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Enabling Patient Centricity

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Exec Chairman & Founder

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US Open notes has already demonstrated the benefits of empowering patients with their records …..

Improved communication, understanding and health outcomes.

Making data portable and reusable takes this to the next level

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A UK Health perspective

*"It has to be based on consent. So **your data about your health is your property**. That is my starting point. That must be the principle that I will put at the foundation of data protection in the NHS"*

Matt Hancock

Secretary of State for Health and Social Care

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The global future of Patient Data …..

Enterprise and Consumer Artificial Intelligence

Consumer IoT and devices

Consumer engagement health / wellness

Precision medicine and personalisation

Portability
Privacy
Security
Consent

Distributed / edge based technology

Smart Cities and Health Eco-systems

Future Agenda: Future of Patient Data:
https://www.futureofpatientdata.org

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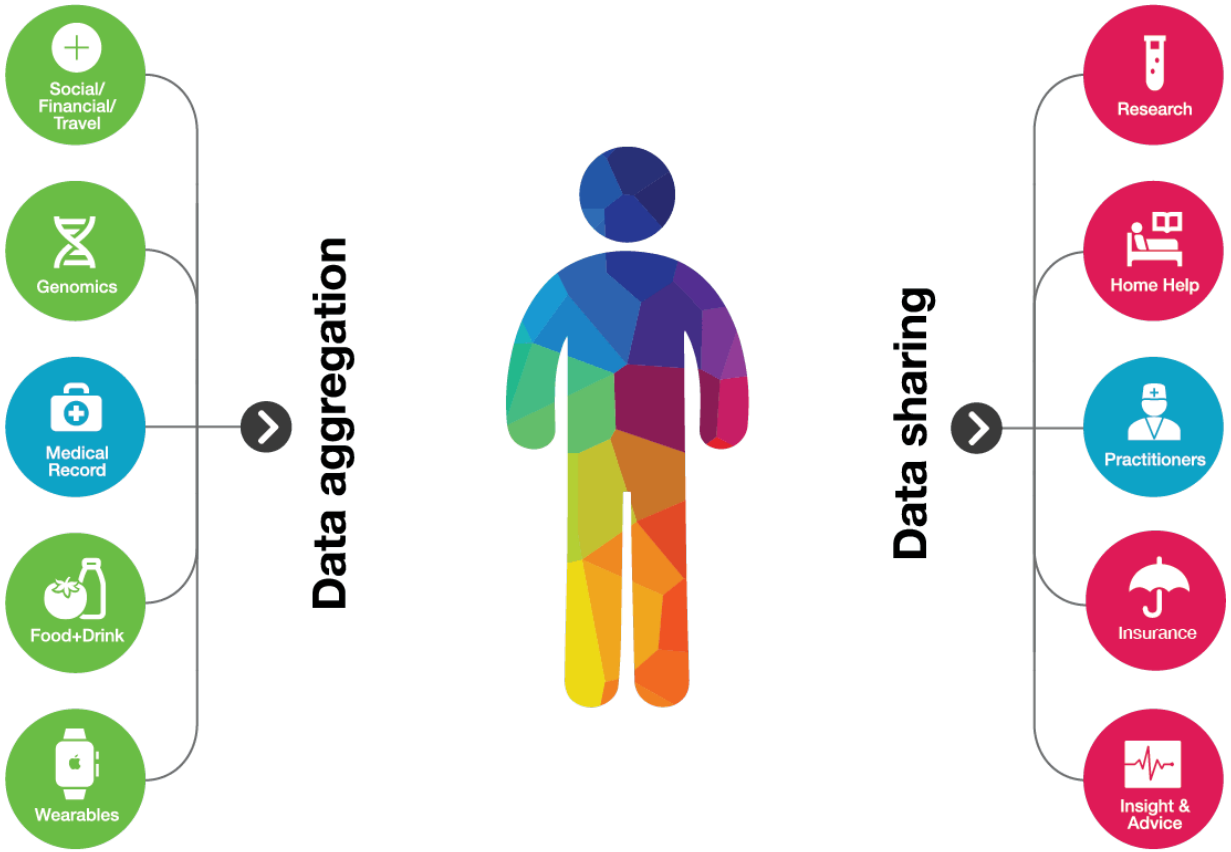
Patient Centricity :

Empowering individuals with their data …..



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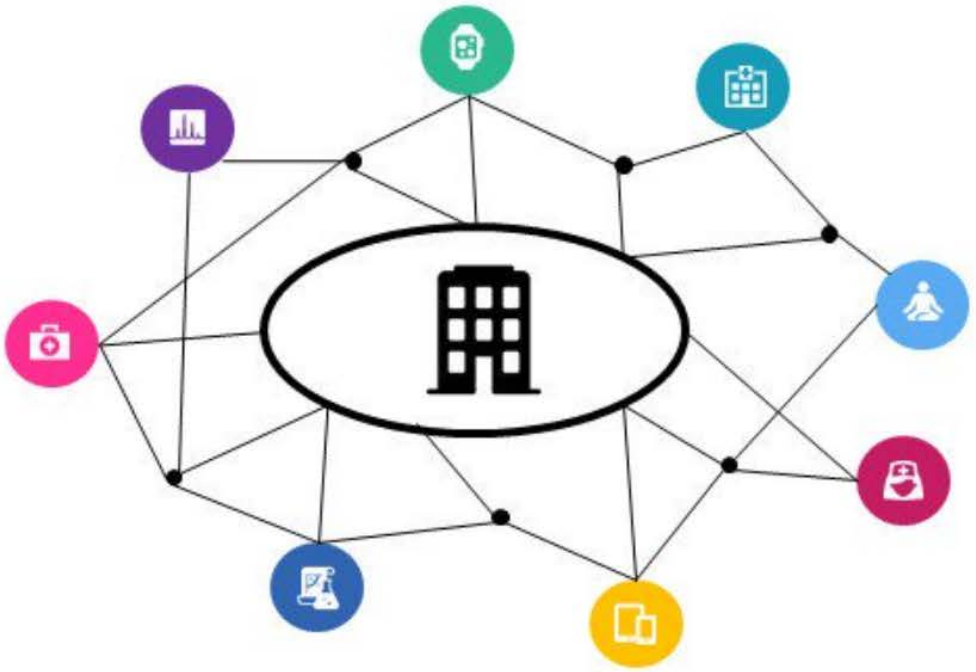
Interoperability Vs Patient Centricity



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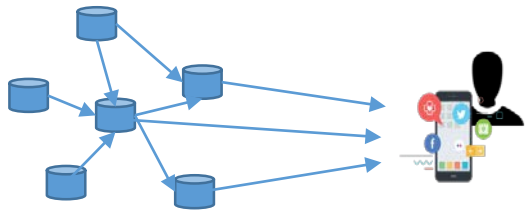
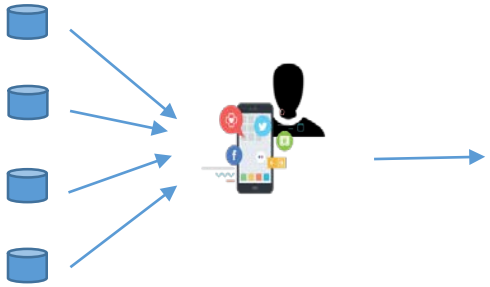
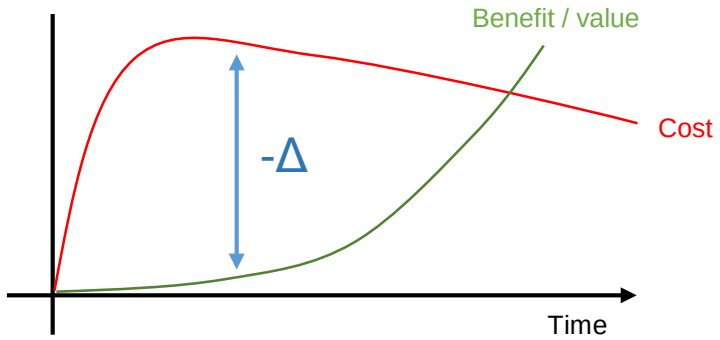
Patient Centricity enables early benefits realisation …….



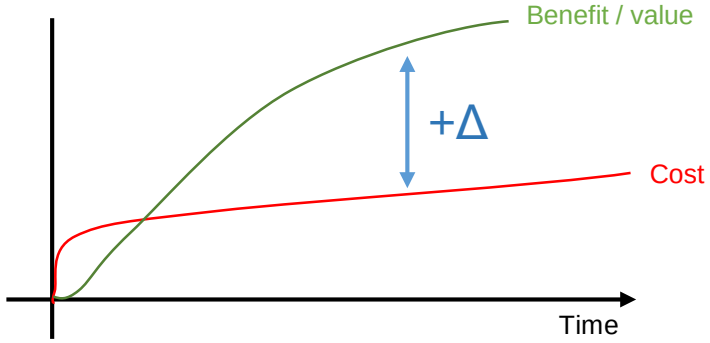
Multiple systems, regions and standards and implementations



Single flow & approach to aggregation, normalisation, consent



Significant upfront capital investment before benefits are realised



Reduced initial capex and earlier benefits realisation.

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Patient centricity benefits

Patient	GP	Hospital	Research	Innovators
Whole patient picture - Rich single source real world longitudinal data		Build stronger relationships and trust with greater value		Maximum privacy and sharing - on device information and processing
Empowered and engage patients	Efficient healthcare and communication		Accelerated research	Catalyst for innovation
	Simplify and improve compliance (GDPR, MU3, ethics, etc.)			
Enables prevention, earlier diagnosis and treatment				
Improved privacy and control	Enables new models of care and care pathways		Richer data – Insight detection	Reduced complexity
Greater choice and flexibility of services	Improve efficiency and care coordination – fewer and better encounters		Direct to patient cohort selection - wider	Direct to consumer
Personalised advice and informed decisions	Greater ability to remote monitor and support		Direct relationship for consent and feedback	Catalyst for new business models
Enhanced care team communications	Understand lifestyle and behaviours with broader phenotypic data		Faster IRB approvals	Faster route to market
Improve health and wellness outcomes	An alternative to using data brokers		Accelerate futility analysis	Simpler to integrate and scale
Simplified health transitions (e.g. claims, onboarding)	Improve engagement in hospital-centred research initiatives		Reduce 4th Hurdle Challenge	More cost effective than data brokers
Facilitates building health related communities			Enhance monitoring of drug effectiveness and adherence	Simpler collection of real world evidence

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Europe: Drivers for Patient Centricity

- Legal Requirement
  - Data portability – Article 20 GDPR
  - Right of Access - Article 15 GDPR
  - Duty of Care towards patients and their data
  - Right to cross border care
- Data portability
  - Need to move data across border
  - Multiple systems and standards
  - Inefficiency an ineffective healthcare
- Innovation
  - Current models prevent innovation
  - Limit self care / management

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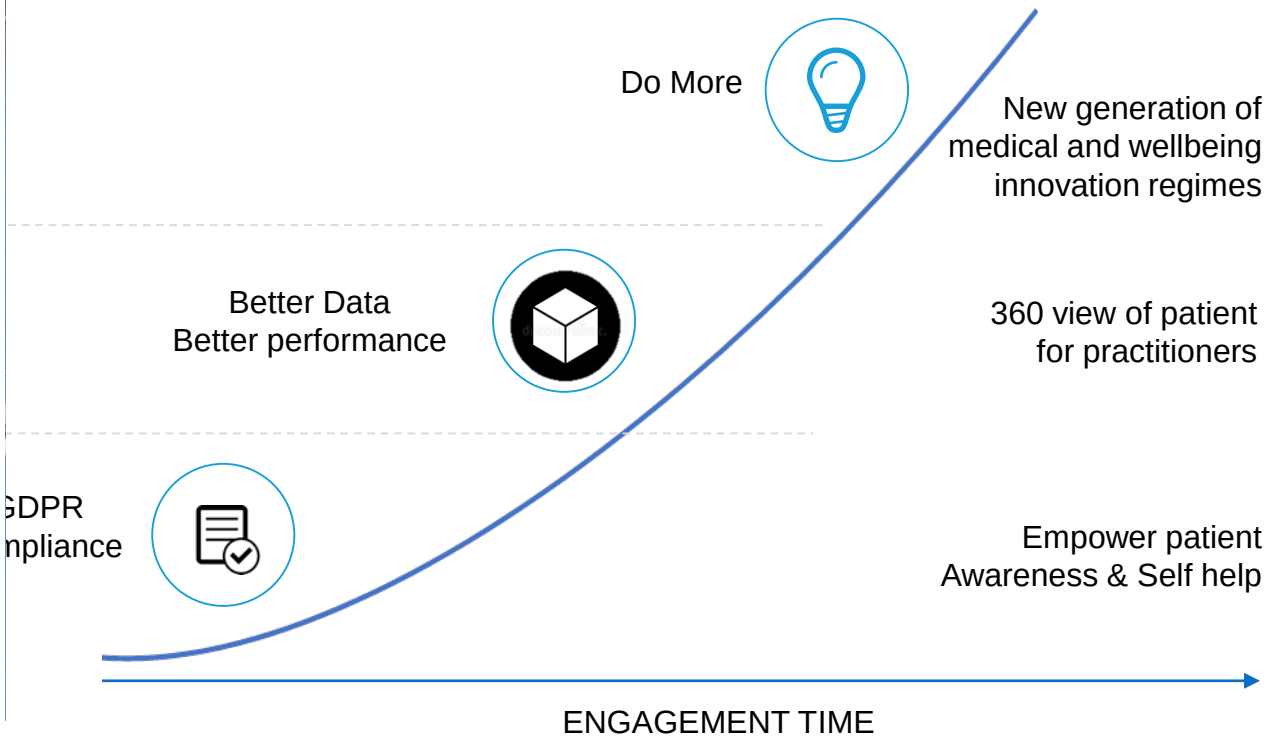
The road to Patient Centricity:
Innovation can only follow data liberation

Patient Centricity
Value Structure



Key Stages to Patient Centricity

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How does digi.me enable Patient Centricity?

The digi.me app creates your own secure personal library and lets you add data from different sources.

You own this library and keep it on your choice of secure cloud storage.

Then you can share your data direct from your device – with you in control.

digi.me Videos

Digi.me vision & app in action
https://digi.me/video.html

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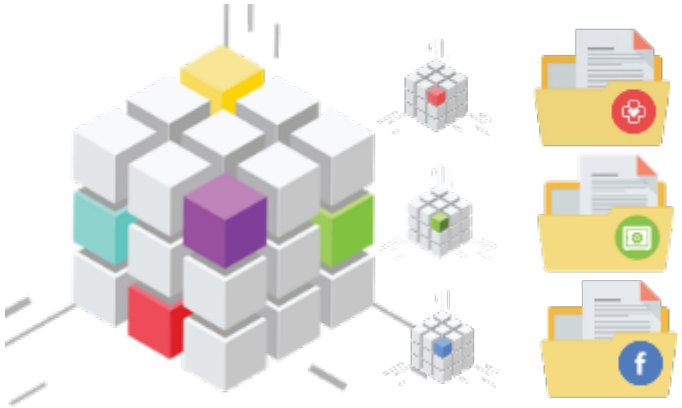
3 Core Challenges we solved

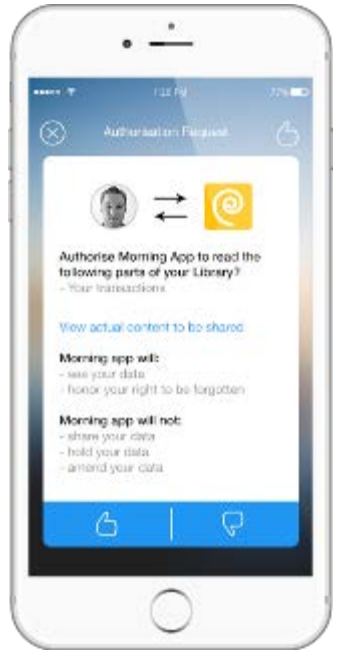
Secure Cloud Data Collection

How to get data from everywhere



Normalisation

How to put data into usable form



User Consent

How to control movement of data

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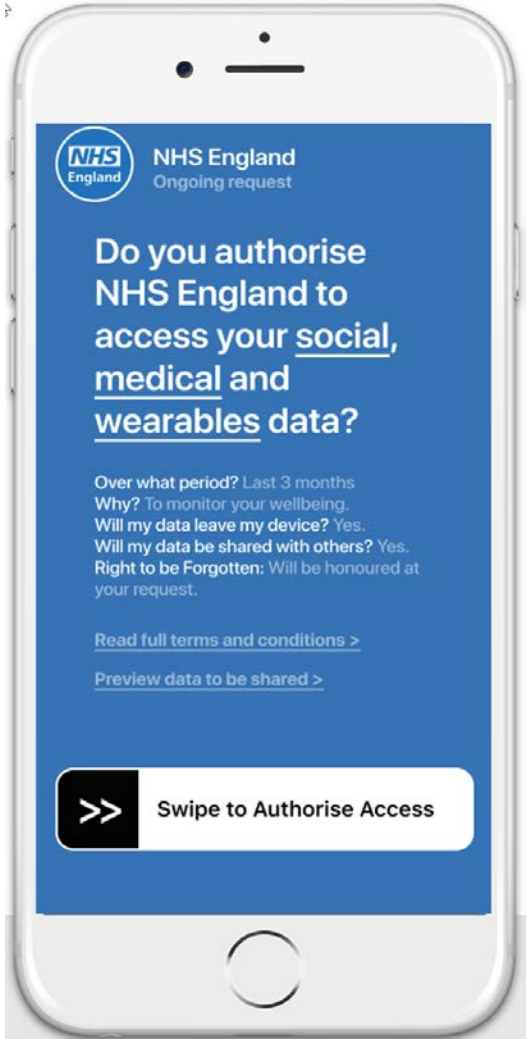
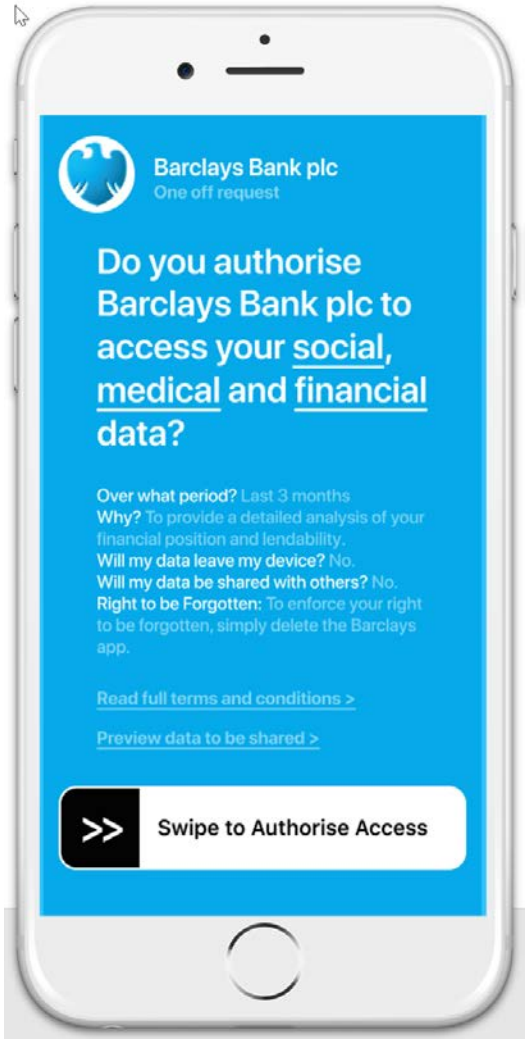
Consent Access – explicit & informed consent





kantara INITIATIVE™

Iteration through user review and in international standards bodies

Consent Receipt WG

Consent Best Practice WG

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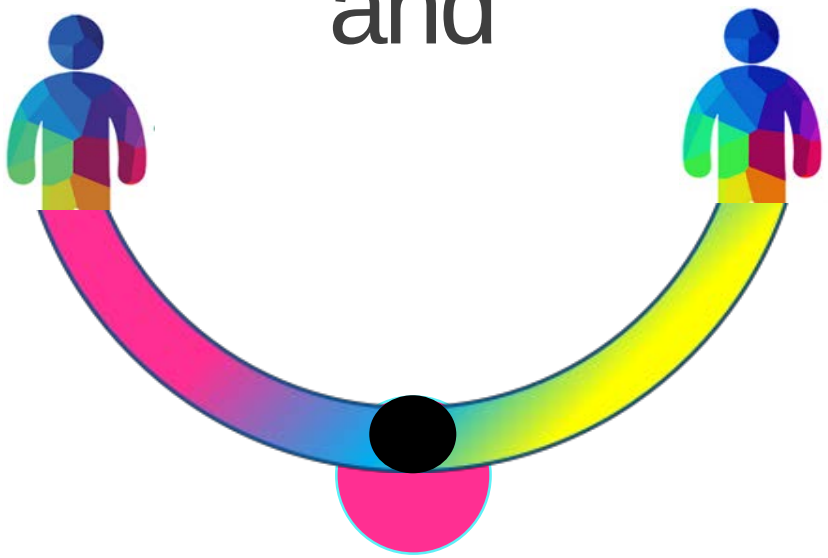
Patient Centricity enables us to do more with data with greater privacy ….

maximum privacy

and



maximum sharing

Better for individuals, healthcare, industry & society

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Iceland Case Study – A world first

- Made one change : Open up an API.
- Worlds first National, citizen facing health record API.
- Independently audited under direction of Department of Health
- Individuals use digi.me to securely download a copy of their data and use it with apps and services.
- Innovation Hub and Iceland Venture Studio spin out businesses attracting inward investment.

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Retina Risk Case Study

Self monitoring for sight-threatening diabetic retinopathy …

- Developed by Doctors in Iceland
- Continuous and passive monitoring which alerts individual to any increase in their risk.
- Lowers risk , saves money, improves quality of life and health outcomes.
- Very high accuracy for prediction validated against 20,000 patients in the UK and other countries.

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United States:
HIPPA Meaningful Use 3

- Requires healthcare providers to open up data
- Mandate incudes patient facing APIs

- Various standards/formats : BlueButton,CCDA, FHIR
  (including Epic and Cerner)

- 150 healthcare providers connected

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What about the NHS ?

- Final stages of GPSoC assurance process.
  - Information Governance
  - Clinical Safety
- EMIS first GP record system to go live
- Working with EHR vendors to bring US capability to Europe.
- Next step: Identifying partner to establish an exemplar innovation hub and the innovation eco-system.

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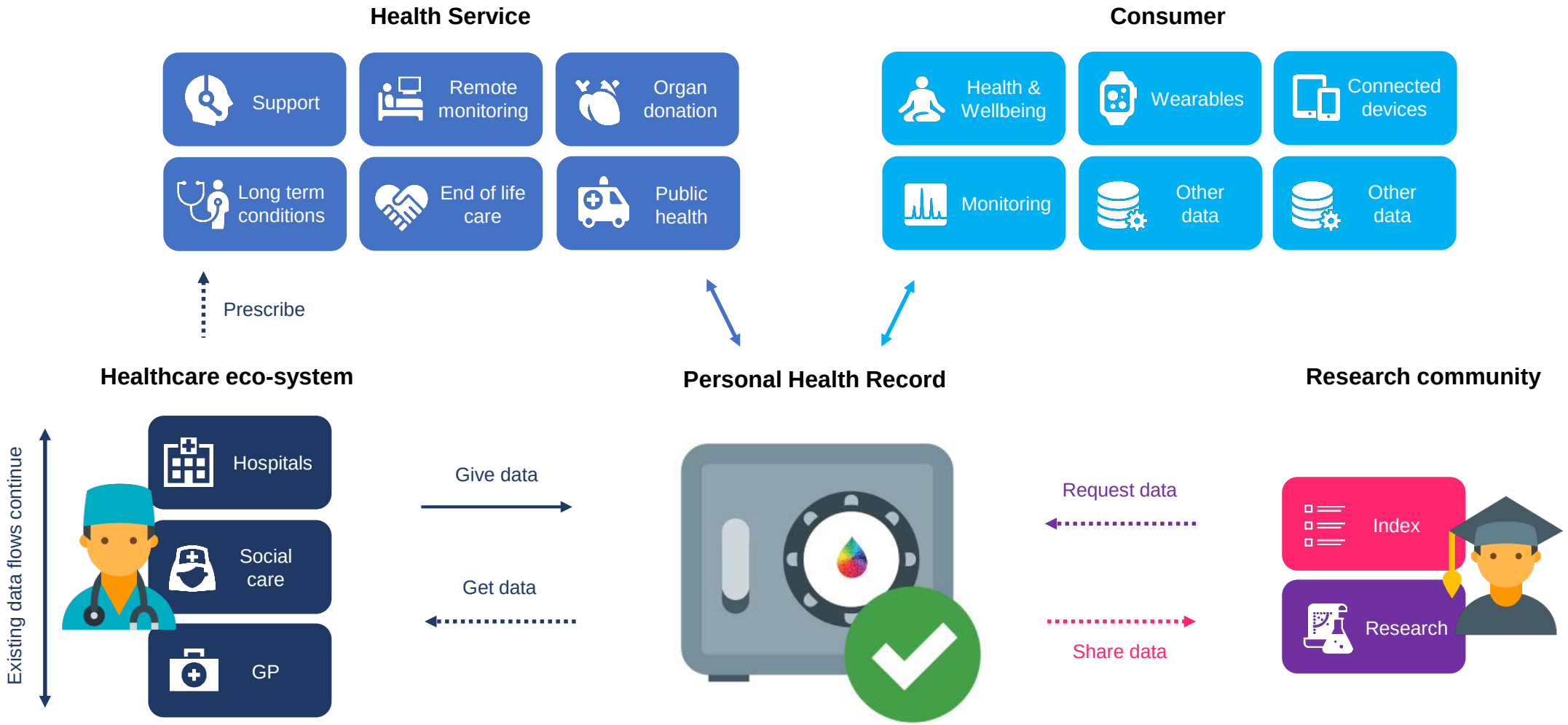
Patient Centricity Eco-System



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… and **requires one thing** : empowering the patient by opening up APIs.

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