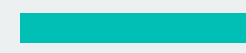


ENOME



*Position Paper*

# Disclaimer



This document is a position paper setting out the current and future developments of the E-Nome Ecosystem being the E-Nome App, E-Nome Research Portal, E-Nome Medical Practitioners Portal, E-Nome Electronic Data Warehouse (EDW) and the E-Nome Core by E-Nome Pty Ltd (E-Nome).

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# 01 Abstract



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Company Overview



The world of medicine is changing rapidly.

While traditional paper based record keeping in the physician's office is being replaced by modern electronic practice management systems, the electronic information in these systems has become entrenched and siloed within the walls of the medical practice. This is in stark contrast to the increasingly mobile consumer who no longer visits the same general practice time after time. Opportunity and convenience influence the choice of medical interactions today.

Visits to corporate medical practices, specialist clinics, emergency departments, pathology collection centres, radiology imaging centres, allied health practitioners, public and private hospitals, all result in disjointed,

siloed electronic medical record stores. Requests to transfer information between providers is usually by either a paper printout, a fax or an email of a PDF document. Even if the originating information is available electronically, the electronic transfer of information between different systems is technically difficult because of the different language and coding schemes used by the various systems.

Also, the specific consent process required to share personal record information, is traditionally difficult and restrictive. Requests for consent usually involve a one-off, time-limited or research specific agreement. These agreements limit how the data can be used by researchers to make new discoveries.

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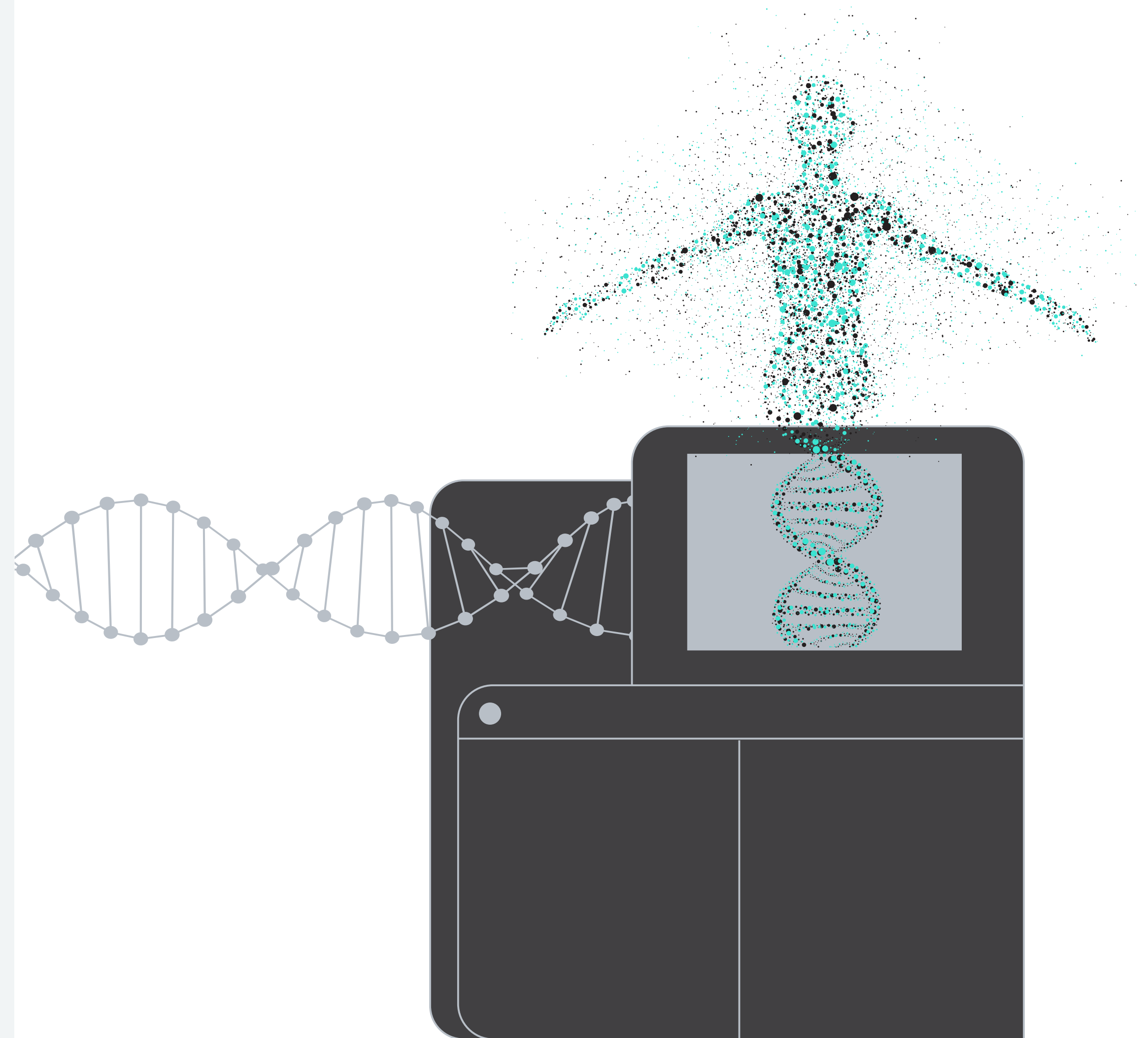
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Company Overview

The beginning of the era of Personalised Precision Medicine (PPM) is here. PPM involves best practice treatment guidelines being customised for an individual, based on their unique attributes, their environment and lifestyle choices, as well as their genomic makeup. Today we strive to treat the individual, and not just 'a' general condition.

The effective development of PPM requires the collection and analysis of large volumes of data that can be subjected to deep machine learning. Universal consent would overcome this limitation but necessarily requires appropriate consumer education to ensure knowledge and understanding of the various disclosure and ethical considerations.



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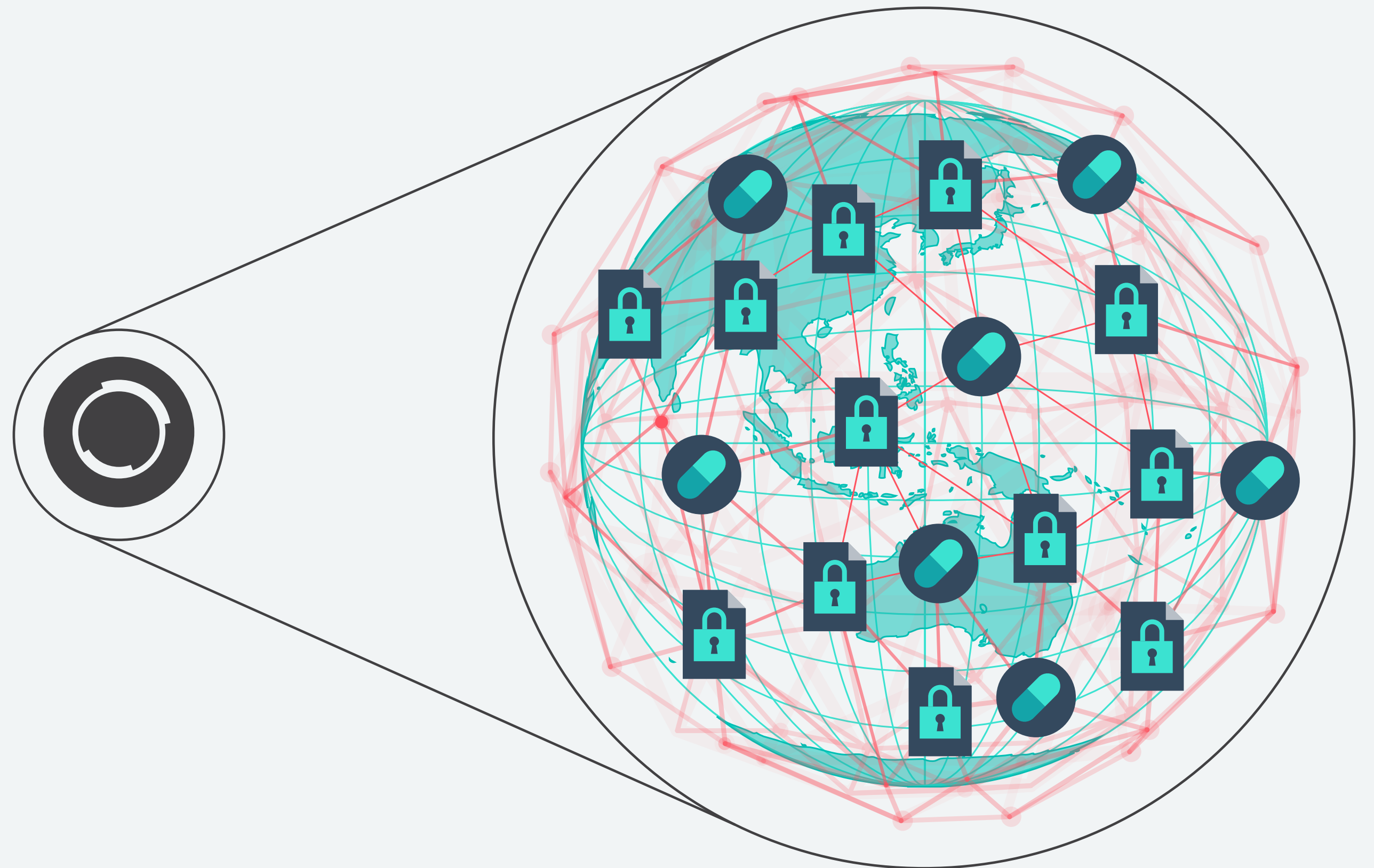
Company Overview

In today's connected world, the aggregation of large volumes of complete longitudinal medical records of an individual, together with their unique genomic data in an accessible database, requires bullet proof privacy, security and access controls for the individual clinical records. As experienced in other non-medical disciplines organised extortion and hacking attempts have resulted in significant breaches. Particularly alarming is that some of these data breaches were not detected for a considerable time after the attack occurred.

The challenge becomes, how can longitudinal personal health information be safely and securely stored and used, to discover new insights that may lead to breakthrough diagnostic and clinical treatment developments?

The patent pending E-Nome system was created to answer this challenge. To provide a consumer with the ability to easily and securely consent, acquire, approve, store and share their personal medical information with anyone they choose.

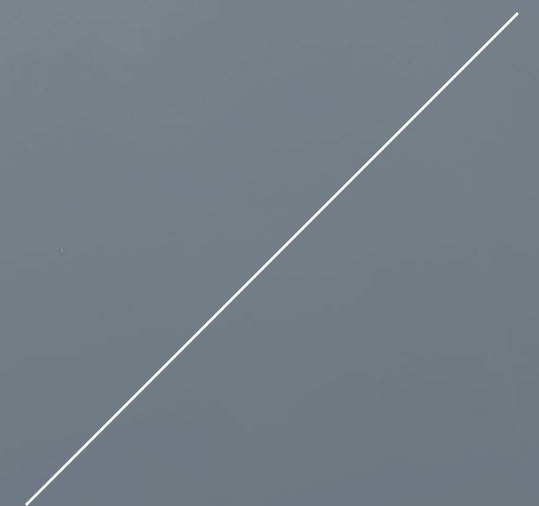
At E-Nome we are applying state-of-the-art distributed ledger blockchain, anonymisation and encryption technologies, to enable secure consumer controlled sharing of medical record information for personal or medical research purposes.



02



# The E-Nome Ecosystem



# The E-Nome Ecosystem

E-Nome's objectives are twofold.

Firstly, E-Nome seeks to improve patient care by empowering consumers to take control of their medical history and enabling them to share their data with medical service providers they choose, with the utmost privacy and security. The simple empowerment of the consumer with their own health data, readily accessible on their mobile device, will lead to greater awareness of health issues and better long term health outcomes.

Secondly, E-Nome is seeking to remove the health data access constraints that are created by the silos of EHR systems today. These silos currently hinder medical research and clinical trials data aggregation. The key constraint stems from the lack of interoperability and consent. Collection of the data between systems is cumbersome and carries significant security risks. Different EMRs exist at all levels of the healthcare system which use different software systems and different coding schemes or ontologies.



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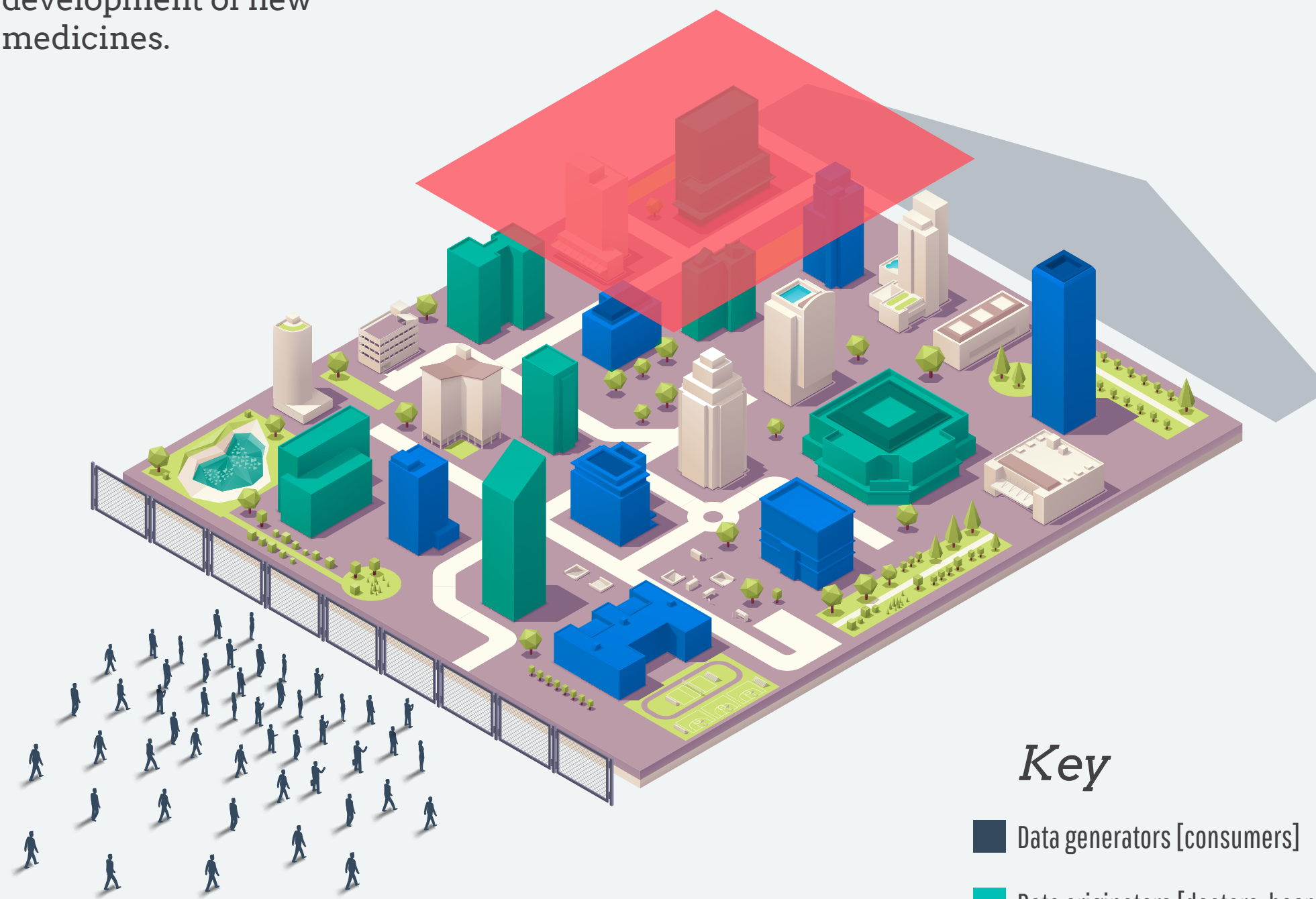




# The E-Nome Ecosystem

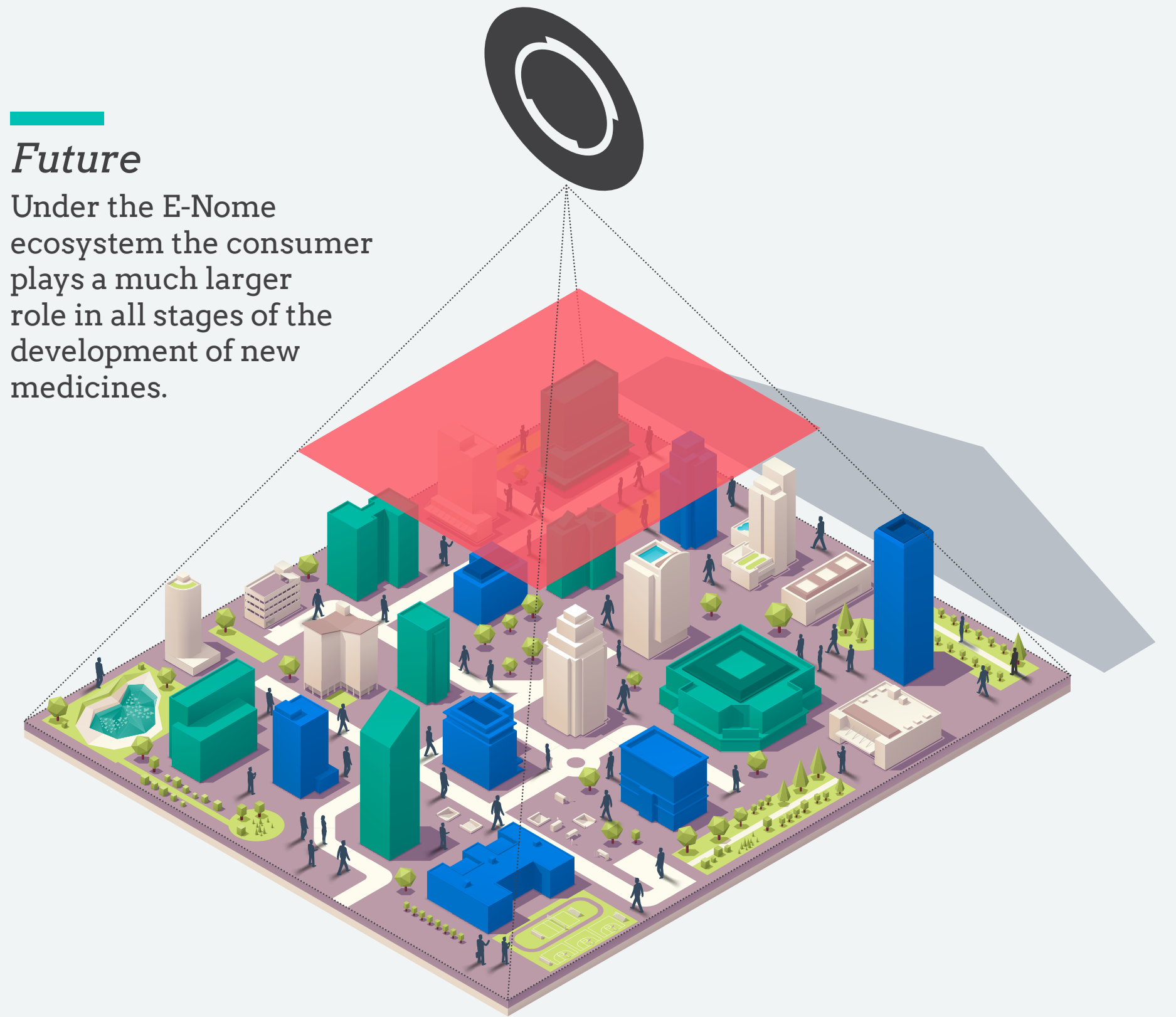
## Present

Consumers play only a small role in the development of new medicines.



## Future

Under the E-Nome ecosystem the consumer plays a much larger role in all stages of the development of new medicines.



## Key

- Data generators [consumers]
- Data originators [doctors, hospitals, radiologists, pathology labs etc]
- Data aggregators [government EMR, software providers]
- Data users [research institutes, pharmaceutical companies, government research agencies]
- Drug development/health management



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# The E-Nome Ecosystem

The E-Nome ecosystem will allow simplification of the data aggregation processes for clinical trials and research. The system will sit beside the existing EHRs and thus enable interoperability. It will standardise the ontology of the data stored in the E-Nome Data Warehouse, (EDW).

With the consumers consent it will provide access to large volumes of de-identified medical data. The innovation of E-Nome is to firstly anonymise the medical record by stripping all identifying information from the

record and attaching a unique cryptographic identifier or key. The data is then stored without identifiers as single episodic records therefore maintaining no linkages to the related episodes.

The system, however, with the application of blockchain technology, provides the capacity to re-link relational data, or records, that belong to the consumer by seeking the anonymised consent of the consumer for access to their keys to re-aggregate the longitudinal data points.



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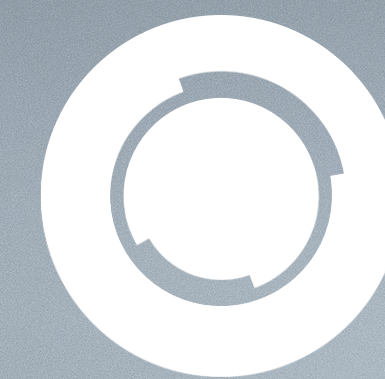
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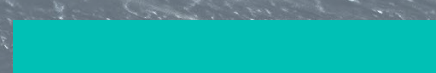
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E-Nome  
Business



# 03 E-Nome Business

## Market Overview

E-Nome's business is about providing a platform by which the Consumer is empowered to be placed in the middle of a global market worth billions of dollars a year trading their data.

Current data collection and transfer is managed by major corporate intermediaries. These corporate intermediaries profit directly from the inefficiency and constraints in data collection. E-Nome is seeking to disintermediate data transfer in the health sector.

Globally, in 2016 an estimated USD 7.7 trillion<sup>1</sup> was spent on health care, of which USD 150 billion or 2% relates to pharmaceutical R&D to fund new drug development.

In 2016 the life science industry spent an estimated USD 22 billion<sup>2</sup> on access to anonymised longitudinal patient data and analytical services.



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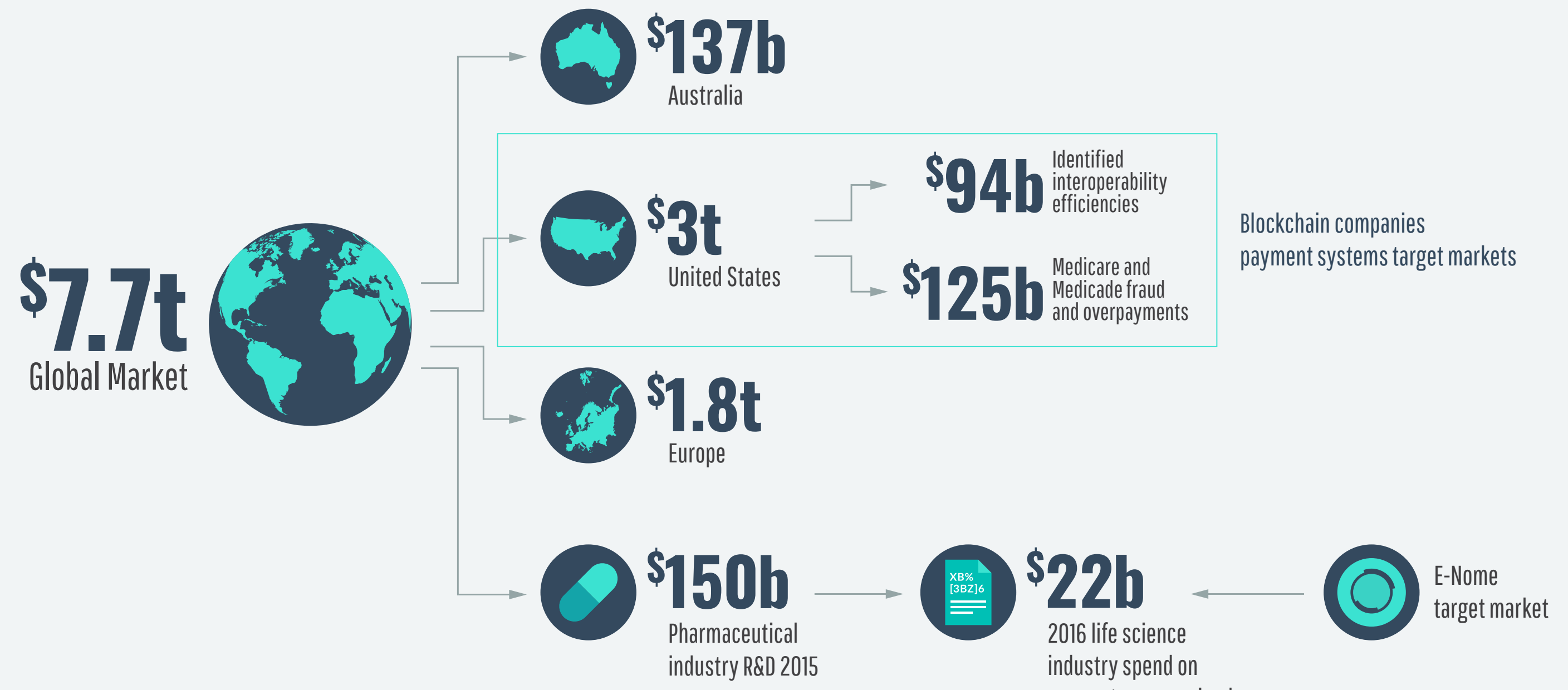
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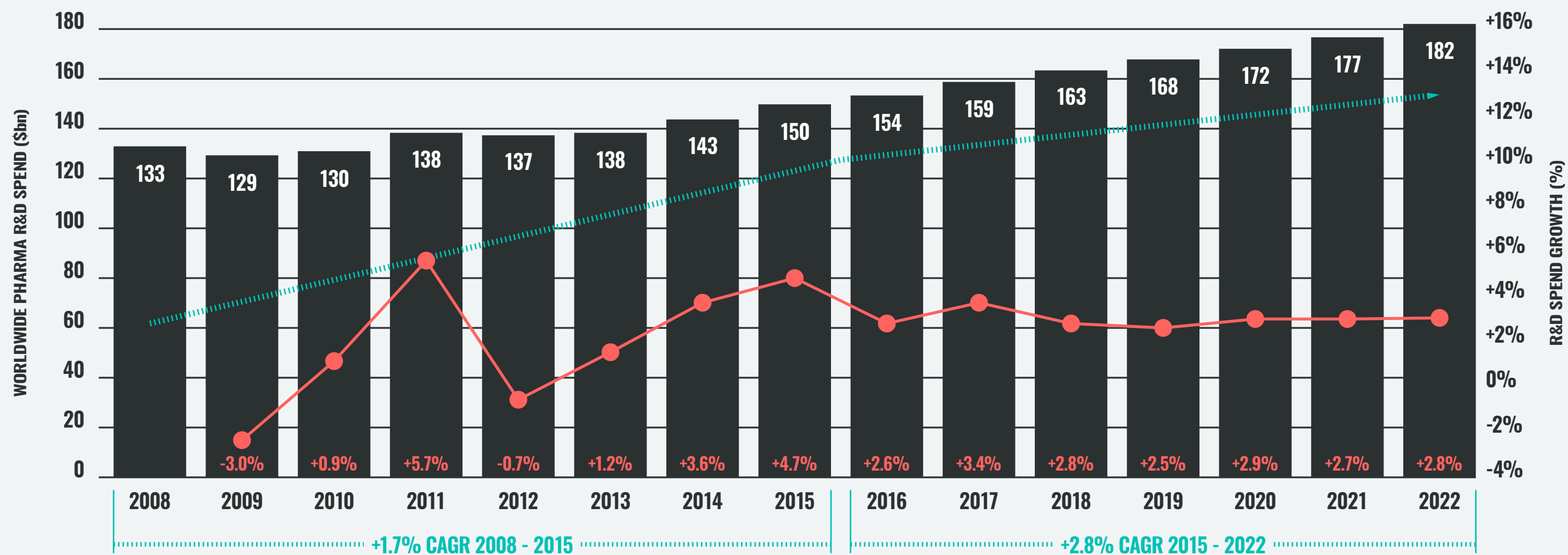


# E-Nome Business

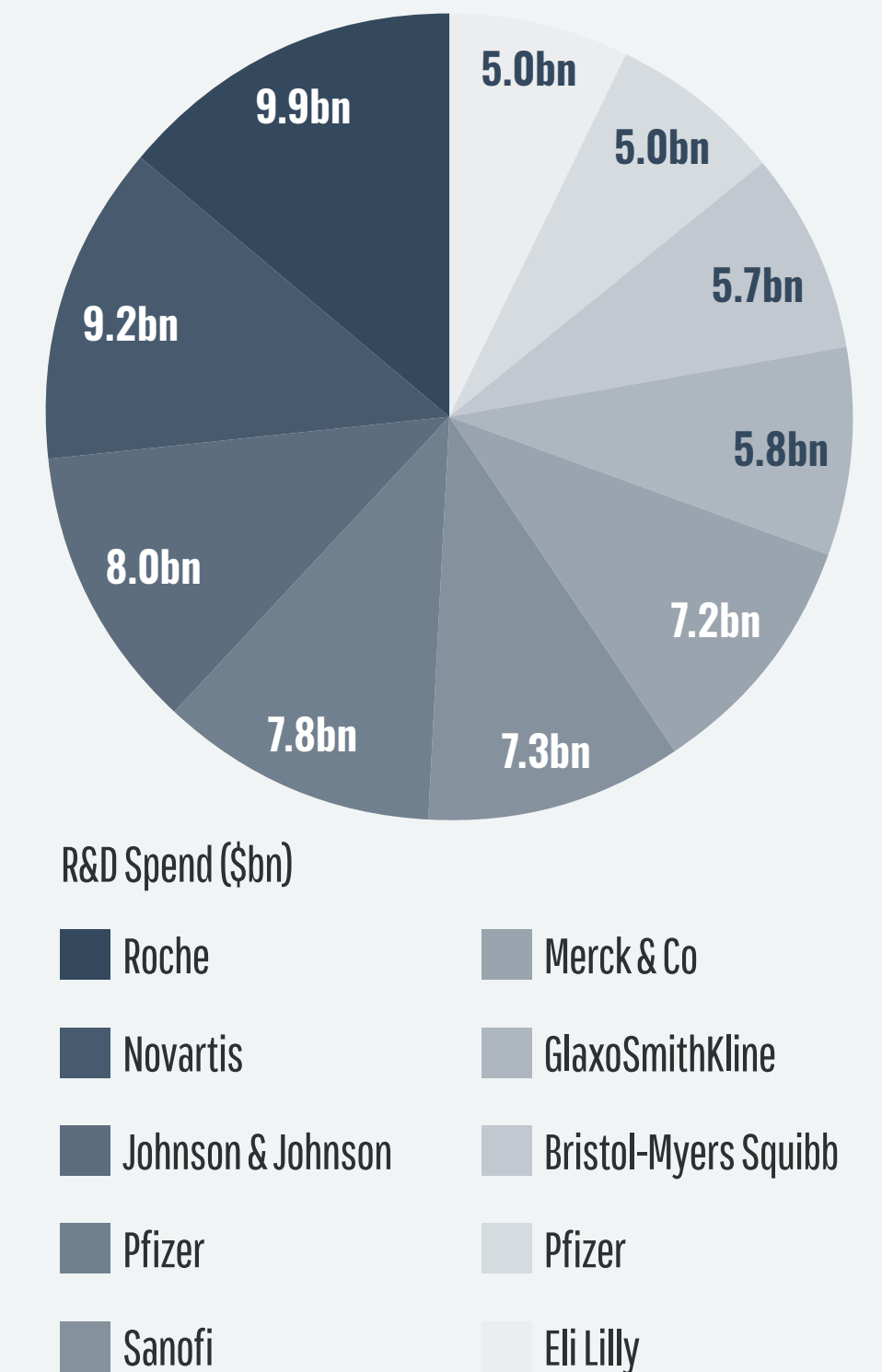
Of all industrial sectors, the research based pharmaceutical industry has consistently invested the most in R&D, even in times of economic turmoil and financial crisis.

Compared with other high-technology industries, the annual spending by the pharmaceutical industry is 5.5 times greater than that of the aerospace and defence sectors, 5 times more than that of the chemicals industry, and 1.8 times more than that of the software and computer services industry.<sup>3</sup>

Worldwide Total Pharmaceutical R&D Spend 2008 - 2022<sup>4</sup>



Top Ten Pharmaceutical R&D Companies<sup>4</sup>



“ In 2014, 5 of the 11 leading global R&D firms were pharmaceutical companies.”<sup>5</sup>



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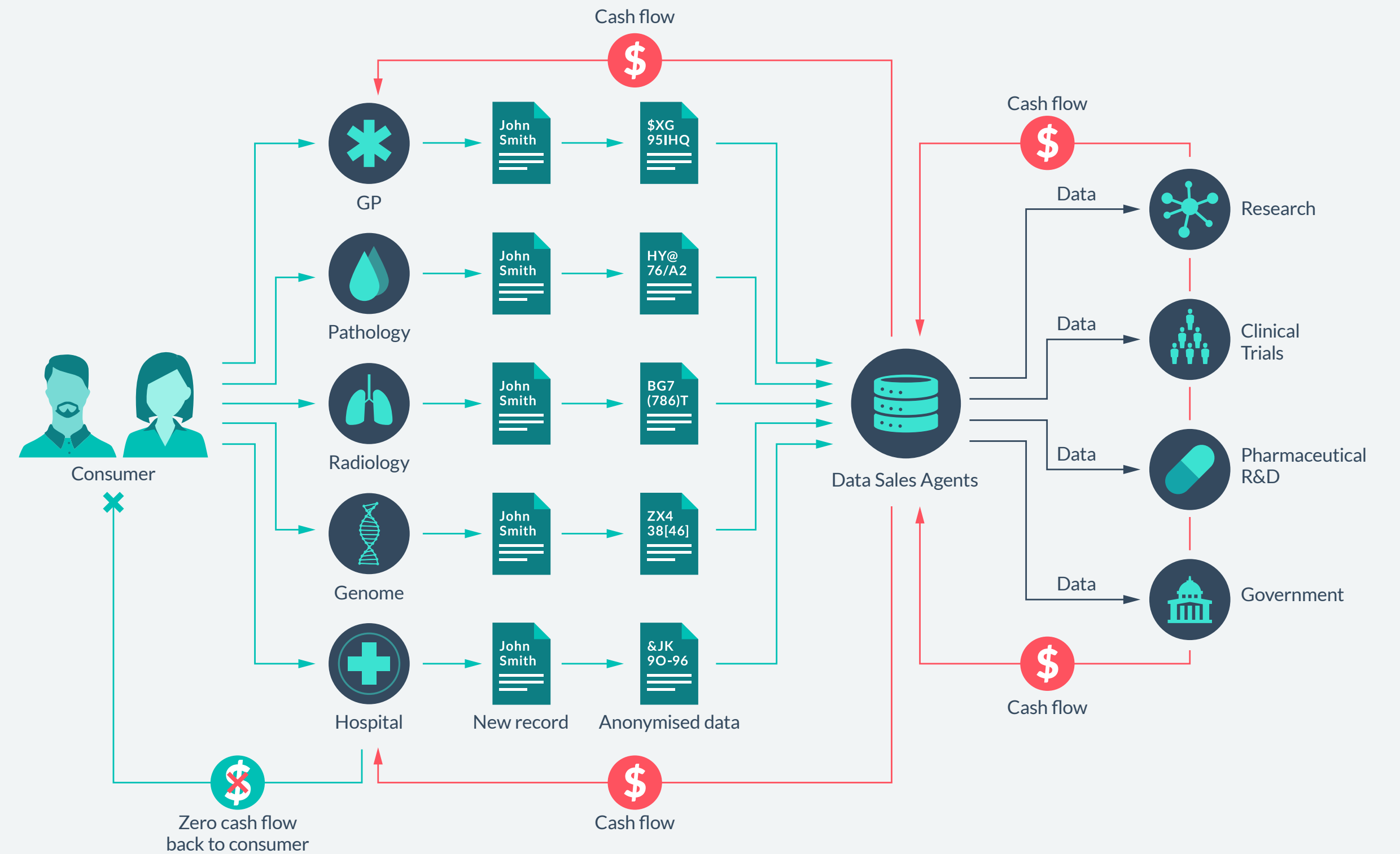
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Company Overview

## The E-Nome Platform

For the first time in history, the E-Nome platform will allow the consumer to actively participate in the global market for longitudinal anonymised medical data sales.

In addition to providing a market place to facilitate the exchange of data, the E-Nome platform may significantly increase the value of the data, by maintaining a dynamic, yet anonymised link to the source. The dynamic link is intended to enable a researcher to track and accumulate data from an anonymised subject over time.



### Today

E-Nome is seeking to disintermediate data transfer in the health sector.

Current data collection and sales is managed by major corporate intermediaries, often without knowledge and consent by the consumer. These corporate intermediaries profit directly from the inefficiency and constraints in data collection and transfer.



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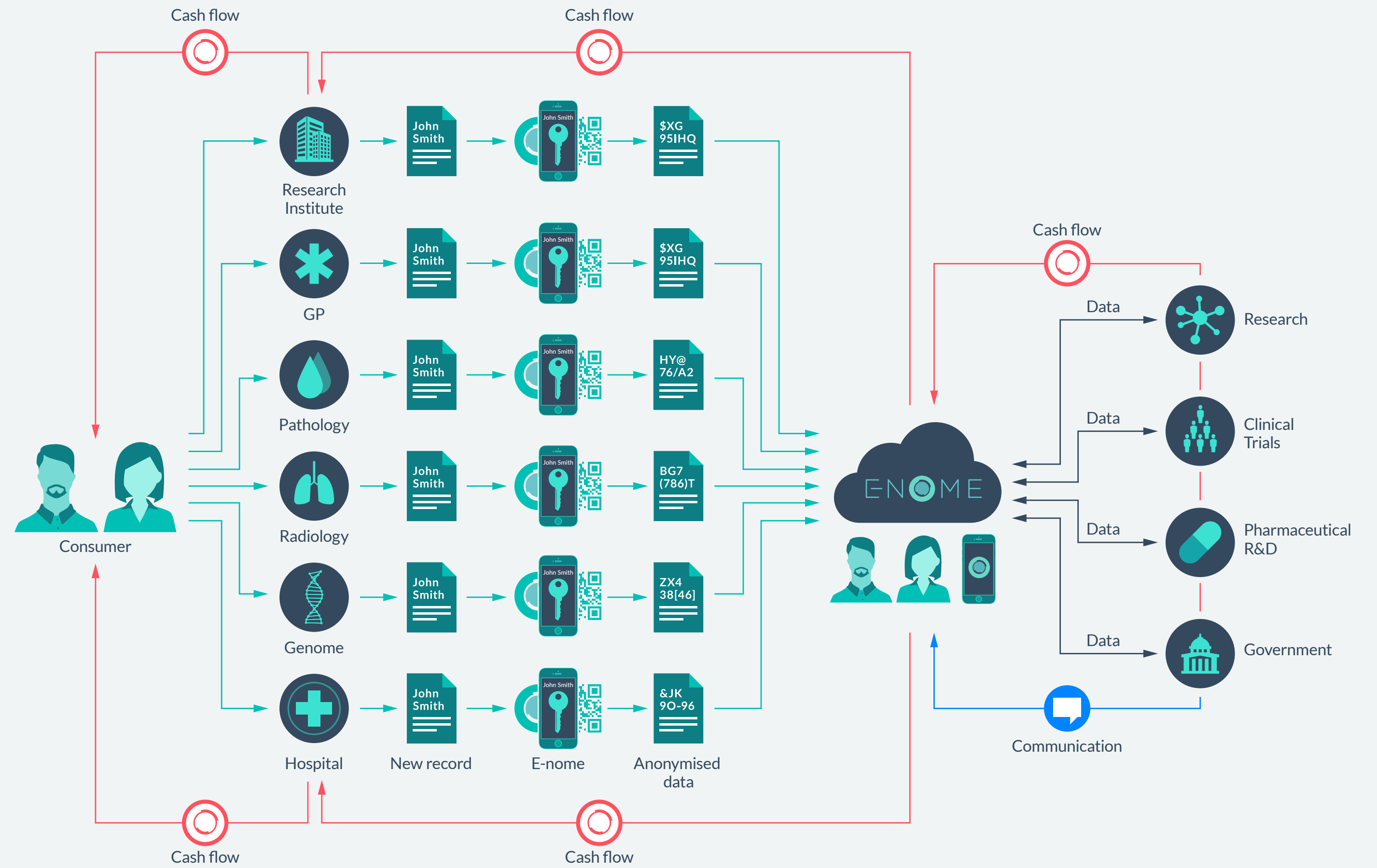
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## E-Nome way

E-Nome's platform will allow a consumer, for the first time, to participate in the value transfer for the data they are generating.



## E-Nome App

The E-Nome App is designed to encourage consumers to build up their medical profile. For example, the value of a consumer's profile significantly increases as the number of profile components increases. Adding the genome enables wider application of the data points in a research study to find new correlations and insights.

By incentivising the consumer to collect their medical data and build up their medical profile, E-Nome has the ability to create a unique consumer consented data base for medical research and clinical trial purposes.

Each profile component will be ranked and priced on a stand alone basis, including;



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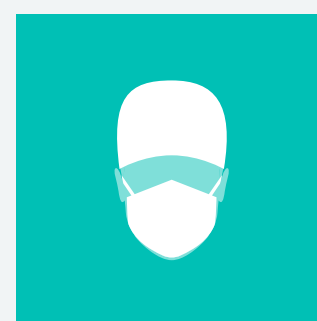
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Sequence/Genome



Procedure



Condition/Problem



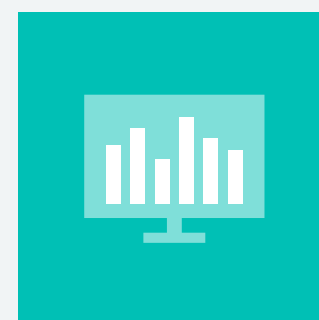
Pathology report



Immunisation



Allergy



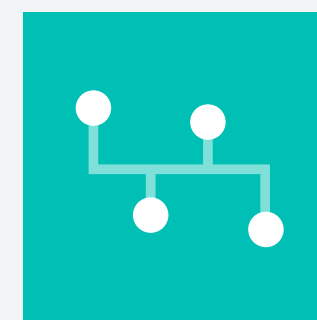
Diagnostic Report



Medication



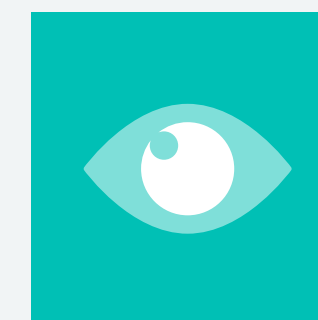
Adverse Event



Family History

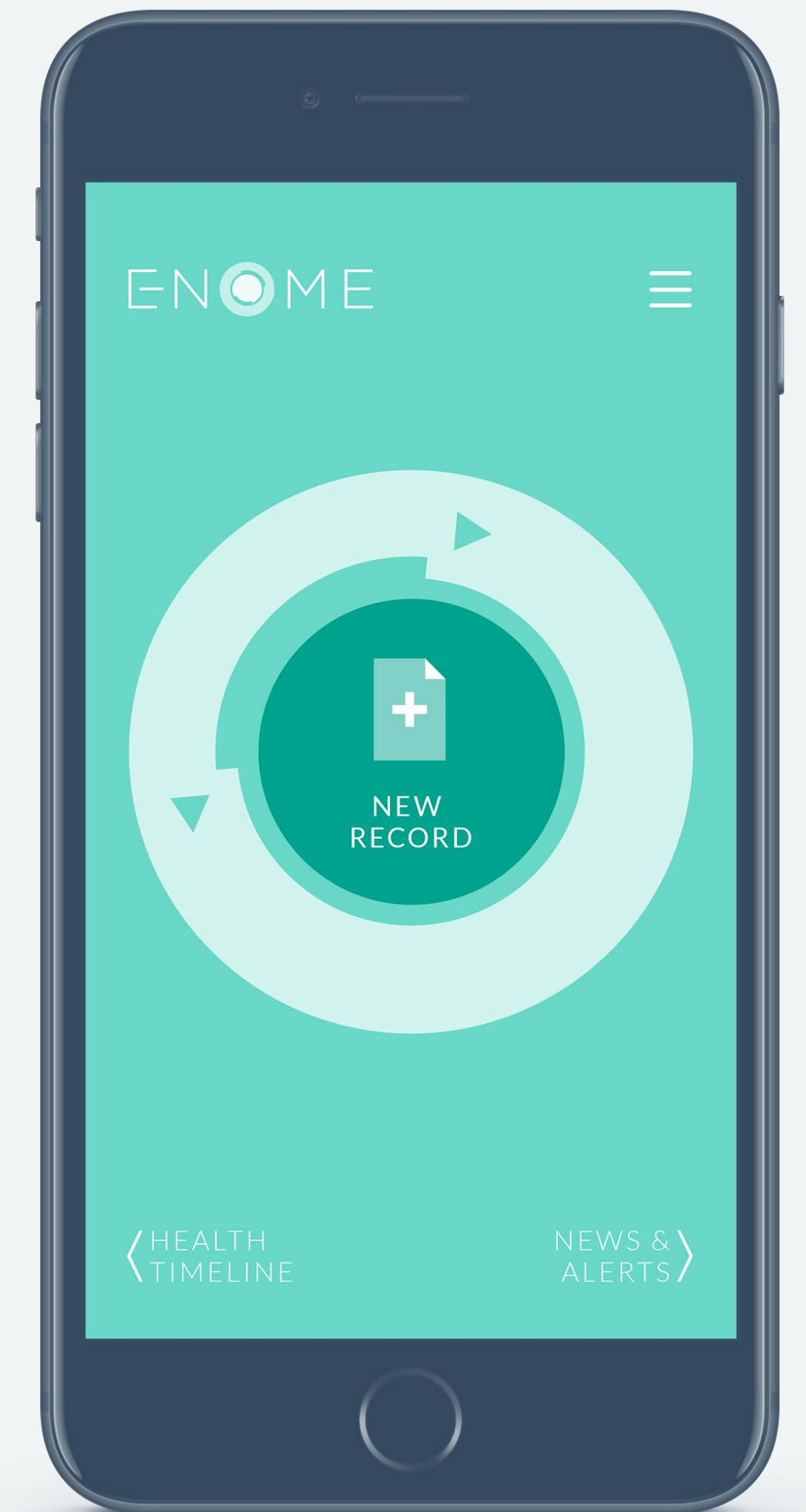


Medical History



Observation

The storage of an individual's anonymised medical record will have a dynamic linkage to their profile components and as such, allow research institutes to better identify consumers with profiles that are matched with their particular requirements.





## E-Nome Research Portal

The E-Nome Research Portal is the platform that facilitates the consumer and the researcher to communicate and exchange value anonymously.

It enables peer qualified medical research institutes to search high level meta data of one, many or all of a consumers medical profile components stored in the E-Nome electronic data warehouse (EDW). The portal acts as the platform for request and payment for the data transfer.

If a researcher finds data of interest, the E-Nome system allows the researcher to leave a share request notification for the consumer to consider allowing the downloading of their medical profile. This feature of the E-Nome system empowers the consumer to consider participating in medical research or clinical trial activities anonymously.

It is also possible for the consumer to consent to their data in the EDW being used by pharmaceutical companies to discover new insights that may lead to breakthrough diagnostic and clinical treatment developments.



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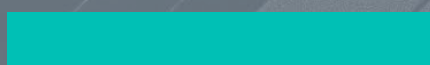
The screenshot displays the E-Nome Research Portal interface. At the top, the 'ENOME' logo is visible on the left, and 'ACME Research' with a shopping cart icon is on the right. The main content area is divided into several sections:

- Search in Records:** A search bar containing 'Diabetes' and a secondary search bar for 'Search by SNOMED/LOINC code'.
- Summary Cards:** Four colored cards showing counts for 'Diagnosis' (84), 'Medications' (49), 'Allergies' (29), and 'Imaging' (9).
- Results Table:** A table with 5 entries for 'Diabetes mellitus type 2' (Code: 44054006). The table columns are Resource, Text, Code, and Profile Components. The second entry is highlighted and has a 5-star rating.
- Footer:** A row of icons representing various medical data types: Genome (1), Procedure (4), Condition / Problem (7), Diagnostic Report (12), Medication (101), Adverse Event (1), Pathology Report (65), Immunisation (2), Allergy (4), Family History (1), Medical History (2), and Observation (100). A 'Request Patient Records' button is located below these icons.

04



# E-Nome Proof of Concept



# Proof of Concept



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## Clinical Trials

Innovative pharmaceutical companies are increasingly incorporating the patient perspective into all stages of drug development, including patient insights on their diseases, symptoms, and treatment options. Finding ways to incorporate a robust, science-based understanding of patient perspectives into decisions that promote innovation and expedite drug development is becoming a critical focus of the R&D process.<sup>6</sup>

E-Nome's system fundamentally changes the relationship between trial participant and the research institute by introducing secure and automated processes for collection, supplementation and verification of data. The majority of data collection methods used today are legacy systems including pCRF or paper based collection.

“

It is estimated that up to 29% of costs associated with Clinical Trials are directly linked to administration, including data collection.<sup>7</sup>

”



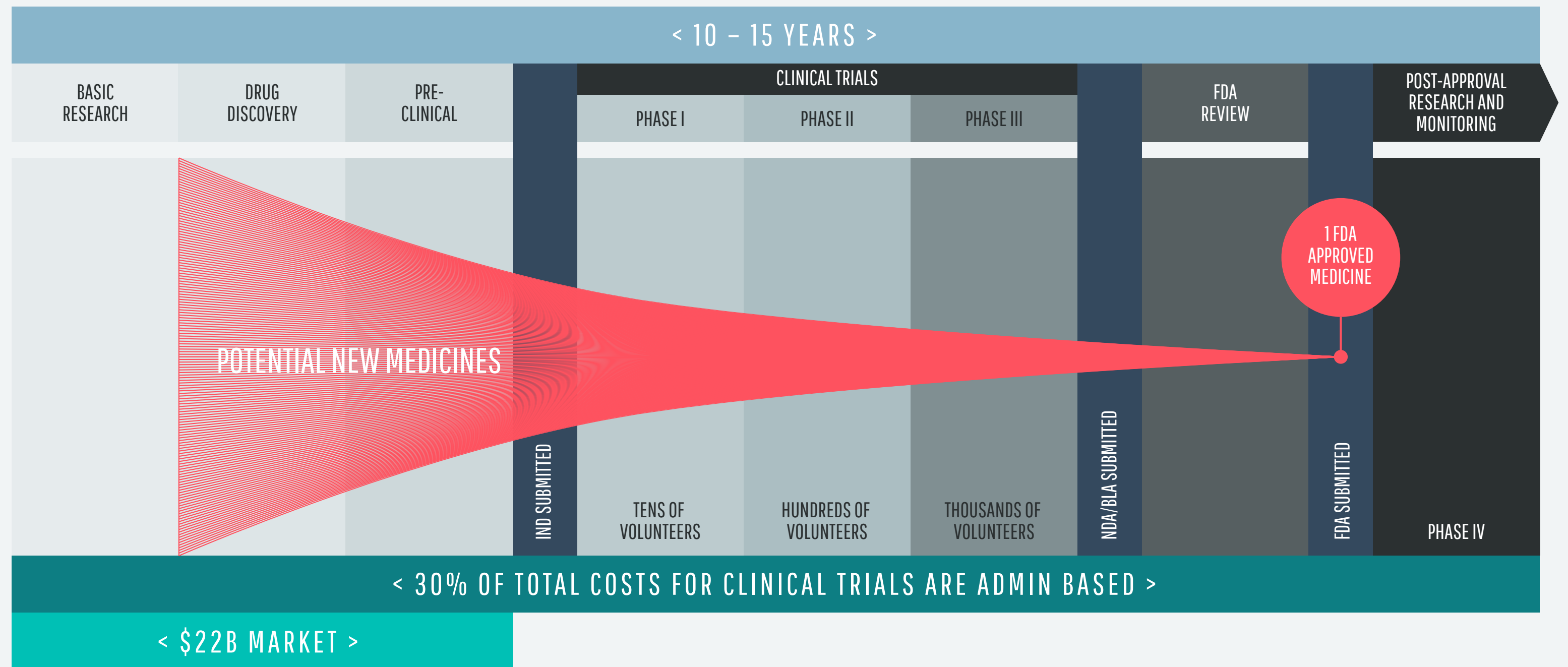
# Proof of Concept

“ .....

The cost of developing a successful medicine can exceed USD 2.6 billion.<sup>8</sup>

Average development timeline of 10–15 years for a medicine or vaccine.<sup>9</sup>

..... ”



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# Proof of Concept

E-Nome's platform for Research Institutes and Clinical Trial's has three main advantages:

## 1. Data supplementation and verification



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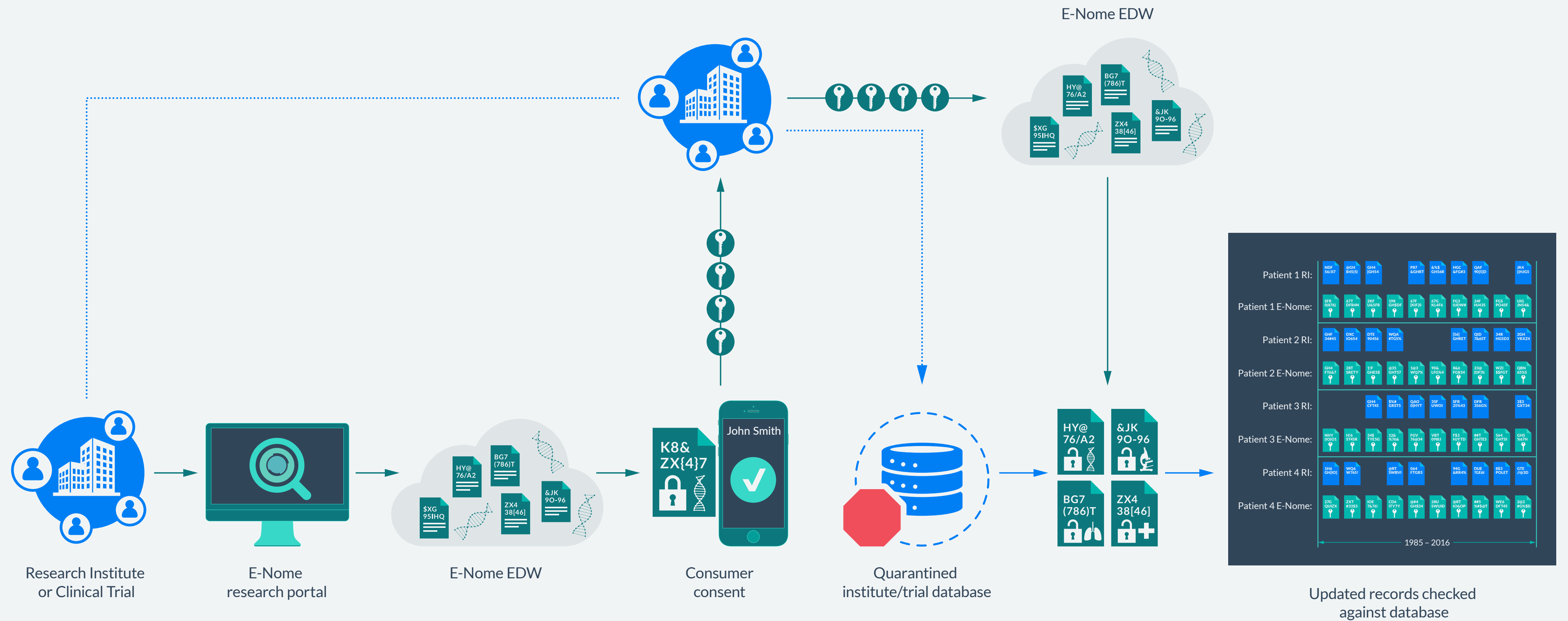
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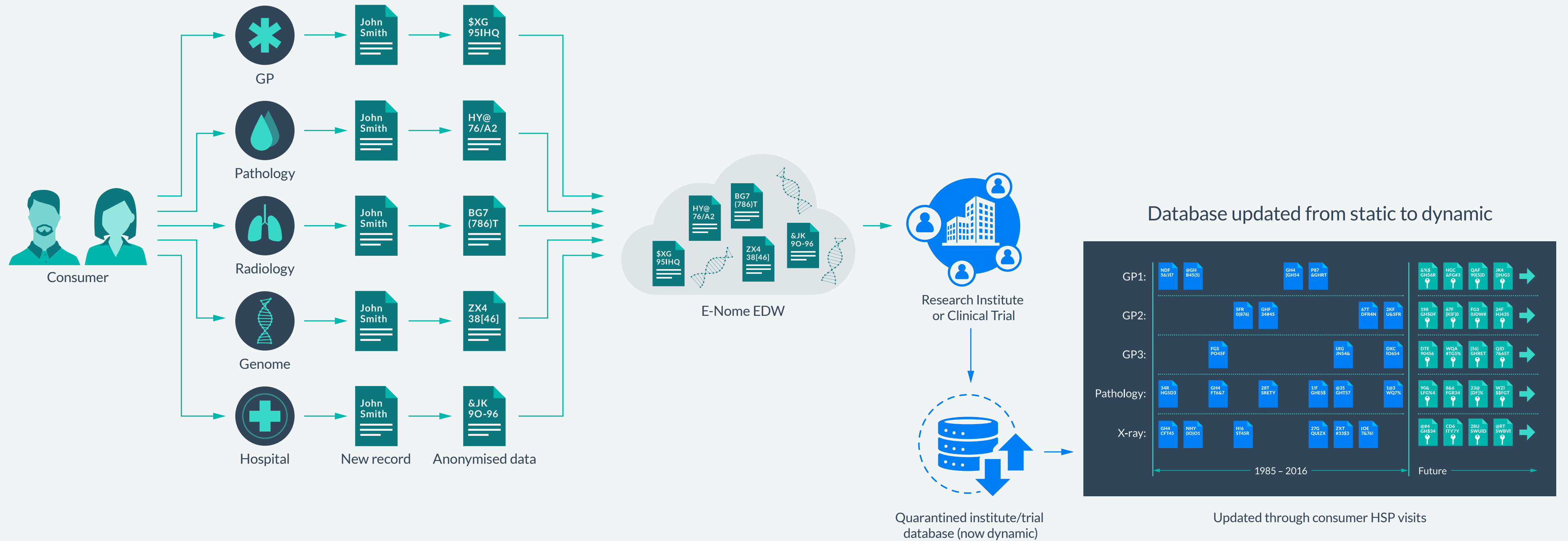
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## 2. Data base updated from static to dynamic



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## 3. Access to significant de-identified data base with ease of access to participants



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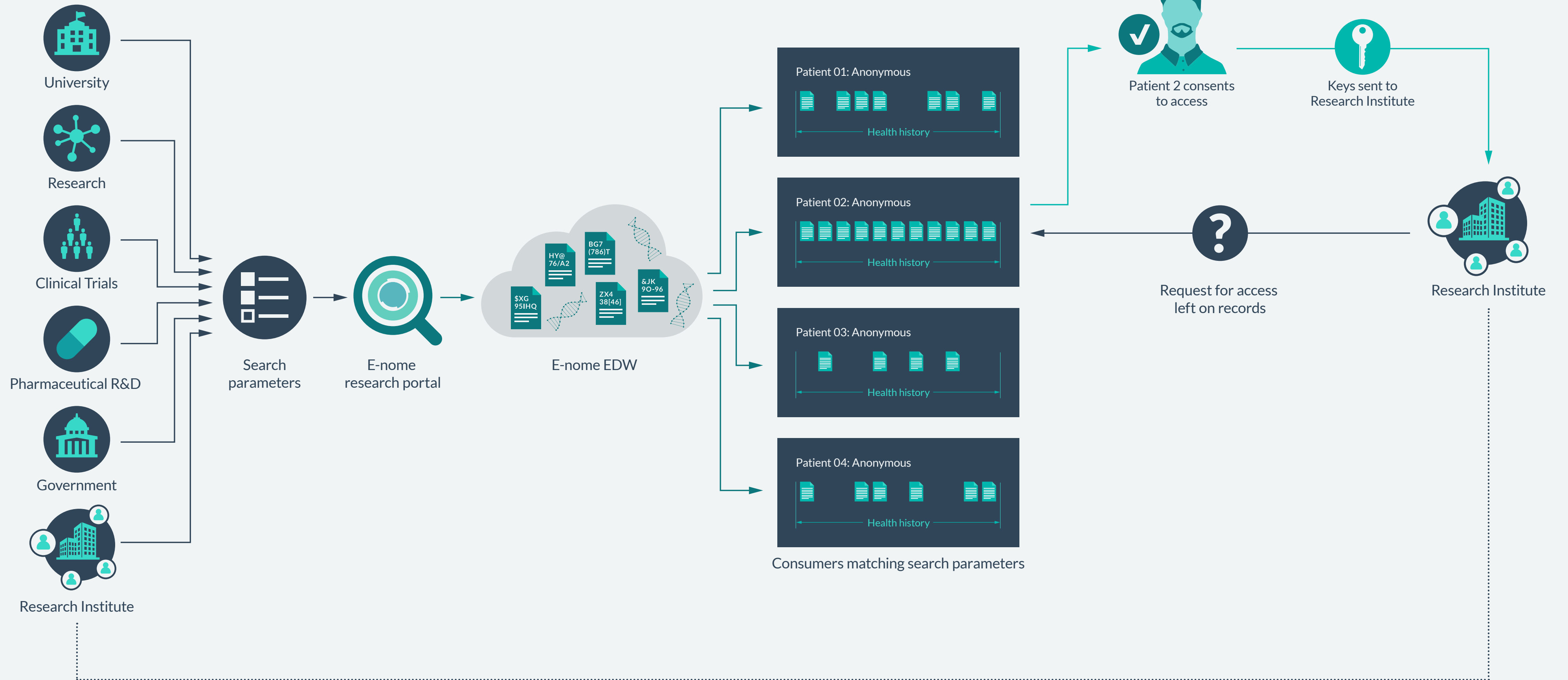
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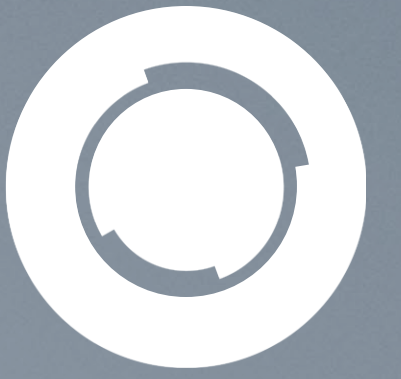
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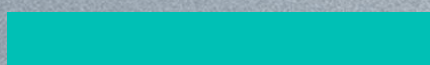
Peer Qualified Participant



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# Proof of Concept Partners





# 05 Partnerships



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## CORNERSTONE PARTNERS

E-Nome has secured two important collaboration partnerships. The first is with the Garvan Institute of Medical Research, one of Australia's leading medical research institutes and one of only 3 organisations world wide that has the ability to map an entire genome for under US\$1,000.

The second is with Tyde which is currently the only company in Australia to be granted level 4 portal operatorship licence into My Health Records. My

Health Records is the Australian government's national level Electronic Health Record push that has over 5 million users and access to 10,149 practices around Australia. E-Nome has signed a conditional subscription agreement, giving E-Nome the right to invest up to 30% equity into Tyde. The investment is the first strategic investment that will deliver content into the E-Nome platform to fast track consumer consented data capture for medical research purposes.

These two agreements are the basis for building the foundation of the E-Nome platform.



## Garvan Institute of Medical Research

E-Nome has signed two Memorandums of Understanding (MOU) with the Garvan Institute of Medical Research. The First MOU covers a strategic overview for collaboration to assess the potential for the E-Nome platform to be utilised within the Garvan's research divisions as well as exploring the potential for genomic storage. The second is specific to a research division within the Garvan, The Bone Biology Division, to deploy the E-Nome system to collect live data within this patient population using the E-Nome system.

The Garvan Institute was founded in 1963 by the Sisters of Charity as a research department of St Vincent's Hospital and is now one of Australia's largest medical research institutions with approximately 750 scientists, students and support staff. In 2014 the Institute became one of only three organisations in the world, and the only one outside the United States, able to sequence the

human genome at a base cost below US\$1,000 each.

The Garvan has undertaken, through its Bone Biology Division, a globally significant long term study of osteoporosis in Dubbo NSW - the Dubbo Osteoporosis Epidemiology Study or DOES,

The DOES, starting in 1989, with over 2000 women and men, is one of the longest running epidemiological studies in osteoporosis worldwide. It has been at the forefront of epidemiological advances in osteoporosis.

The Garvan collaboration gives E-Nome an important foundation partner for a beta trial of the system. This partnership will allow E-Nome to trial the software within the DOES to verify the value enhancement from the data capture made available to the researchers as well as attempt to quantify the potential cost reduction in data management generally.



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# Partnerships

## Tyde

Tyde puts consumers in total control of their health, offering a unique care co-ordination platform built using the Australian Government's My Health Record system.

Tyde is a consent engine allowing safe, secure and seamless communication between all members of the patient's care team.

It is fully connected to the Australian government My Health Record, potentially reaching the entire Australian population with user consent.

My Health Record is the world first national level EMR fully open to third party developers.

Tyde is the only platform that has permission to host the My Health Record data on its own infrastructure. All other players in the market have 'read only' access. By hosting the My Health Record data on its own infrastructure, Tyde can conduct a range of analytics jobs on the My Health Record data (and any other data it links to) in order to provide optimal clinical insight and drive improved health outcomes.



### MYHEALTH RECORD OVERVIEW

- Almost 21% of Australia's population is registered for a My Health Record
- Over 5 million people have a My Health Record, with an average of 1 new record being created every 38 seconds.
- Over 10,149 healthcare providers are connected, including GPs, hospitals, pharmacies, aged care residential services, allied health.
- Over 11,352,898 prescription and dispense records have been uploaded.
- Over 2 million clinical documents uploaded.<sup>10</sup>

The Australian Government announced in the 2017 Budget the creation of a My Health Record for every Australian to begin nationally from mid 2018. This is in effect the Government mandating that all Australians will automatically be signed up for My Health Record data collection unless the consumer opts out.



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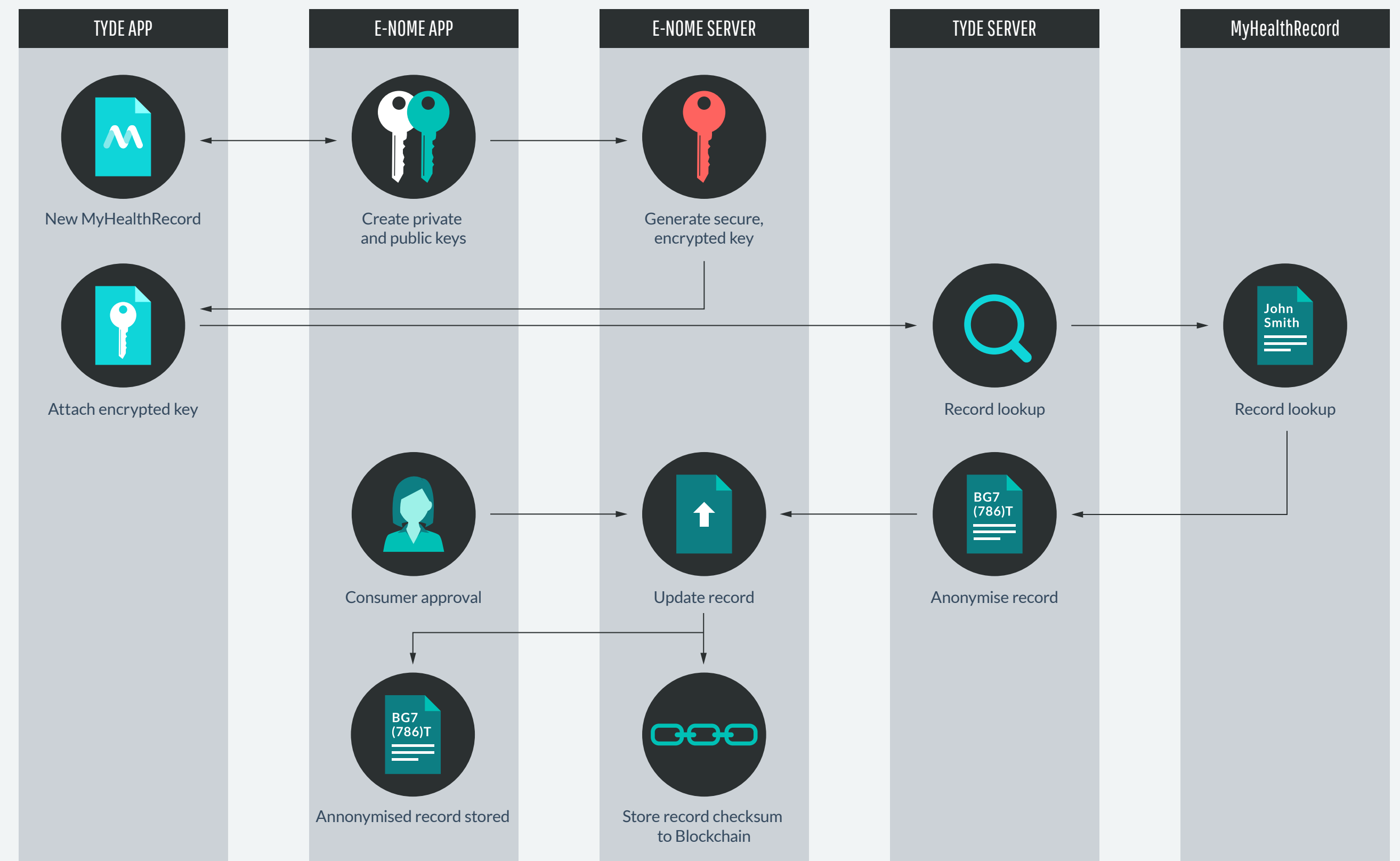
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The Tyde/ E-Nome agreement will allow E-Nome to be the private anonymised platform that will allow a consumer, at the time of initial consent for uploading My Health Record data to Tyde, to consent to their data being copied across onto their E-Nome app to give them access to the E-Nome ecosystem.

Consumer's data will be anonymised and sent to the E-Nome EDW as well as the consumer's E-Nome app. This will allow the consumer to utilise E-Nome's unique consent mechanism to give them access to clinical trials as well as medical research.

This partnership will allow E-Nome, through Tyde, to have direct live access to a consumer's My Health Record account to capture any data that may be already available, significantly fast tracking the data being made available on the E-Nome platform for research purposes.

E-Nome's strategic investment for 30% of Tyde is the first key pillar to delivering partnership content onto the E-Nome platform to fast track consumer consented data collection for medical research.



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# Company Overview

## Board of Directors



**Nicholas Curtis AM**

Nicholas Curtis AM, Co-Founder and Chair; Nick's career spans more than 30 years in the resources and finance industries. Nick has always had a deep personal interest and commitment to the health care sector. This is evident through Nick's significant voluntary community involvement in health care. From 2004 until 2011 he was a Director of the Garvan Institute of Medical Research. From 1999 he was a Director of St Vincent's Health Australia Ltd, St Vincent's Healthcare Ltd and was Chairman of the Board of St Vincent's & Mater Health Sydney Limited from August 2004 to October 2009. Nick is currently Chairman of the St Vincent's Precinct Research Executive Council. In 2011 Nick received the Ernst and Young Entrepreneur of the Year award for the Australian Eastern Division. On 13 June 2011 Nick was awarded an AM (member of the Order of Australia) for his services to the community through executive roles supporting medical research and healthcare organisations and also for his work fostering Australia-China relations.



**Steven Rubic**

Steven Rubic; With over 25 years' experience in leadership roles in the health services sector, Steven brings a wealth of industry and business expertise to E-Nome. Steven holds a Bachelor's of Health Administration (UNSW), has completed an MBA (MGSM) and is a Fellow of both the Australian Institute of Company Directors and the Australasian College of Health Service Management. Presently he is the CEO and Managing Director of I-MED Radiology Network the largest medical imaging network in Australia. Prior to taking on the role at I-MED in 2012, Steven was CEO of St Vincent's & Mater Health Sydney. He is also a director of the Chris O'Brien Lifehouse and has previously served on a number of boards including those of Macquarie University, the Garvan Institute of Medical Research and is a former Chair of the NSW Private Hospital's Industry Association.



**Peter Leonard**

Peter Leonard is a data and technology business lawyer. Peter was a founding partner of Gilbert + Tobin and he has worked as a legal and commercials adviser to global and Asia Pac data, communications and technology businesses for over thirty years. Peter chairs the Australian IoT (Internet of Things) Alliance's Data Access, Use and Privacy work stream, the Law Society of New South Wales Privacy and Communications Committee and the Australian Computer Society's Artificial Intelligence Ethics Committee. He serves on a number of advisory boards, including the NSW Data Analytics Centre, and a number of boards of directors. He is a former global chair of the International Bar Association's Technology Committee, former global vice-chair of the IBA's Communications Committee and former director of iappANZ.



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## Management Team



David Roffe

David's passion is to support clinicians manage risk and provide better patient care by the pragmatic application of engineering and computer science in healthcare. He has successfully lead dynamic IT teams who have made significant contributions to the Australian health industry by the strategic development and commercialisation of best practice clinical information systems. David has significant experience at Chief Information Officer level in several Public and Private health organisations.



Penny Gormly

Penny has twelve years executive management experience within the health sector, including membership of a number of Federal Government Advisory Committees. Her most recent role was General Manager Education, Training and Development at the Royal Australian and New Zealand College of Ophthalmologists. Penny has an Advanced MBA from the University of Queensland and a Masters of Accountancy.



Shane Hartwig

Shane Hartwig is a Certified Practising Accountant (CPA) and chartered Company Secretary and holds a Bachelor of Business degree, majoring in Accounting and Taxation from Curtin university of Technology in Western Australia. Shane is involved in the areas of Initial Public Offerings, capital raisings, prospectus and information memorandum preparation and project management, company assessments and due diligence reviews, mergers and acquisitions and providing general corporate advice. Shane has over twenty years' experience in the finance industry both nationally and internationally (Bankers Trust) with exposure to both the debt and equity capital markets.



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Oskar Buhre

Oskar Buhre has ten years of executive experience in analytical consulting and corporate advisory. In addition, he has been a founding team member of a number of financial service and consumer application start-ups.

His comprehensive and intuitive understanding of a business' core cashflow drivers provides him with the ability to quickly ascertain those drivers, to achieve results efficiently and effectively.



Tommy Ng

Tommy has a Bachelor degree in Computer Science and Pure Mathematics, and a Bachelor degree (with honours) in Electrical Engineering, both from the University of Sydney. For over 25 years he built, deployed, and managed IT Infrastructure and computing systems. He has particular interest in developing innovative biomedical and clinical solutions. He has served major hospitals in Sydney. Prior to taking on the role of CTO at E-Nome, he was the head of Architecture, Planning, and Strategy at St Vincents Health Australia.

## Blockchain Advisor



George Samman

After co-founding BTC.sx (now Magnr), a bitcoin trading platform in 2013, George is a blockchain/cryptocurrency consultant and advisor to global financial institutions, startups and law firms. He writes on blockchain technology and use cases at sammantics.com. George holds a MA in international finance from Columbia University and a BA in Political Science from University of Delaware.



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## Co-founders



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### Nuno Martins

Electronics engineer, A.I. and robotics. Expert in crypto currency applications. Highly experienced with Bitcoin Daemons and server systems, Security specialist, hacking prevention. Blockchain and Ethereum master. Full stack developer.



### Gov Van Ek

Gov has a PhD from University of Manchester in Total Technology and before Ledger Assets, he was Managing Director of a number of private and listed companies. He is an investor and business founder and launched his first software company in 1991. Gov is experienced in concept development, systems architecture and design, commercial matters and has expertise in human/computing interface design and A.I.



### John Bulich

John is a Director and Co-founder of Ledger Assets, a Perth-based blockchain developer specializing in the creation and commercialization of technical and commercial blockchain systems. Ledger Assets has successfully developed and deployed world-first blockchain-based products proving the provenance of artefacts including evidence-grade photography, video, document management and medical records management.

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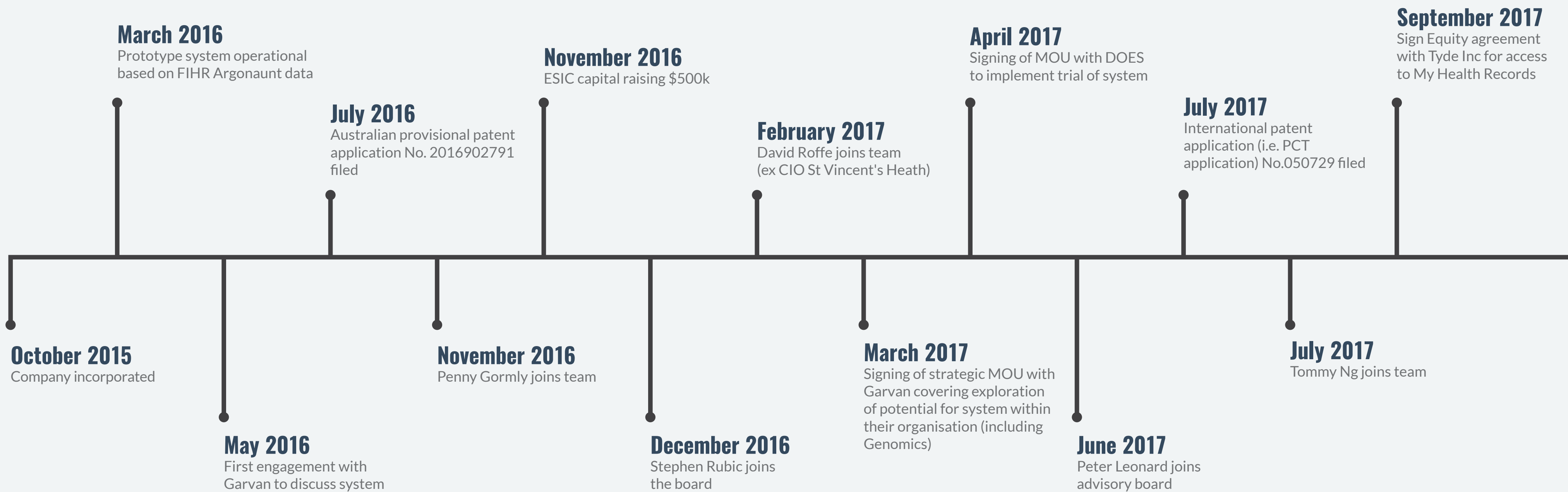
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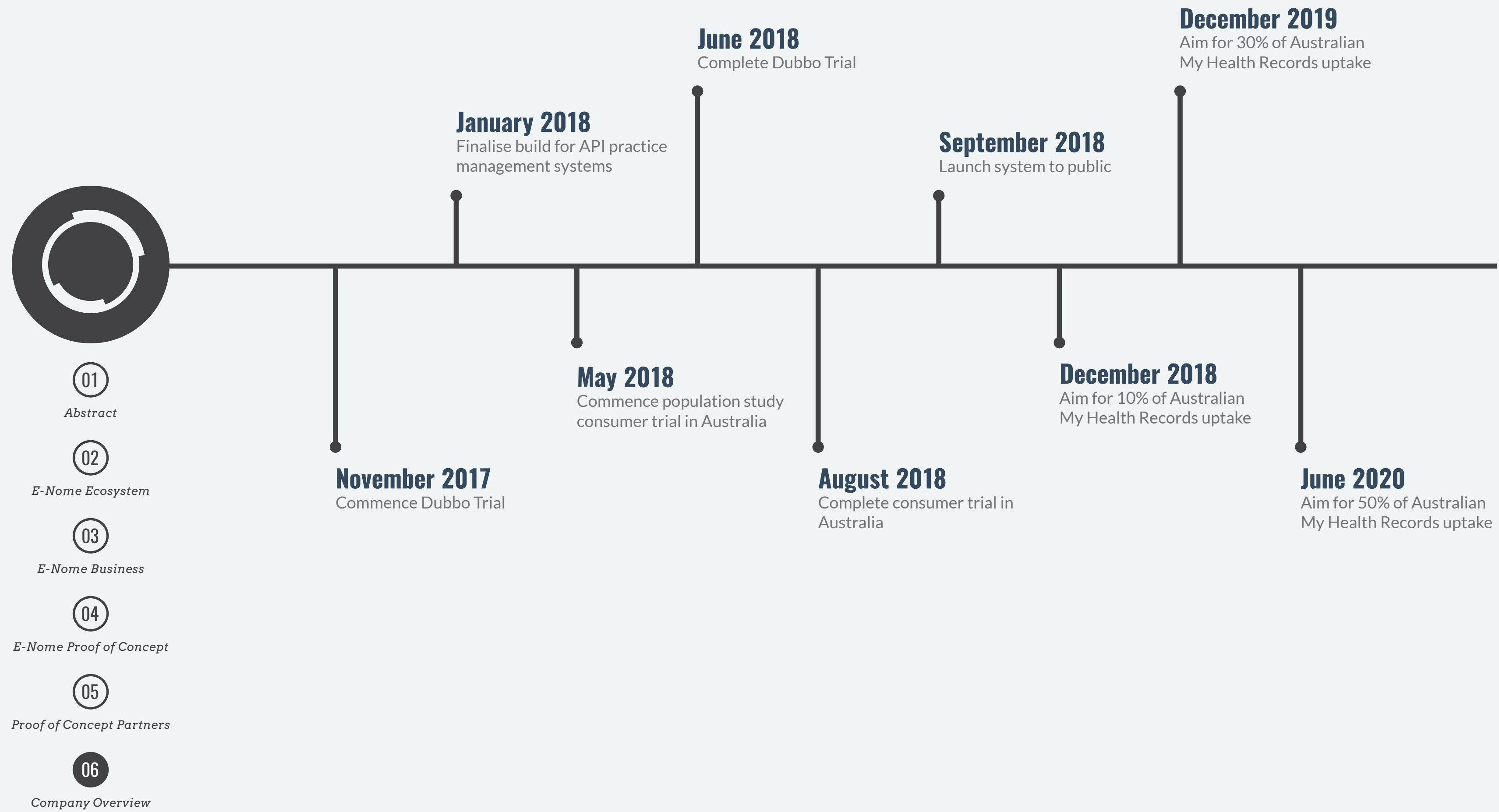
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