts with a digital service – such as logging in online, making a purchase using a credit card, or visiting a health clinic in person – information is being generated, captured and stored against a digitised representation of that person. Organisations are then able to analyse these service interactions and develop more advanced service opportunities that can meet the needs and personal preferences of the individual.

As a person adds a new digital service into their lifestyle, they accept a set of terms and conditions that allow the service provider to manage, manipulate and monetise their personal information. Many people are oblivious or apathetic to the fact that they are sharing an enormous amount of personal and sensitive information about themselves, undermining the value of their personal data as they sign away control and ownership in exchange for access to a digital service or application.

> *“Data are to this century what oil was to the last one: a driver of growth and change. Flows of data have created new infrastructure, new businesses, new monopolies, new politics and economics.”*
>
> THE ECONOMIST (2017)

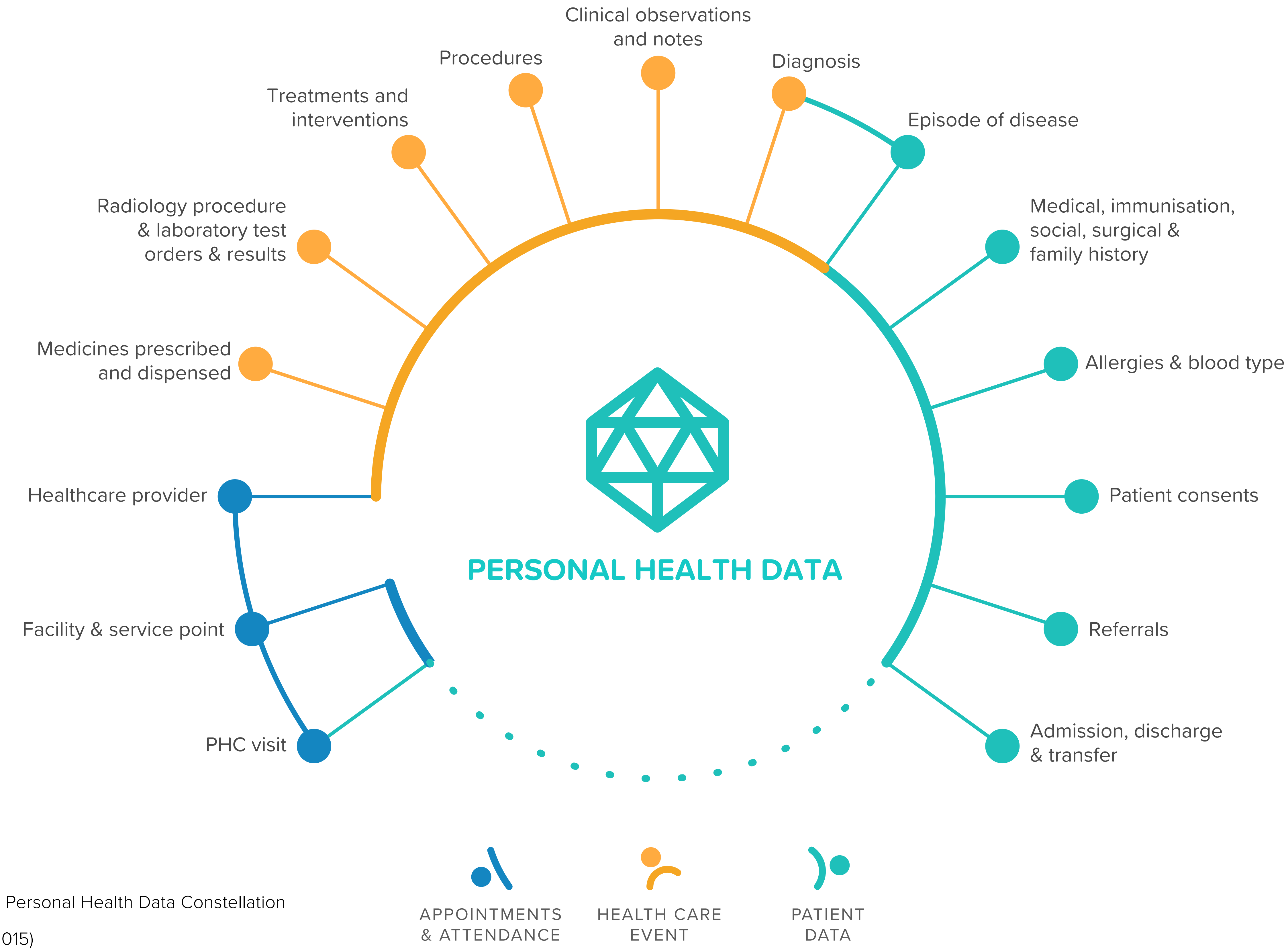


Figure 1.2: Primary Health Care Personal Health Data Constellation

Attribution: Kotzé and Foster (2015)

DIGITAL HEALTH DATA

WITHIN MEDICAL SERVICES THERE ARE

Each time you use a public or private health service, information is captured about your visit, diagnosis and treatment. This information is typically recorded and stored in 'data silos' across many different locations, both nationally and abroad. These silos are built to be secure and trustworthy, however this comes at a cost: it is more difficult to open datasets for use outside of public services, such as for health research and development projects.

Figure 1.2 displays the complexity and depth of information that is captured during interactions with health services. This information, were it made available alongside other data sources (such as demographics) would provide a deeper and more immediate value for health research studies. There is a challenge when addressing the balance of costs versus benefits of making data available to researchers. However it is considered essential that this data remains open and freely accessible to academic and public researchers, not least to ensure access to data for replication of results (Institute of Medicine, 2010).

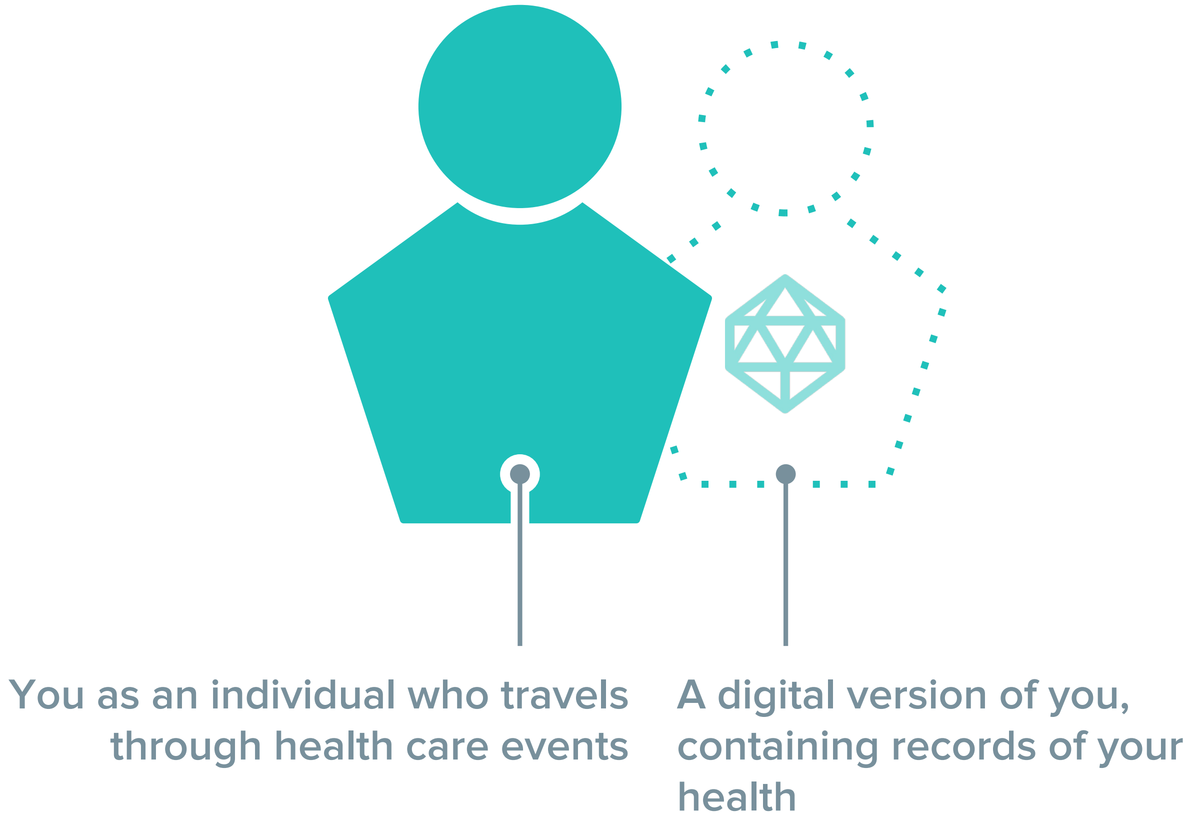


Figure: Your digital health persona

> *"Health research enhances the possibilities of leading a good life with or without disease."*
>
> DET ETISKE RÅD / DANISH COUNCIL OF ETHICS (2015)

> *“Europe is very proud of its cultural diversity; however, exploitation of the data made available through advances in genome medicine, imaging, and a wide range of mobile health applications or connected devices is hampered by numerous historical, technical, legal, and political barriers.”*
>
> AUFFRAY ET AL. (2016)

HEALTH DATA LANDSCAPE IN DENMARK

DENMARK IS WELL POSITIONED TO SEEK OUT NEW WAYS IN WHICH TO UTILISE AND INCREASE THE VALUE OF ITS GREAT DATA RESOURCES

In comparison with similar systems around the world, Denmark is generally regarded as having some of the most advanced, progressive health care and data systems in the world (Det Etiske Råd, 2015). Since the 1970s public health services in Denmark have been recording and storing health data for citizens and residents. Given Denmark's great data resources, it is well positioned to seek out new and innovative directions in which to utilise and maximise the value of this information.

Like other Nordic countries, Denmark can be regarded as a frontrunner in the collection of public health information. For many decades, Denmark has kept and maintained large-scale records of demographic, clinical and treatment information relating to its citizens and residents (Leapcraft ApS, 2015). This information is captured and registered by many medical professionals such as clinicians, nurses and health service administrators, each of whom can belong to either a public or private health service.

Aside from providing an immediate benefit for individuals who receive medical diagnoses and treatment, this health data offers a secondary value in that is can be accessed and used in public health research studies. The act of requesting access to health data in Denmark is closely regulated, with an ethics committee forming an important part of the process in deciding whether or not to allow access to a set of data.

Access to healthcare datasets in Denmark today remains limited by a number of such administrative and technical frameworks that are in place to regulate the access of data (Leapcraft ApS, 2015). Despite Danish research institutions having the power to grant access to some health registers, access to other registers requires researchers to seek approval from multiple agencies. In these circumstances, the request-to-access process can take between 12-18 months. If this time period were reduced, then it would speed up the pace at which research could be performed.

EU DATA PROTECTION REFORM

ALLOWING PEOPLE TO REGAIN CONTROL OF THEIR PERSONAL DATA

EASIER ACCESS TO YOUR OWN DATA

Individuals will have more information on how their data is processed and this information shall be available in a clear and understandable way.

A RIGHT TO DATA PORTABILITY

It will be easier to transfer your personal data between service providers.

A CLARIFIED "RIGHT TO BE FORGOTTEN"

When you no longer want your data to be processed, and provided that there are no legitimate grounds for retaining it, the data will be deleted.

Figure 1.3: Most notable fundamental rights for citizens

Attributions: European Commission Press Release (2015)

DATA REFORM IN EUROPE

ALLOWING PEOPLE TO REGAIN CONTROL OF THEIR PERSONAL DATA

The rate of technological change in the 21st Century has meant that the data protection laws set out in the 1990s are no longer fit-for-purpose. People continue to develop ever more complex digital lives, signing up to hundreds of digital services and accepting terms and conditions that permit service providers power and control over how personal data is captured, stored and used.

Two-thirds of Europeans are said to be concerned about not have complete control over the personal data they generate online (European Commission, 2016), with many worried about the ways in which companies use their personal data.

By May 2018, across Europe, countries will need to have amended laws around the protection and use of personal data. Each set of national laws will be based on the same set of principles as described by the European General Data Protection Reform. Figure 1.3 indicates some of the most notable rights for citizens in the upcoming data reform.

> *“The data protection reform will strengthen the right to data protection, which is a fundamental right in the EU, and allow [Europeans] to have trust when they give their personal data.”*
>
> EUROPEAN COMMISSION (2015)

“Data can only benefit society if it has society’s trust and confidence. Now that data is being used for so many purposes, people are not just asking about who is holding information and whether it is being kept securely – they also want greater assurances about precisely what is being done with it.”

DEEPMIND BLOG (2017)

THE CHALLENGE TO BUILD TRUST

THE NEED FOR PUBLIC SUPPORT OVER THE USAGE OF PERSONAL HEALTH DATA

Studies indicate that, in general, the public have few reservations about allowing their personal health data to be used for research purposes. However, such studies have also revealed how there are low levels of awareness among the public in how their personal data is stored and managed.

In recent history, there have examples where governments have caused public controversy in attempting ‘open’ datasets of public health information without adequately consulting citizens over the intended use of data. In the United Kingdom, the (now cancelled) "care.data" project, while considered a failure, at least drew attention to the importance of ensuring public support for how data are used (Aitken et al., 2016).

Soon there will be opportunities for technology to reduce the amount of time it takes for the public to provide consent over data usage. It is thought that blockchain technology could allow citizens to make a decision for themselves over who can access their personal data. This type of individualised control could result in an increase in legitimate data available for research.

> *“Public involvement is key to successful use of large scale health data. The public need to be able to access clear, high quality, up-to-date summaries of the scientific discoveries and healthcare improvements made using data from healthcare records. This would improve patient trust, reduce opt-outs, and let patients share the value of data sharing.”*
>
> VAN STAA (2015)

> *“A blockchain-enabled, trusted exchange of health information could provide a longitudinal view of the health of an individual, generate new insights about population health, and support the move toward value-based care.”*

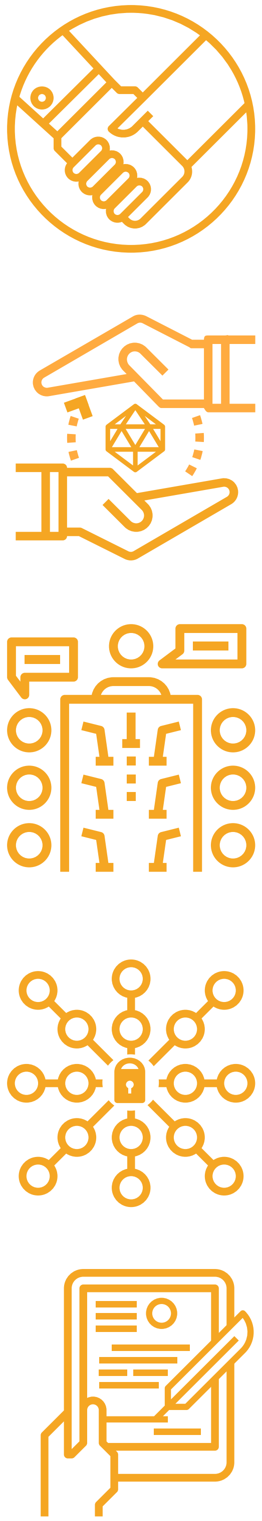
DELOITTE WHITEPAPER (2016)

BLOCKCHAIN OVERVIEW

A TECHNOLOGY WITH THE POTENTIAL FOR PROVIDING INDIVIDUALS WITH TRANSPARENCY, TRUST AND CONTROL OF THEIR DATA

Blockchain technology is a shared, immutable record of peer-to-peer transactions built from linked 'transaction blocks' and stored in a distributed ledger (Deloitte Whitepaper, 2016). The technology makes use of distributed, digital transaction records which are copied and linked together across multiple computer systems and shared between many different parties. to create a certain and verifiable record of every single transaction record (Auffray et al., 2016).

Organisations are only just beginning to speculate on the opportunities this technology could create for the distribution and activation of biomedical and healthcare data (Figure 1.4). Blockchain has the potential to be revolutionary in situations where there is a need for parties to generate and validate shared data transactions, and build trust without the need to depend on inefficient, centralised intermediaries. By announcing and vetting each transaction publicly, the technology itself is heralded as a way to offer transparency, anonymity and trust between users.



DISINTERMEDIATON OF TRUST

Everyone has access to a distributed ledger (public record) which can maintain a secure, peer-to-peer exchange without the need for complex brokered trust.

SHARED DATA

Shared data enables near real-time updates across the network to all parties, allowing for a single, shared record of truth.

DISTRIBUTED FRAMEWORK FOR DIGITAL IDENTITIES

Using private and public identifiers (secured through cryptography) to create a singular, more secure method of protecting the identity of individuals.

DISTRIBUTED, SECURE ACCESS

Distributed, secure access to patient longitudinal health data across the distributed ledger.

SMART CONTRACTS

Smart contracts create a consistent, rule-based method for accessing patient data that can be permissioned to selected organisations.

Figure 1.4: Blockchain opportunities within healthcare

Attribution: Deloitte Whitepaper (2016)

DONATE YOUR DATA

2. THE SERVICE

+

Giv Blod
givblod.dk/

Providing blood to help others during a medical emergency or course of treatment.

Organ Donor
organdonor.dk/

Providing a new lease of life by offering your body tissue to those in a medical crisis.

Donate Your Data

Allowing access to your health records to be anonymously used in medical research.

Figure 2.1: Types of health donation services

INTRODUCING THE SERVICE

PROVIDING CONTEXT BY PARTNERING WITH EXISTING HEALTH DONATION SERVICES

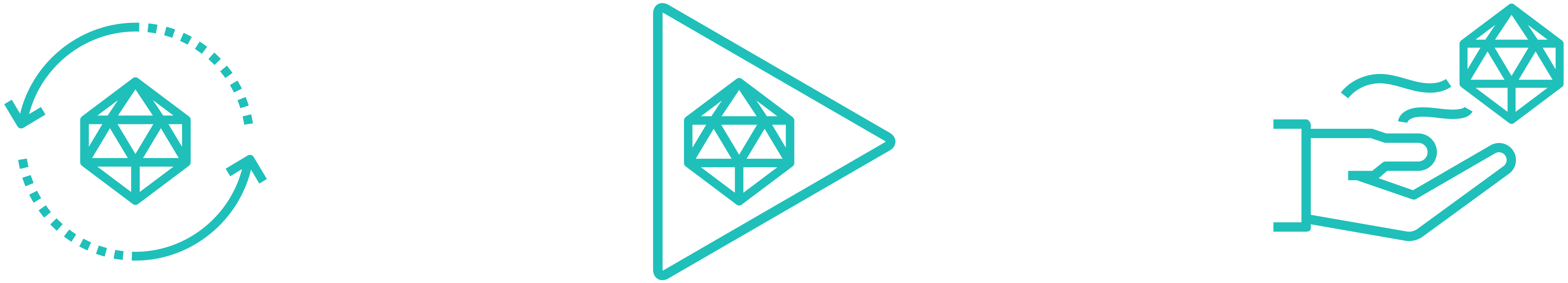
Discussions on the subject of data can be abstract and there is a risk of improperly introducting a 'data donation service' to the general public. In order to counter this risk, to increase the likelihood of public understanding, it is suggested that the Donate Your Data service is positioned alongside existing health donation services in Denmark (Figure 2.1).

Giv Blod is one of the most recognisable health donation services in Denmark today and would be a valuable partner during the rollout of the Donate Your Data service. It is thought that it will be possible to complement the existing donation service by introducing a touchpoint to allow blood donors an opportunity to request access to their personal health information. For example, when a blood donor attends an appointment, while they are waiting to give blood they could be presented with a digital touchpoint for registering as a health data donor. This could also then allow the person to provide consent for their personal health data to be used for research studies.

Donate Your Data is conceived as a pilot service for investigating how people respond to a future where they are in control of their personal health data.

DONATE YOUR HEALTH DATA

THREE CHOICES FOR WHEN YOU GRANT ACCESS TO YOUR HEALTH DATA



DONATE ALL PREVIOUS HEALTH DATA

Select to share your anonymised health history and make an immediate contribution towards the efforts of researchers across Denmark.

DONATE ALL HEALTH DATA GENERATED IN FUTURE

Give consent for your future health data to be anonymised and made available for researchers to conduct ‘live health studies’ as they develop reactive solutions to meet the needs of the population.

DONATE ALL YOUR HEALTH DATA UPON DEATH

Allow your entire health history to be anonymised and made available after you die for researchers to continue to identify trends during long-term long-term health studies.

Figure 2.2: Options when choosing to donate your personal health data

DONATION OPTIONS

HOW YOU CAN DONATE YOUR HEALTH DATA

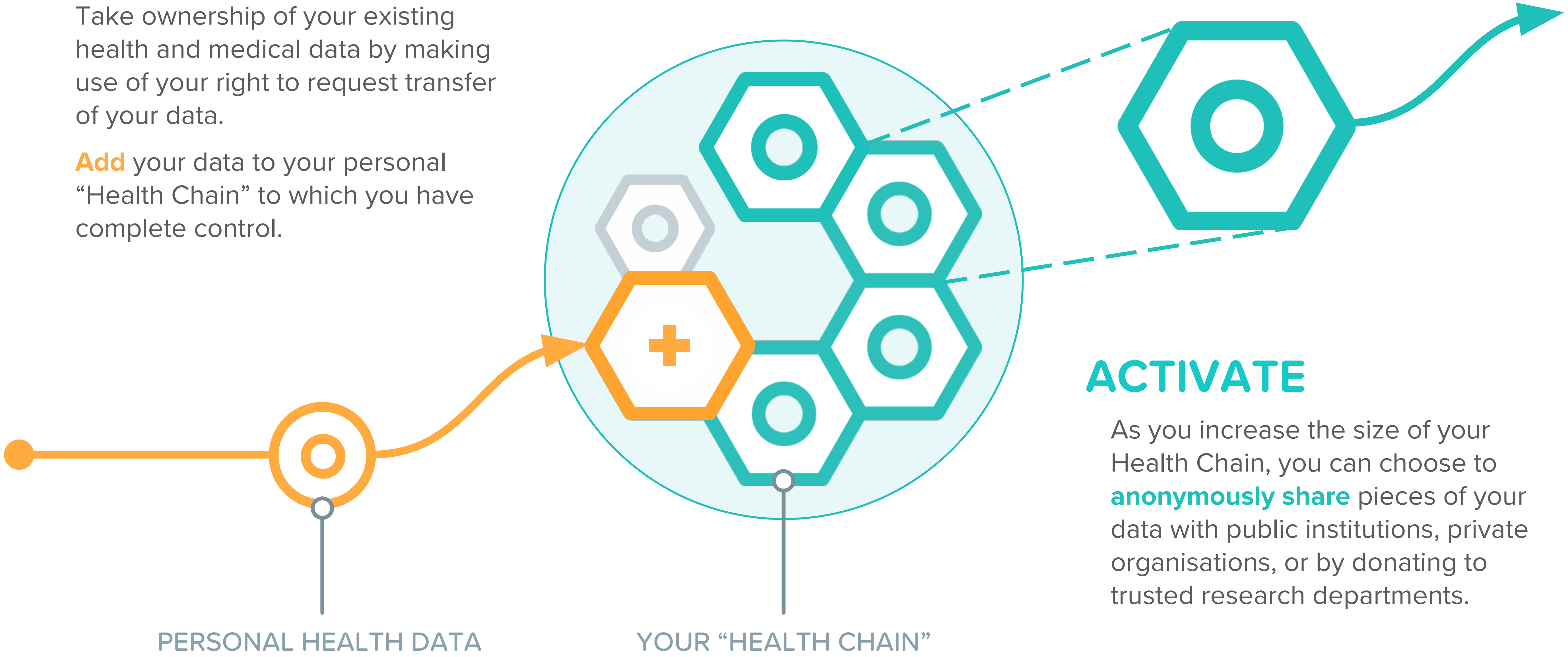
It is proposed that options for individuals joining the service are kept relatively simple. To begin with, people who register as a 'data donor' will be able to choose from three donation options (Figure 2.2). They can choose to donate all existing personal health data (requiring migration from existing databases), opt to donate all future health data (giving permission for 'live' data to be accessed by researchers) or, as a minimum, give permission for their entire health history to be donated upon death.

It is anticipated that these three options will provide individuals with a fine degree of control over what data they are comfortable to share. Furthermore, they are expected to cause the individual to consciously consider the effects of their decision, increasing their understanding about the importance of data management and control.

CLAIM

Take ownership of your existing health and medical data by making use of your right to request transfer of your data.

Add your data to your personal "Health Chain" to which you have complete control.



ACTIVATE

As you increase the size of your Health Chain, you can choose to **anonymously share** pieces of your data with public institutions, private organisations, or by donating to trusted research departments.

Figure 2.3: A two-step approach to owning and controlling personal health data

CLAIMING AND ACTIVATING DATA

GOING BEYOND CONVENTIONAL REWARDS TO PROVIDE LONG-TERM INCENTIVISATION

It is imagined that the service will be presented as a 2-step process for allowing individuals to receive ownership and control over the use of their health data (Figure 2.3). The first step is the point at which a person claims their personal health data. The second, is for the person to 'activate' their data by giving their consent over where their information can be accessed and used.

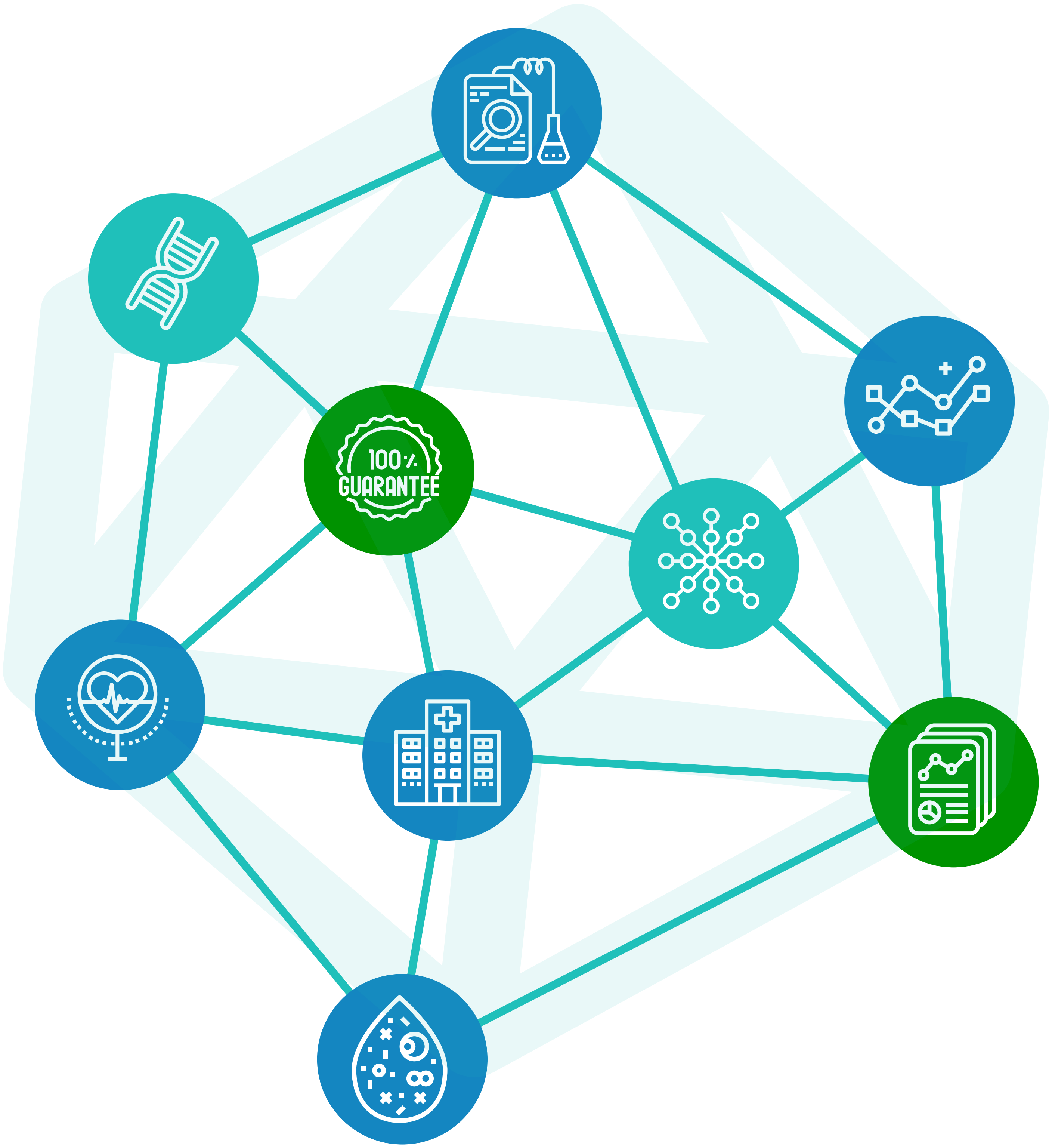


Figure 2.4: Representation of a Health Chain

THE HEALTH CHAIN

INDICATING HOW PERSONAL HEALTH DATA CAN BE RETRIEVED AND ENRICHED ALONG WITH OTHER SETS OF DATA

In order to provide researchers with the necessary depth of information required for health studies, it is proposed that a 'health chain' is offered to each individual who chooses to register with the service. This 'connected data ecosystem' would be created by collecting structured datasets from a various public, private and personal sources.

Ideally, each Health Chain would represent the entirety of an individual's digital health record, and would also include other fundamental datasets (such as demographic data) that are required for the majority of research studies. The illustration in Figure 2.4 depicts how relations between different datasets could produce more contextual meanings when analysed as part of a research study.

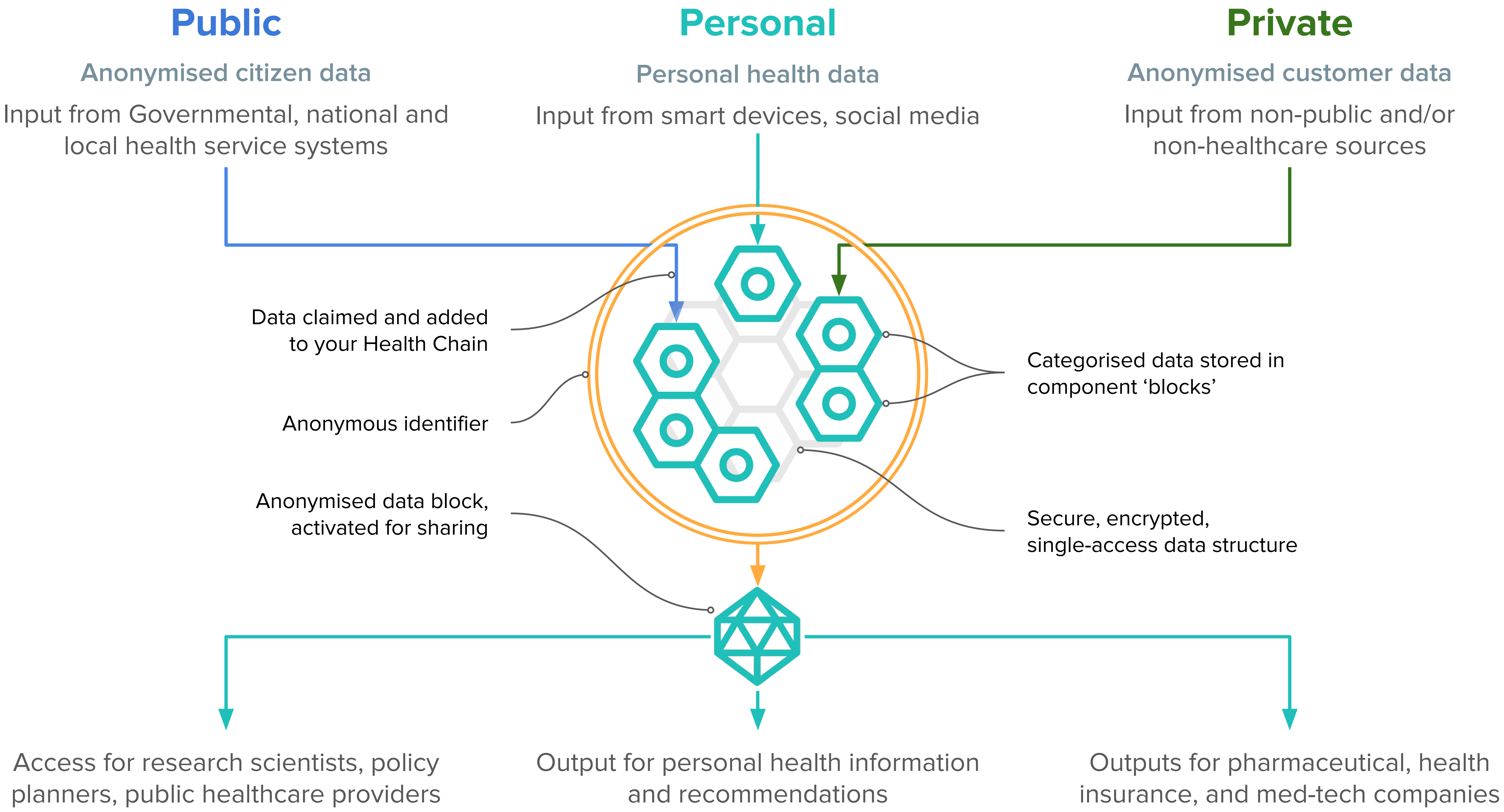


Figure 2.5: Types of personal data

Attribution: Annemette Borch (Data for Good Foundation)

SERVICE DATA

IDENTIFYING HEALTH INFORMATION SOURCES AND POTENTIAL DATA BENEFICIARIES

In order to create a personal health chain, donors would first need to make a request to access personal data that is already being stored by different organisations. Figure 2.5 indicates how data would transition from existing public, private and personal sources, into the control of the individual, before being shared based on their preference and given consent.

In order to claim a worthwhile amount of actionable data in the first instance, a pragmatic approach would be to request all personal health information that is currently stored by public health services across Denmark. This request could build upon the work already at "Sundhed.dk", an online portal which gathers and displays citizen health data from across health services in Denmark (Sundhed.dk, 2016), with Donate Your Data going a step beyond this service to act as the mechanism for activating personal health data.

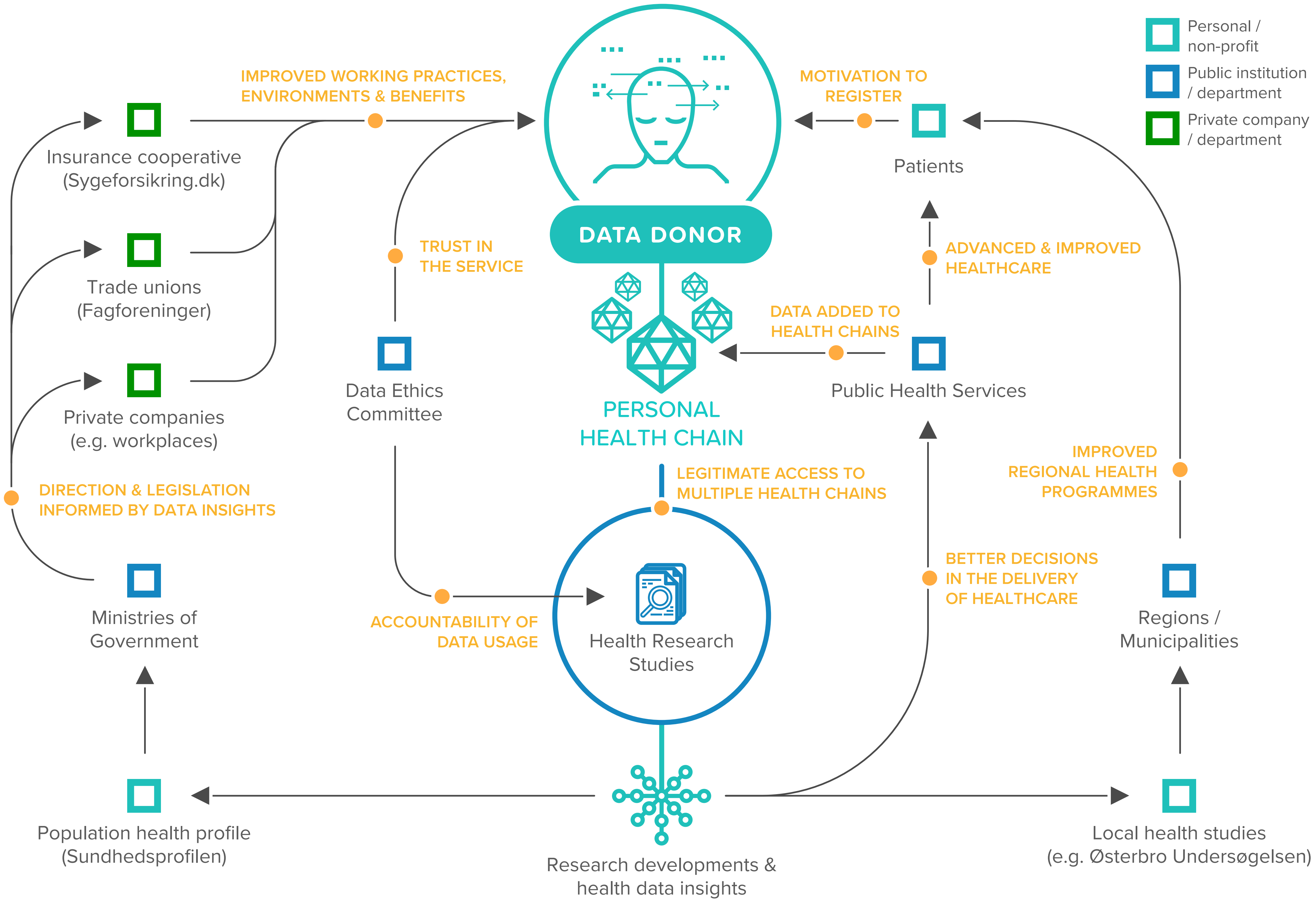


Figure 2.6: Service architecture and value constellation of the Donate Your Data service

VALUE ARCHITECTURE

DONATE YOUR DATA CREATES NEW OPPORTUNITIES FOR INDIVIDUALS AND HEALTH RESEARCHERS

With control of their personal health data, an individual is free to make choices on what to do with this digital resource. Those who choose to share their data for use in health research studies could expect to receive either a short or long-term return on their donation.

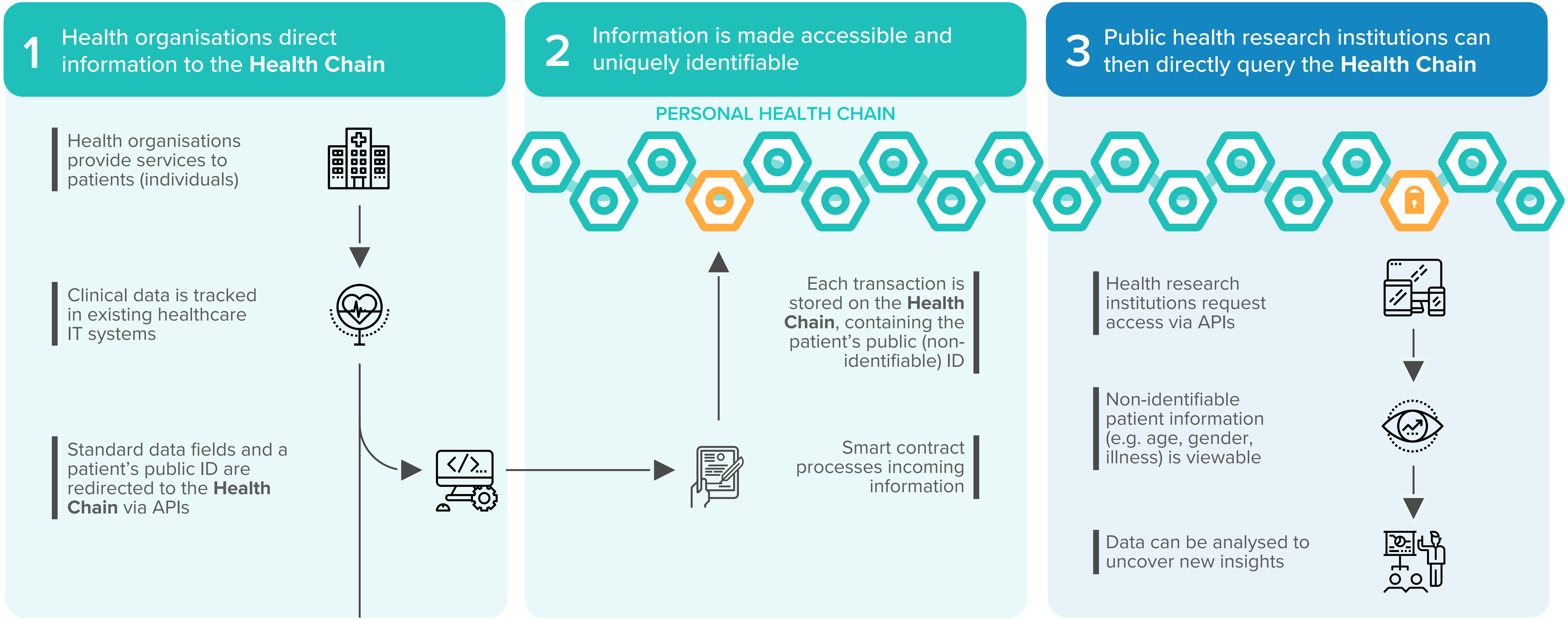
Upon completion of a study, researchers would be able to inform all participants that their data donation contributed in research of a specific topic. This action would create a loop whereby donors gain transparency over how their data has been used. They would then be better positioned to make further decisions on how to control and share their digital health data.

In the long-term, donors may end up receiving customised health treatments developed according to their unique biological response during previous conditions and treatments.

Figure 2.6 illustrates how a donated health data can have benefits beyond primary healthcare. As the data is studied, insights are produced that can then inform public and private insitutions about the state of regional or national health. This form of big data analysis can be used to develop health and wellbeing programmes for local communities and people groups.

DONATE YOUR DATA

3. THE SYSTEM



1 Health organisations direct information to the **Health Chain**

Health organisations provide services to patients (individuals)

Clinical data is tracked in existing healthcare IT systems

Standard data fields and a patient's public ID are redirected to the **Health Chain** via APIs

2 Information is made accessible and uniquely identifiable

PERSONAL HEALTH CHAIN

Each transaction is stored on the **Health Chain**, containing the patient's public (non-identifiable) ID

Smart contract processes incoming information

3 Public health research institutions can then directly query the **Health Chain**

Health research institutions request access via APIs

Non-identifiable patient information (e.g. age, gender, illness) is viewable

Data can be analysed to uncover new insights

Figure 3.1: Journey of personal health data through the Health Chain Ecosystem

Attribution: Deloitte Whitepaper (2016)

TRANSITION OF DATA

HOW HEALTH DATA IS STORED AND SHARED USING PERSONAL HEALTH CHAINS

It is proposed that blockchain is the technology that will underpin the Donate Your Data service. The service would work by adding health data and personal information to a distributed ledger (Figure 3.1, Steps 1-2) in order for individuals to receive control over access to their health data. By operating as a donation-based service using blockchain technology, Donate Your Data will provide researchers with immediate and legitimate access to health data without the need for lengthy approval processes.

The technology promotes transparency between parties while offering a high level of security and anonymity to the individual – the combination of which will build trust in the act of data sharing and encourage more individuals to donate. As more donors join the service, a greater amount of data will be made available for research purposes, which will increase the reputation of the service and the value of the data itself.

Personal Health Chain

Each individual is in control over who can access and add digital information to their data chain.

Individual
Any individual who is registered within the Danish health system.

Health care event
Data that is generated when an individual is diagnosed and/or treated at a health service.

Centralised data
The information from a health care event is captured and stored securely.

Accessible data
Each health service allows each Personal Health Chain to read stored data, using a custom-built API.

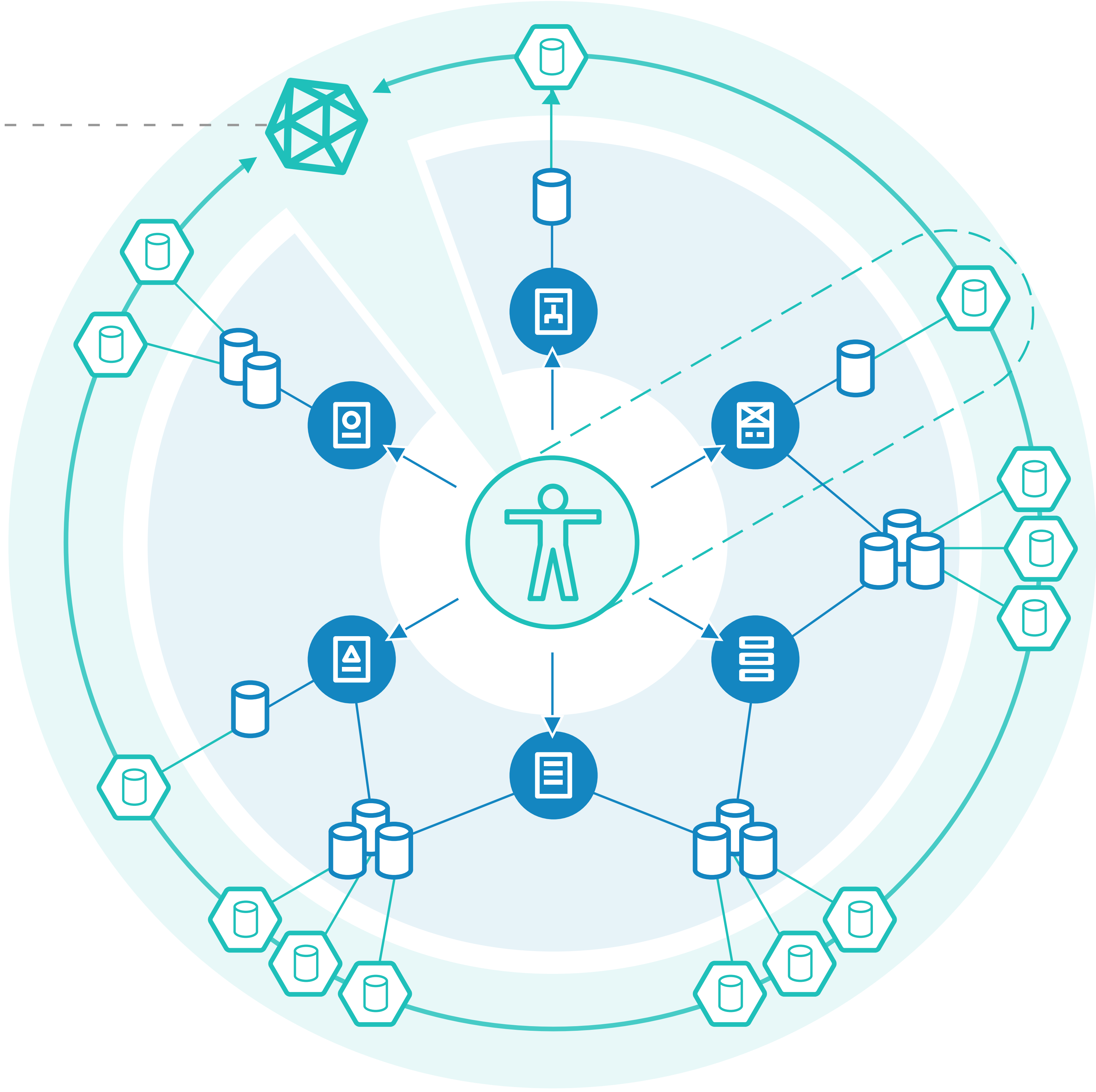


Figure 3.2: Personal Health Chain Ecosystem

COLLECTING FUTURE DATA

HOW PERSONAL HEALTH DATA IS COLLECTED

Figure 3.2 suggests how data can be accessed using an individual's "Personal Health Chain". Data is made accessible through an application programming interface (API) that allows the service to read the data stored in isolation by individual health services. Blockchain technology therefore acts as a 'golden thread' that allows individuals to provide anonymised health data for use in research studies. Figure 3.3 illustrates the steps by which data is made available to the health chain.

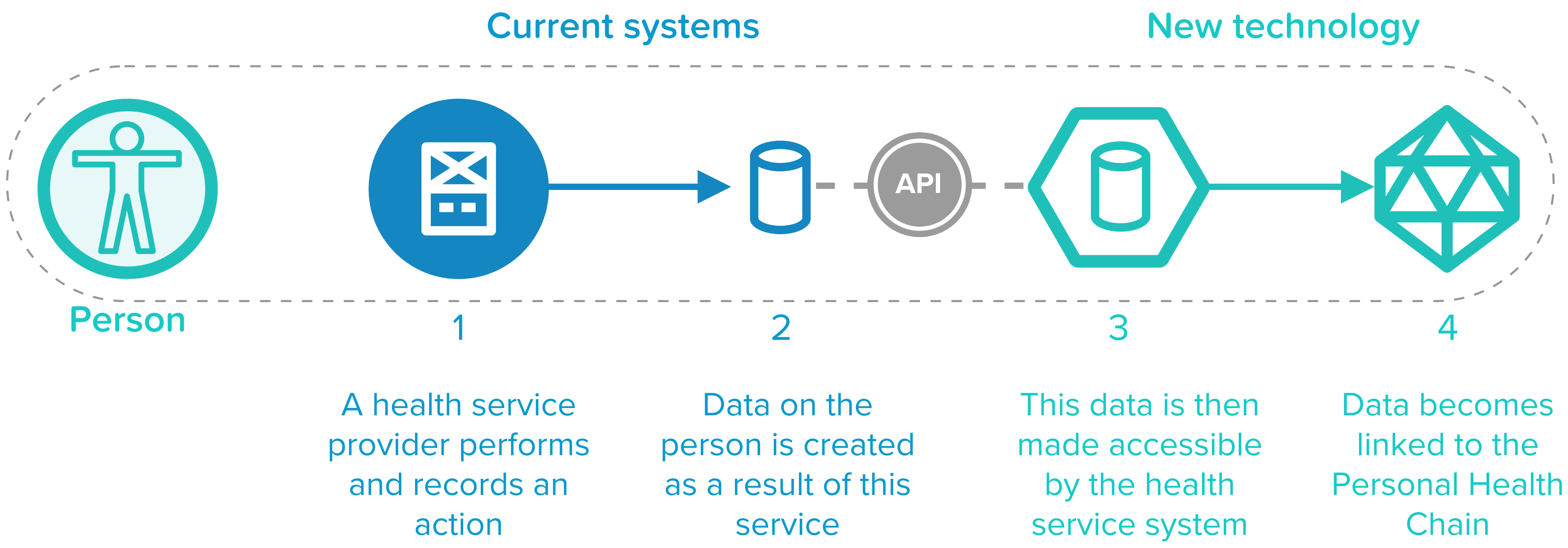
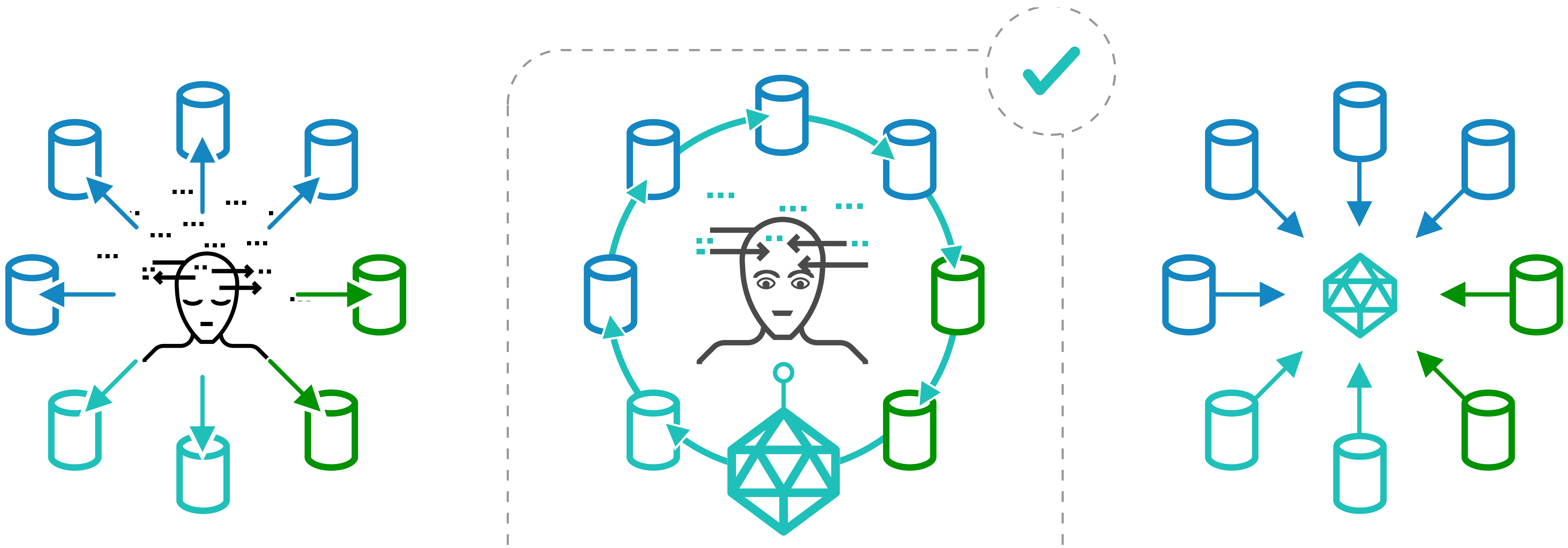


Figure 3.3: Making data available to the Personal Health Chain



No change

Centralized control remains, while systems become more connected through the use of existing technology. Provides minimal control for individuals as infrastructure would remain state-owned and managed.

Hybrid approach

You become the gatekeeper for your personal information, controlling who can access your data. **Blockchain-style** technology is used as a ‘thread’, allowing for seamless and secure view-only access to existing records.

Full adoption

Take complete ownership of your personal health data by migrating all information to a **Blockchain**. Implementation would take many years and require enourmous amounts of energy in order to operate.

- Public health service data
- Private health service data
- Personal health measurement
- Personal health chain

Figure 3.4: Methods for implementing blockchain technology

SYSTEM IMPLEMENTATION

INTEGRATING BLOCKCHAIN TECHNOLOGY WITHIN EXISTING HEALTHCARE DATA SYSTEMS

Today, healthcare data systems are typically centralised data silos, existing in isolation and with heavily restricted access. This is a result of national data protection laws and the importance placed on maintaining secure and accurate datasets.

Blockchain, on the other hand, describes the opposite of this design. It supports a decentralised database structure that offers more open, controllable access while retaining security through its distributed ledger structure.

However, adding information to a blockchain requires a high amount of energy due to the nature of its verification process (Deepmind Blog, 2017). This is regarded as unsustainable on an individual level, and unsuitable for the purposes of the proposed personal health chain.

It is proposed that a hybrid implementation approach would be most suitable for building the Donate Your Data service system (Figure 3.4). Instead of acting as a form of storage, blockchain technology would provide the control by which people can view and allow access to their information. It would be used alongside existing data silos, primarily as a communication mechanism between parties. This suggested hybrid approach allows for existing systems and data structures to continue to operate, with minimal disruption to existing health services.

In order to implement the service, the owners and operators of existing health systems will need to develop a suitable API for allowing access into different health data storage systems. Following this, it would be possible to run a pilot project to test and prove the Donate Your Data service.

DONATE YOUR DATA

4. CONSIDERATIONS

A SMART DONATION SERVICE

GOING BEYOND CONVENTIONAL REWARDS TO PROVIDE LONG-TERM INCENTIVISATION

Today, registering as a blood or organ donor typically requires an individual to complete a paper form to indicate their desire and provide their consent. However, service platforms such as Sundhed.dk have begun to make the move towards the digitisation of consent, offering Danish citizens and residents visibility of their personal health data as well as the option to register online as an organ donor.

In general, those who donate often find that their initial ‘good feeling of giving’ will wear off after a short period of time. Many of today's donation systems (whether health related or not) fall short of providing any medium or long-term follow up communication for donors. Through its use of blockchain technology, Donate Your Data would be able to provide an opportunity for researchers to send out messages to donors upon completing a study. This could be achieved without the need to reveal personally identifiable information communication through the same encrypted method used to share data.

RISKS AND LIMITATIONS

SERVICE AND TECHNOLOGY LIMITATIONS

Blockchain technology has yet to become adopted into mainstream services. Today, adding new information to a blockchain requires a great deal of energy. For example, in order to regulate the generation of new Bitcoins, a complex mathematical problem must first be solved (mined) by a computer. This limitation is a fundamental aspect of the design of the Bitcoin system, and is purposefully designed to provide the necessary stability on which a financial system should operate.

Donate Your Data has been designed to make use of the potential benefits offered by blockchain technology. At present, there are no known ways to develop the back-end structure for this service, although this is soon set to change as global technology companies create development platforms for created service that harness the capabilities of blockchain technology.

Aside from the challenges of implementing a cutting edge technology, the wider service design will need to address a number of non-technical challenges, such as overcoming ethical concerns and legal frameworks.

While being an attractive, short-term solution to support greater sharing of personal information, there may come a point at which research requires personally identifiable information, such as in the case of identifying a rare, or serious medical condition.

If during the course of a study a researcher were to find an undiagnosed serious medical issue, then would the researcher be responsible for informing the citizen? If so, how could they manage this if the data they were studying could not be traced back to the individual?

There is a great deal more to discuss in terms of data ethics, too much to consider at this stage. For all future developments using this technology, attention and time must be given to ensuring that services build trust among users, and promote ethical usage of personal health data.

NEXT STEPS

DEVELOPING A PILOT PROJECT AND INTRODUCING THE SERVICE TO THE PUBLIC

Donate Your Data is intended to be a catalyst for a future where personal control of data is desired and regarded as valuable for the individual. As with blood, organs and body tissue, health data ought to be seen as a valuable donation for helping advance and hasten the future of patient-centric medical services.

To continue this project it is vital to identify a set of core people and organisations who will support and sponsor a series of research trials and service prototypes for qualifying the idea, validating assumptions and testing the concept on the wider public. Working alongside existing health donations services it will soon be possible to unlock the full potential of digital health data. This could then bring about a new generation of data-driven treatments and individualised health services.

As Donate Your Data develops and gains attention, and as the technology behind the service is proven, it is hoped that many more personal data-driven services will be invented with the needs of the individual at the centre.

REFERENCES

Aitken, M., J. de St. Jorre, C. Pagliari, et al. (2016). *Public responses to the sharing and linkage of health data for research purposes: a systematic review and thematic synthesis of qualitative studies.* BMC Medical Ethics (2016) 17:73

Auffray, C., R. Balling, I. Barroso, et al. (2016). *Making sense of big data in health research: towards and EU action plan.* Genome Med (2016) 8: 71.

Data for Good Foundation. (2016). *What is Data for Good Foundation.* Retrieved April 12, 2017 from: http://dataforgoodfoundation.com/en/what-why

Deepmind Blog: Suleyman, M. and Laurie, B. (2017). *Trust, confidence and Verifiable Data Audit.* Retrieved 28 March 28, 2017 from: https://deepmind.com/blog/trust-confidence-verifiable-data-audit/

Det Etiske Råd / Danish Council of Ethics. (2015). *Research with health data and biological material in Denmark.* Retrieved April 12, 2017 from: http://www.etiskraad.dk/~/media/Etisk-Raad/en/Publications/Research-with-health-data-and-biological-material-in-Denmark-Statement-2015.pdf

Deloitte Whitepaper (2016). [PDF] *Blockchain: Opportunities for Health Care.* Retrieved March 7, 2017 from https://www2.deloitte.com/content/dam/Deloitte/us/Documents/public-sector/us-blockchain-opportunities-for-health-care.pdf

The Economist. (2017). *Fuel of the future: Data is giving rise to a new economy.* Retrieved May 18, 2017 from: http://www.economist.com/news/briefing/21721634-how-it-shaping-up-data-giving-rise-new-economy

European Commission (2015) [Press release] *Agreement on Commission's EU data protection reform will boost Digital Single Market.* Retrieved April 21, 2017 from http://europa.eu/rapid/press-release_IP-15-6321_en.htm

Institute of Medicine: Grossmann, C., A. W. Goolsby, L. Olsen, and J. M. McGinnis. (2010). *Clinical data as the basic staple of health learning: Creating and protecting a public good: Workshop Summary.* Washington, DC: The National Academies Press. Retrieved April 12, 2017 from: https://www.ncbi.nlm.nih.gov/books/NBK54304/

Kotzé, P. and Foster, R. (2014). *A conceptual data model for a primary healthcare patient-centric electronic medical record system.* Proceedings of the IASTED International Conference Health Informatics (AfricaHI 2014) September 1 - 3, 2014. Gaborone, Botswana.

Leapcraft ApS: Venkatraman, V., P. Mani and A. Ussing. (2015). *Mapping the Healthcare Data Landscape in Denmark.* Retreived April 8, 2017 from: http://www.cphhealthtech.dk/~/media/chc/rapporter/mapping%20the%20healthcare%20data%20landscape%20in%20denmark%20for%20web.ashx?la=en

Poikola, A., K. Kuikkaniemi and H. Honko. (2015). [PDF] *MyData: A Nordic Model for human-centered personal data management and processing.* Retrieved May 24, 2017 from: http://julkaisut.valtioneuvosto.fi/bitstream/handle/10024/78439/MyData-nordic-model.pdf?sequence=1

Sundhed.dk. (2016) *Visioner og mål (Vision and Objectives).* Retrieved April 25, 2017 from: https://www.sundhed.dk/borger/service/om-sundheddk/om-organisationen/visioner-og-maal/

van Staa T-P, B. Goldacre, I. Buchan, L. Smeeth. *Big health data: the need to earn public trust.* BMJ 2016;354:i3636.

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