

Access to health data
-
a global movement

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Aim

- At the end of the presentation I'd like you to believe three things:
 - Patient digital access to their data is a good thing
 - That the Internet of Me is a good thing
& can be private & secure
 - That the personal data economy will have significant advantages for patients, clinicians and Government
- If I don't then please challenge me at the end of the presentation

Key Market Trends

CONSUMER

THE DATA
GENERATION

CHOICE

DATA
ANALYSIS

INSIGHT

PERSONALISATION

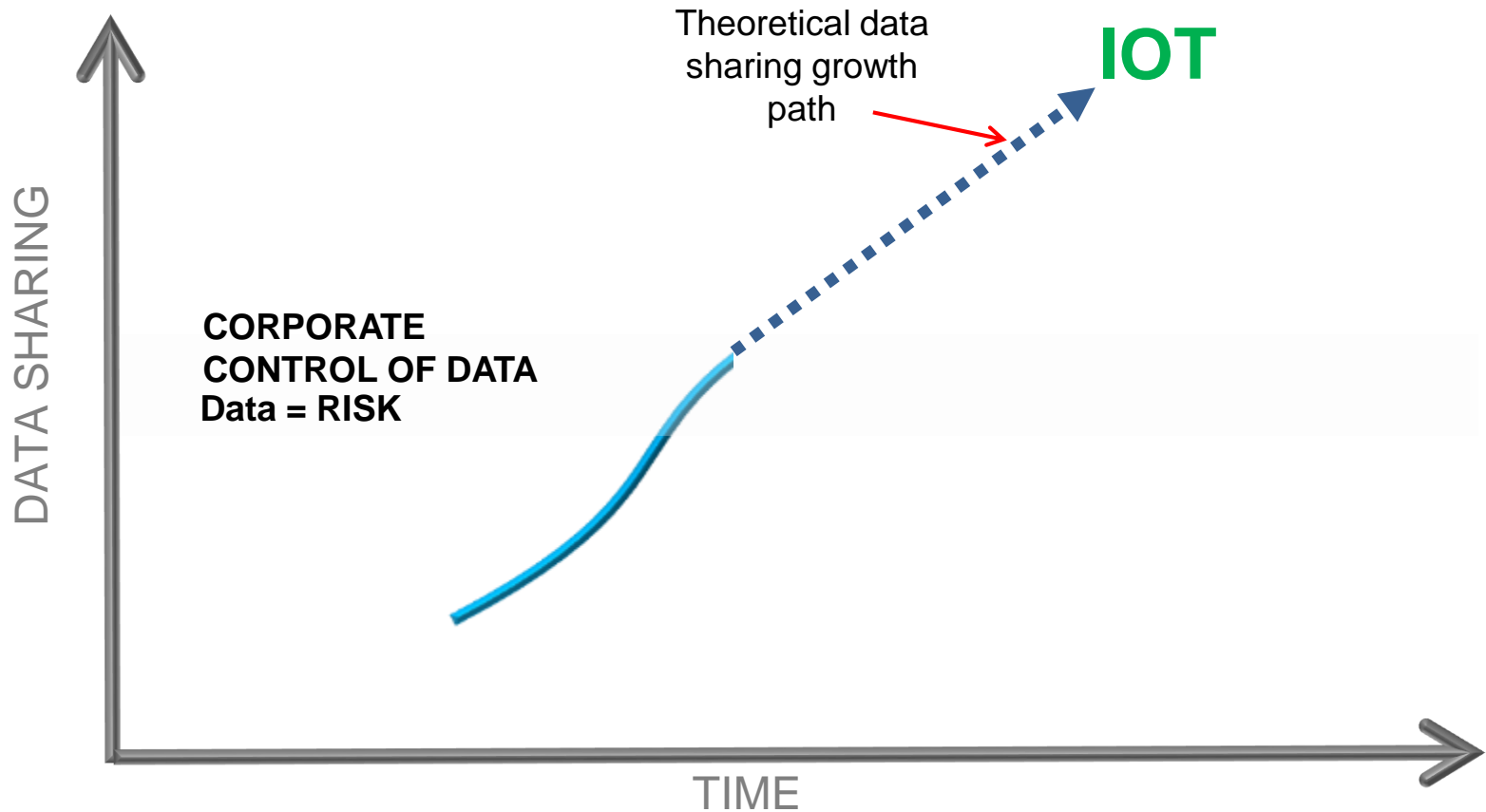
SERVICES

DATA
PROTECTION

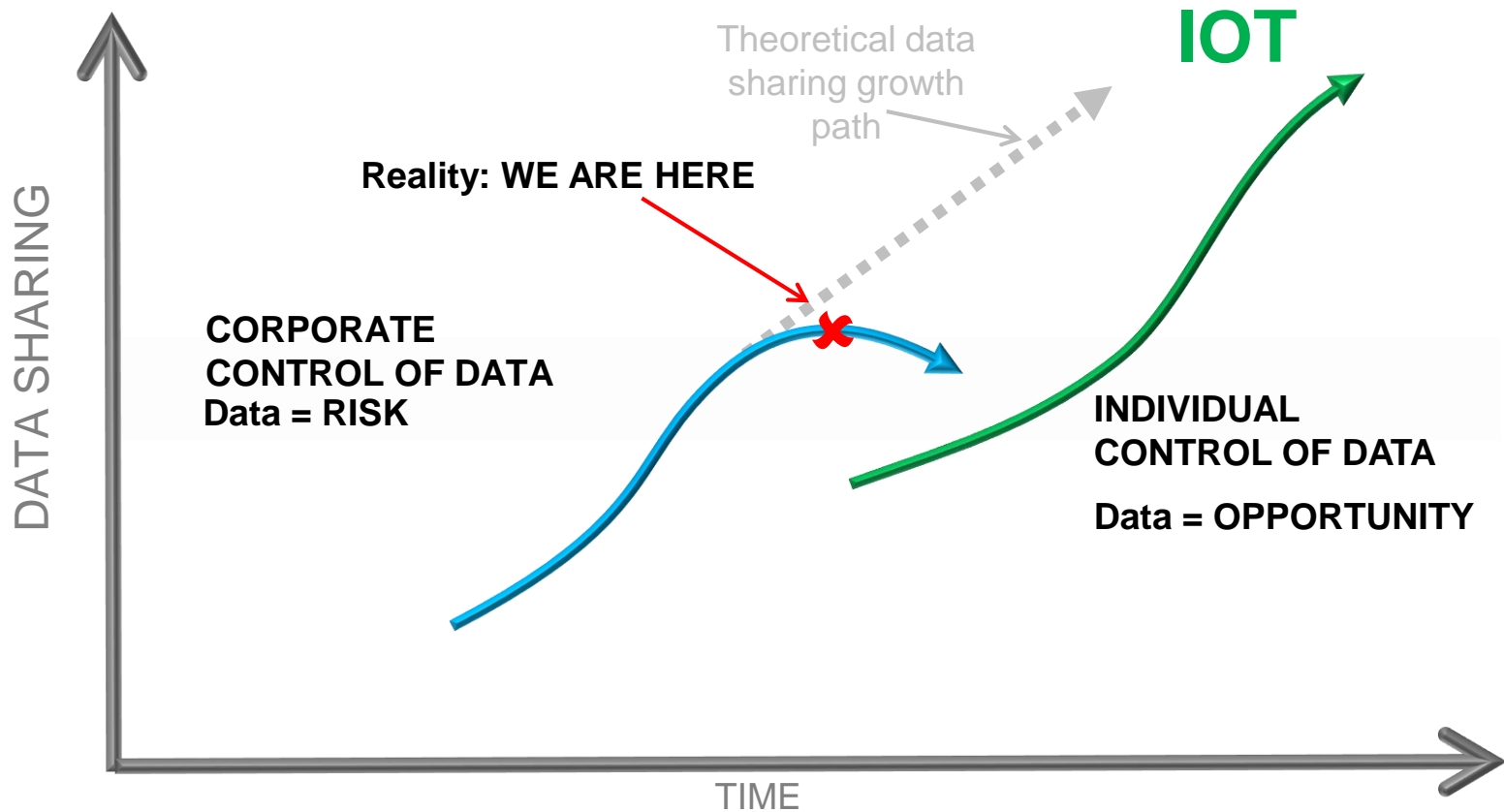
CONTROL

The end result is a change of control over Personal Data from the Corporation to the Individual.

THE CHANGE IN CONTROL OF PERSONAL DATA



THE CHANGE IN CONTROL OF PERSONAL DATA



NEW REGULATIONS

EU General Data Protection Regulation

- Privacy by design
- Explicit & informed consent
- Data portability
- Right to Forget

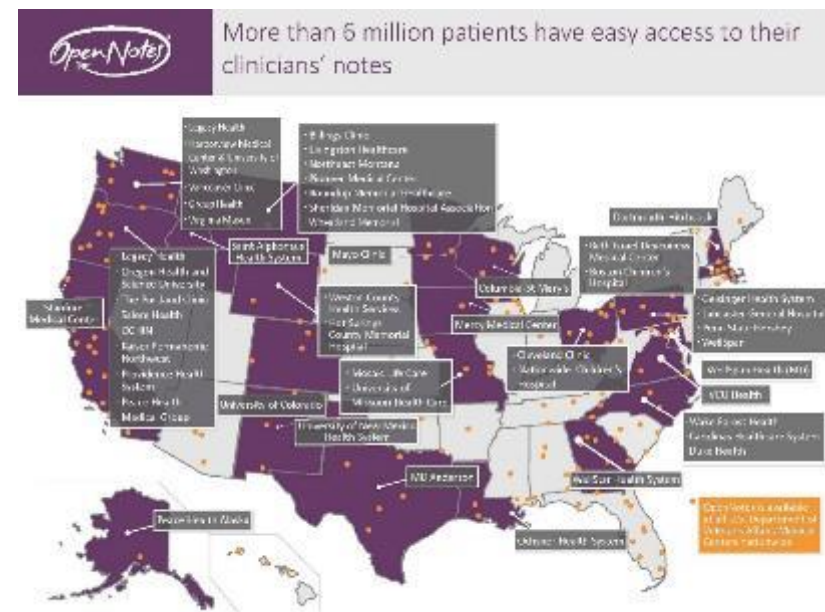


So what does this mean for patient data?

- Primarily it means that patients have a right to their medical data – all of it
- This right has existed for years:
 - 1996 HIPAA in US
 - 2009 Iceland
- As systems go digital, patients can access through their Electronic Health Records (HER)
- However, consistent right now to see ALL data
 - A requirement already in the US through Meaningful Use 2 & 3 which mandates VDT (View, Download, Transmit)

Is patient access good or bad?

- US Open Notes program largest study since 2010
- Upfront doctors had many concerns including:
 - Visits taking longer
 - More time addressing patient queries outside of visits
 - More time writing/editing notes
 - Changing way write notes
 - Patients lack of understanding/fears





Open Notes study - results

- Many different papers & studies arising over the last few years with clear conclusions:
 - **Improved patient understanding** of health information
 - 77-85%
 - With few being worried, confused or offended (5% or less)
 - **Better relationships** (with doctors),
 - 69-80% felt better prepared for visits
 - **Better quality** (adherence and compliance; keeping track) & improved self-care (patient-centredness, empowerment)..
 - 70-72% of patients reported taking better care of themselves
 - 76-83% reported remembering the plan for their care better
 - 77-87% felt more in control of their care
 - 60-78% among those taking medications reported



Open Notes Study - summary

At the end **99% of patients** wanted to continue sharing notes

and **no doctor** asked for the notes to be turned off."

"Viewing their records appears to empower patients and enhance their contributions to care, calling into question common provider concerns about the effect of full record access on patient well-being"

"Ultimately, patient access to all health record notes may translate into care that is more effective and more satisfying—for both patients and for health professionals."

"It's like Freedom of Information - seems scary at first, but people get used to it."

And this even before further enhancements which allow a 2 way exchange of data including modern sensors and other

It's not just health data.....

- The Personal Data Economy also includes:
 - Finance, social, retail, entertainment, wellness/fitness, telecoms & more
- But how do individuals access their data?
 - And how is that data private and secure

PERSONAL DATA IS SCATTERED ACROSS MANY ONLINE ACCOUNTS AND SERVICES



Users often can't have access to all their data. They also doubt that any business can hold their personal data private.

Businesses at war with consumers; only access thin, low-grade data.

79%

of consumers believe the main use of personal data is for the economic gain of organisations rather than theirs *

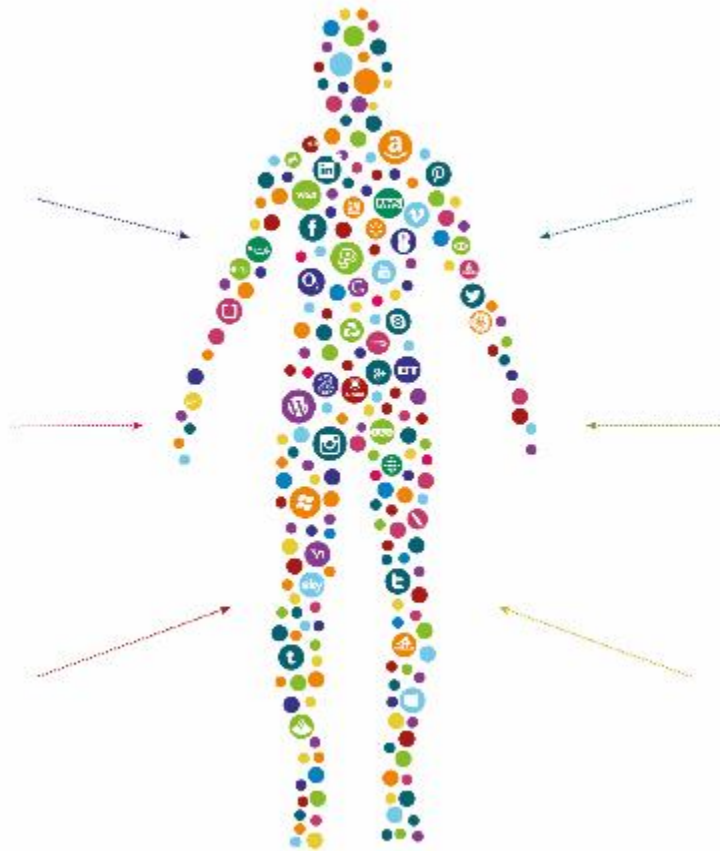


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COMBINING ALL PERSONAL DATA IN ONE SAFE PLACE OFFERS NEW LEVELS OF INSIGHT

Users can keep their personal data secure, protect their privacy, and get a complete picture of themselves.

**I own & control
my own data**



94%

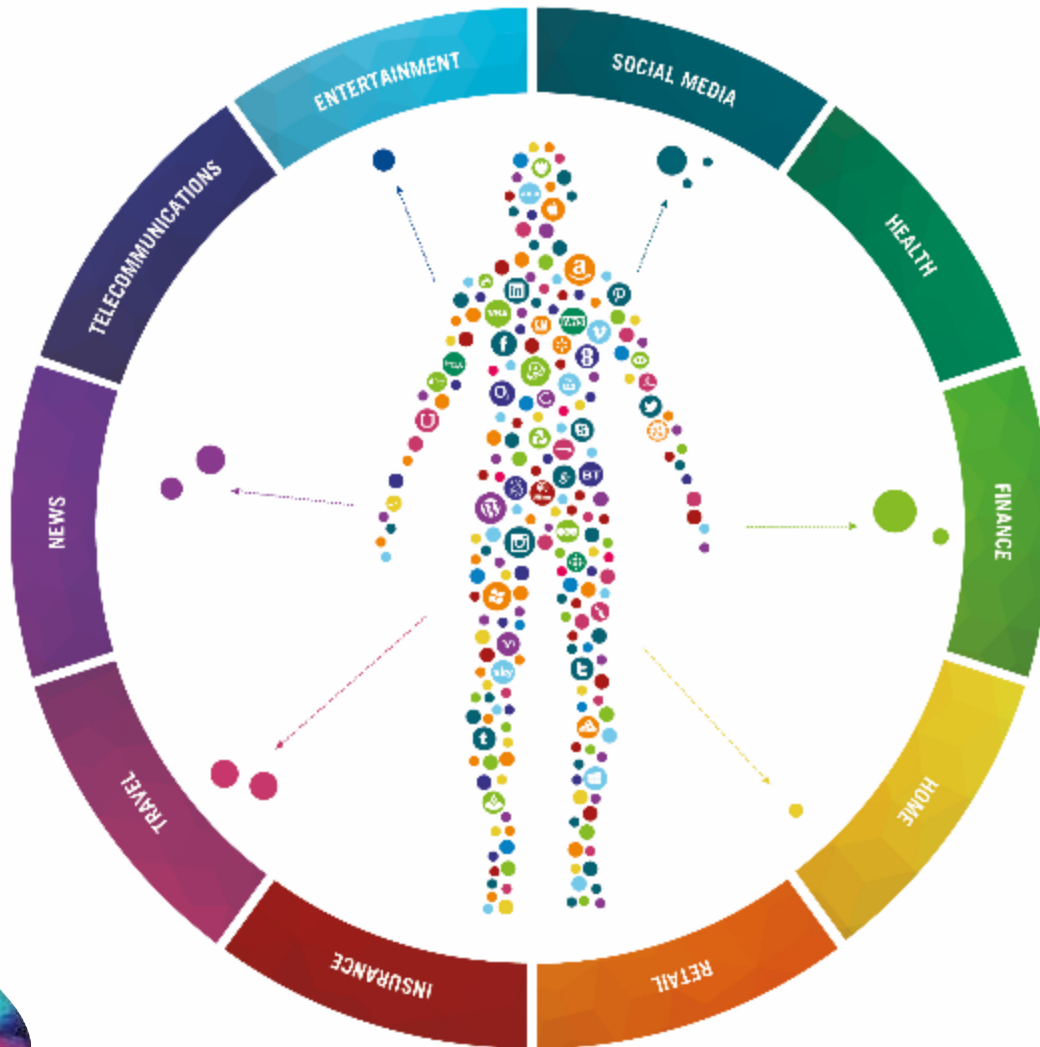
of consumers want
more control over their
personal data *



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THE INTERNET OF ME

PUTTING YOU AT THE CENTRE OF YOUR CONNECTED LIFE



Users can choose to share their richer data with organisations that can offer personalised experiences, services and products in return

Businesses can offer more tailored services and experiences, building trust and loyalty with their customers

81%

believe that industries boundaries will blur as **platforms reshape industries** into **interconnected ecosystems** *



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A hollistic picture of personal health

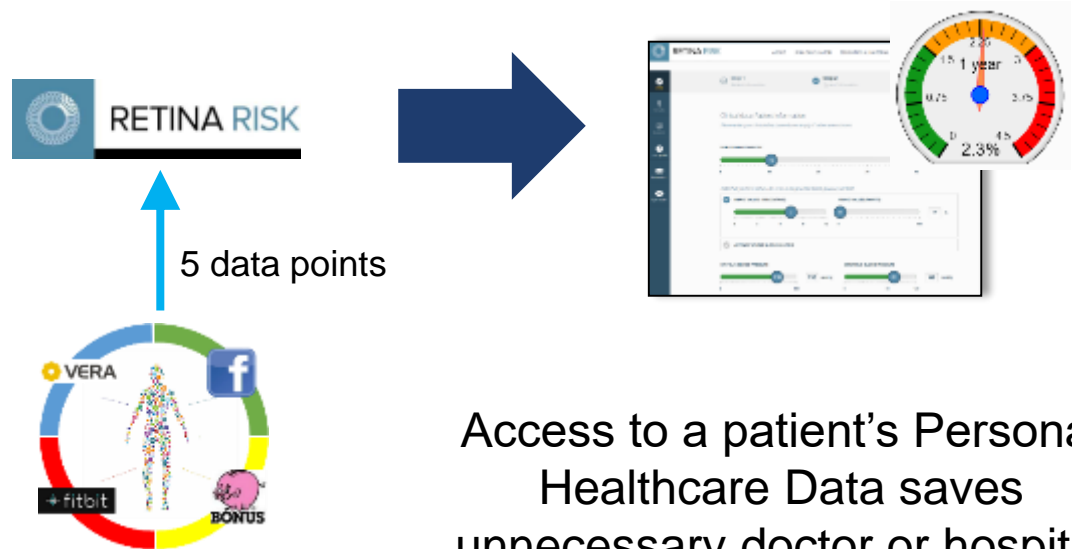


- Health & lifestyle data from apps and devices
- Users see the complete picture of their health
- Rich health data can be shared in return for benefits and advice (decision support)
- Healthcare firms help user live a healthier life

Personal Healthcare data reduces waste

Retina Risk™ requires 5 data points to evaluate when a patient needs to see their doctor

- Today ,this data in inputted manually with the inherent human error and inconsistencies
- Tomorrow , it is passive and 100% accurate



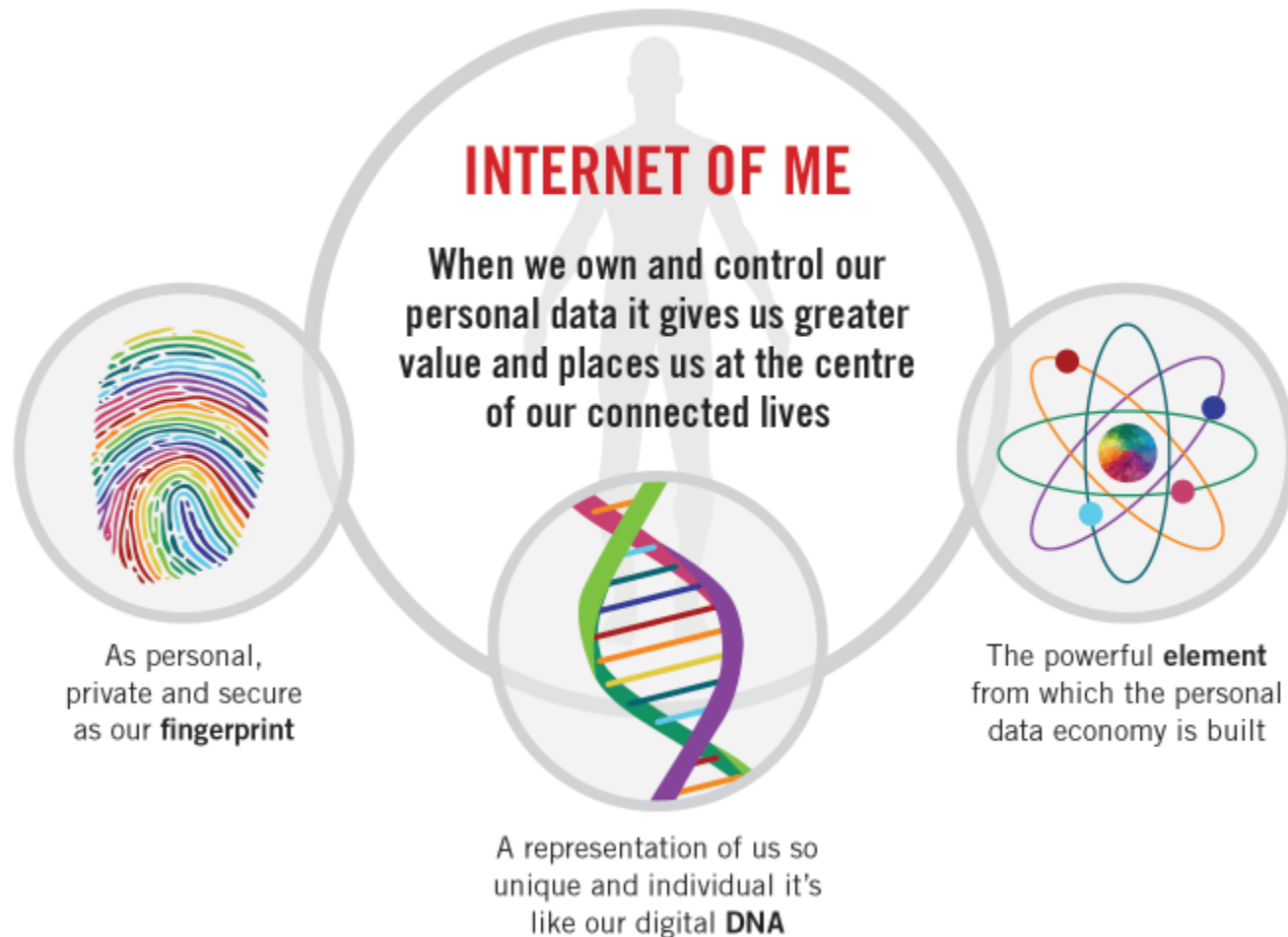
Access to a patient's Personal Healthcare Data saves unnecessary doctor or hospital visits

In the UK , this service ALONE would save the NHS over £40M GBP/ year

Internet of Me

Better for me as an individual

- But also for those I interact with



IoM – Healthy Advantages

Patient



Medical Professionals



Improved understanding of health information
Better relationships (with doctors)
Better quality (adherence and compliance; keeping track)
Improved self-care/decision support
Available for others (travel, care givers)

Whole patient picture – better information & accurate diagnosis

More efficient (less time/cost)

Better outcomes

Healthier population = higher productivity

Reduced inefficiencies and waste

Lower cost

And better for medical research too & others

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Better Health!

Aim

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An Opportunity to Lead

Iceland can lead the world in the Internet of Me & Personal Data Economy by:

- Adopting the principles of EU GDPR
 - Which includes protections for citizens
- Releasing Government personal data
 - Starting with healthcare data
- Stimulate the Personal Data Economy in Iceland
 - By encouraging applications to utilise permissioned personal Healthcare data