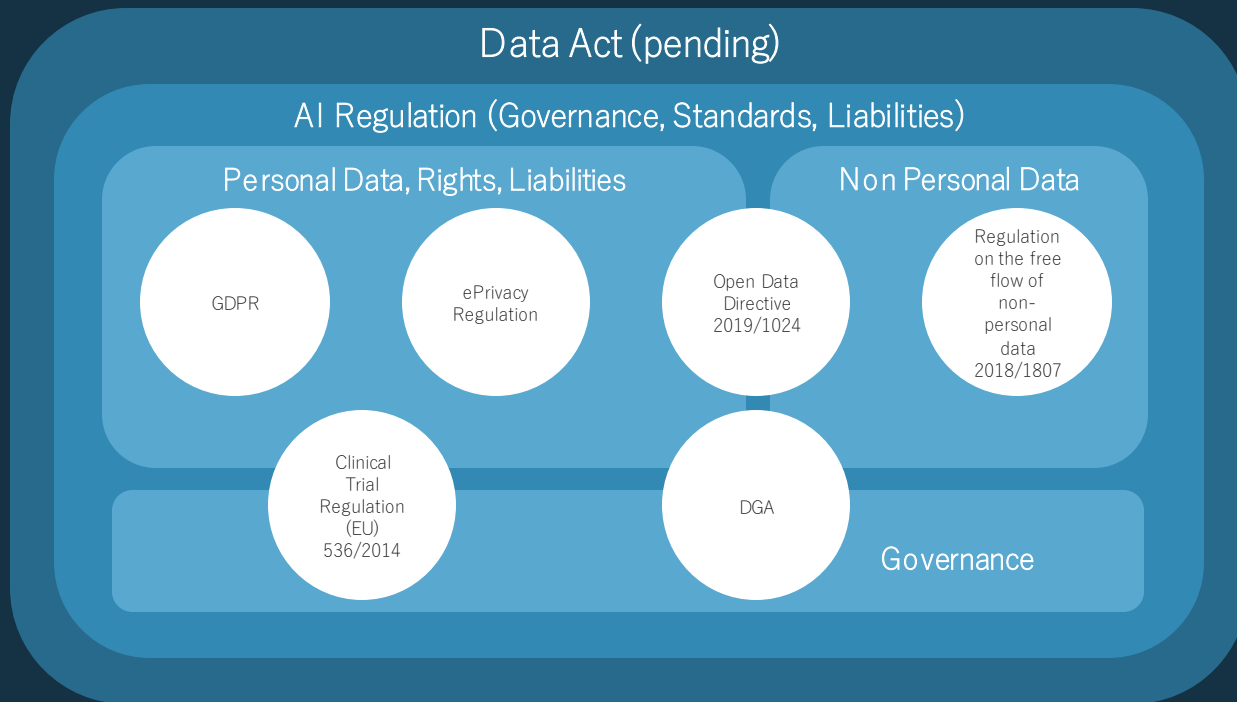


Health IT MyData

Alexandros Nousias NCSR-D, MyData Greece,



Legal Taxonomy



EU Data Strategy (2020)

Common European Health Data Space (EHDS)

- Delivery
- Research
- Policy

EHDS main pillars

Common European Health Data Space (EHDS)

Common European Health Data Space (EHDS)

Data
Governance

Data Sharing

Infrastructure

MyData4Pandemic's

Mobility use case: Responsible freedom of movement during pandemics

Post Marketing Surveillance use case: Increased safety and try in mass vaccination programs



As a Citizen, aware that pandemics can come..

I need to have access to information

- on health and basic hygiene measures
- on vaccination needs when travelling

I want to show I comply with the different local requirements on vaccination

I am ready to share location data & proximity tracking (as long as they are anonymized) - unless specifically agreed

MyData4Pandemic's

Mobility use case: Responsible freedom of movement during pandemics

Post Marketing Surveillance use case: Increased safety and try in mass vaccination programs



As a Citizen, in case of a pandemic like COVID19..

I need to have access to trustworthy information & understand what measures are of application and how/ why they apply to me and to others

I want

- to maximize my freedom of movement
- while minimizing the risk of contagion for others and my own risk to become infected

I am ready to share my data to an organization I can trust to manage these data in a secure way, while ensuring data privacy and giving me control whenever relevant (less critical)

Polarities in Covid era

Two equally desirable things that seem in opposition to one another

Reducing virus spread

Social/Financial Resilience

Social Distancing

Contact Tracing

Contact Tracing

Privacy

Shape Experience

Free Will

Bluetooth

GPS

Centralized

Decentralized

Obligatory

Voluntarily

Storage

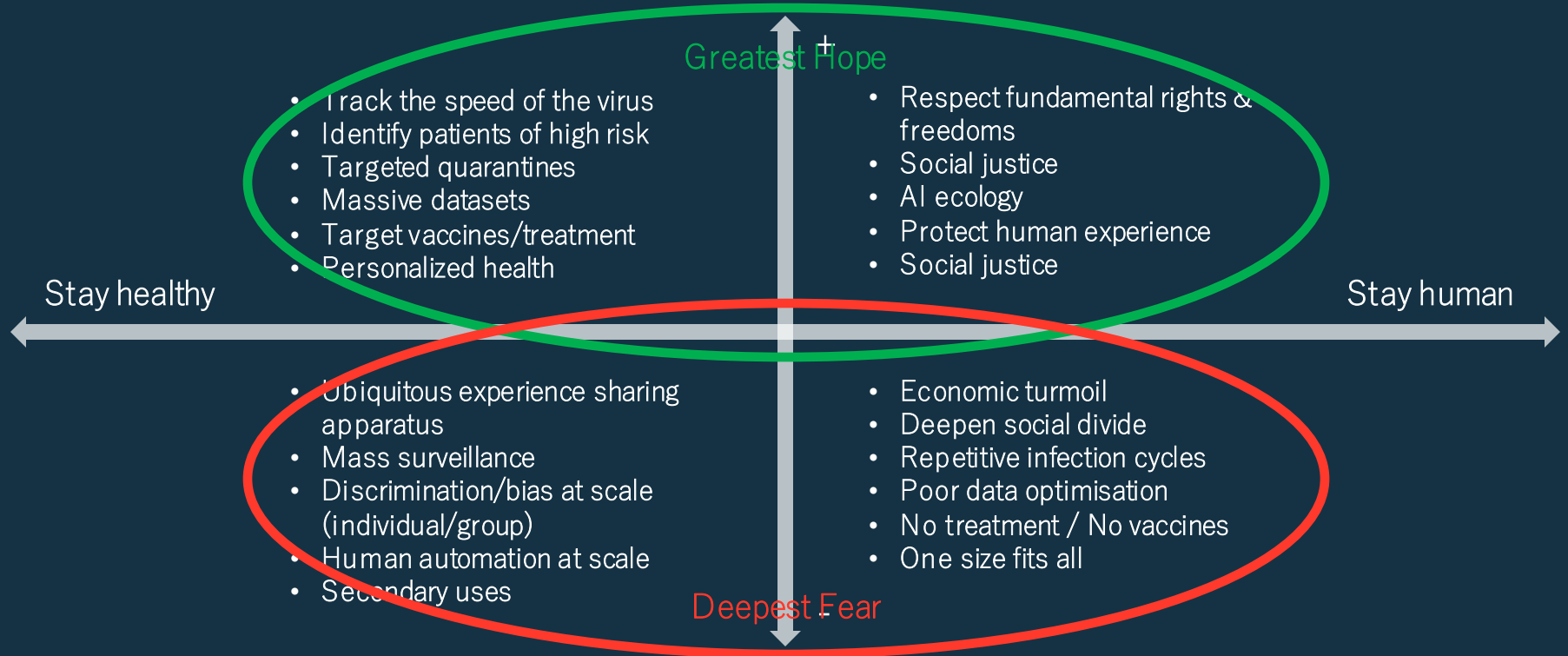
Access

Public Interest

Legal Obligation... or maybe consent?

Polarity Map

Pros and cons to make choices when confronting a polarity



The Dynamic of a Polarity

Pros and cons to make choices when confronting a polarity

Greatest Hope

Stay
healthy



Stay
human

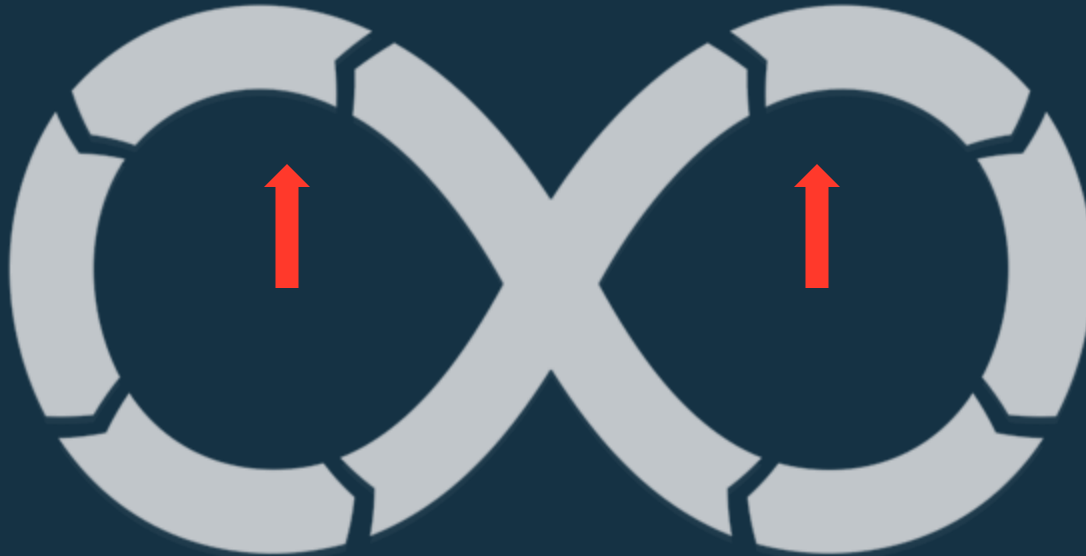
Deepest Fear

Raising the Butterfly

Optimizing choices when confronting a polarity

Greatest Hope

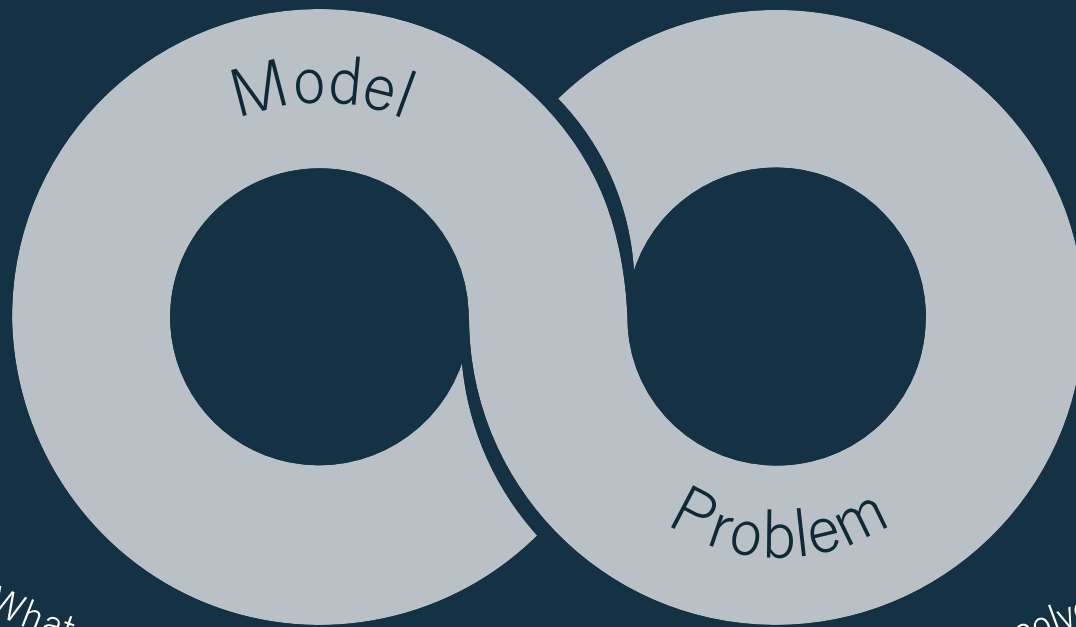
Stay
healthy



Stay
human

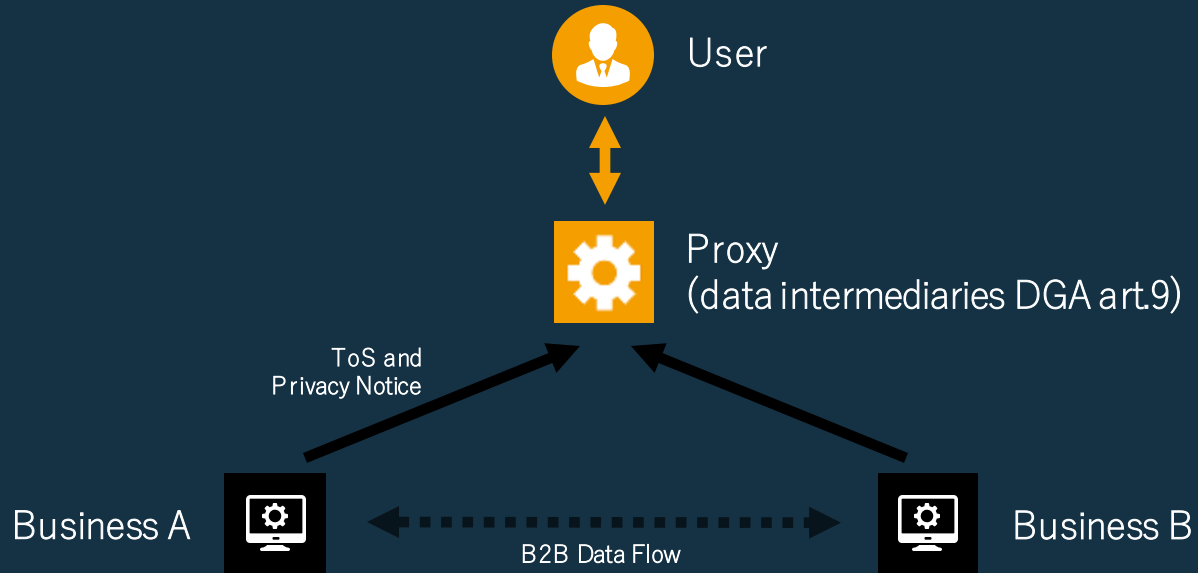
Deepest Fear

The real question



What model do you want to use? vs. What problem do you want to solve?
What problem do you create?

The Paradigm of *Now*



MyData Model

Compared to the aggregation model, MyData is resilient system because it is not dependent on a single organization or technical infrastructure



MyData Principles

Compared to the aggregation model, MyData is resilient system because it is not dependent on a single organization or technical infrastructure



MyData Roles

MyData Account Model

The architecture: Interoperable & standardized MyData accounts.

For individuals: The account model provides individuals with an easy way to control their personal data from one place even while the data is created, stored, and processed by hundreds of different services.

For developers: The account model facilitates access to data and removes dependencies on specific data aggregators.

MyData accounts will generally be provided by organizations that act as MyData operators. An individual or organization may fulfill one or more roles in the architecture.

Data source
A data source collects and processes personal data which the other roles (including Persons) may wish to access and use



Person

An individual that manages the use of their own personal data, for their own purposes, and maintains relationships with other individuals, services or organizations



MyData Operator (Intermediary)

A Personal Data Operator enables individuals to securely access, manage and use their personal data, as well as to control the flow of personal data with, and between, data sources and data using services

Consent Flow

Data Flow

Data using service

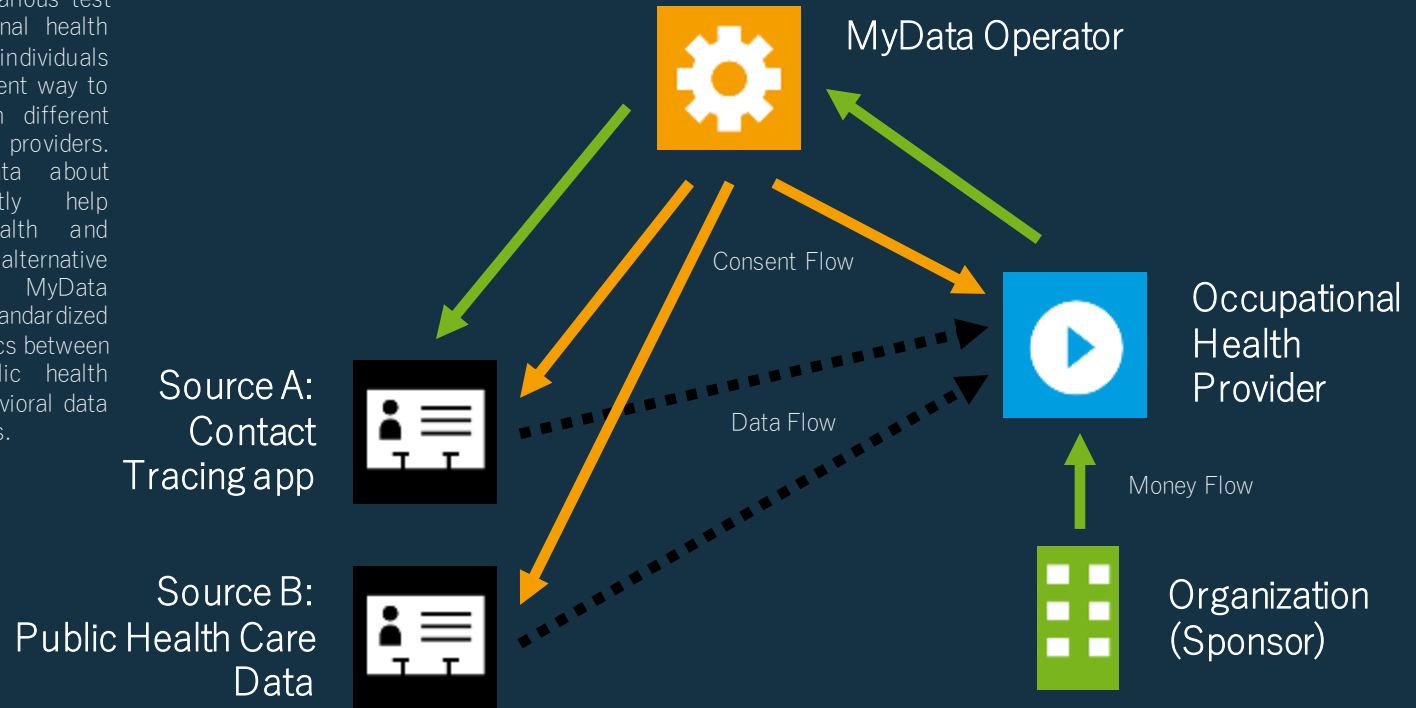
A data using service can be authorized to fetch and use personal data from one or more data sources



MyData Example (health)

MyData and Occupational health

Clinical data usually consist of various test results and diagnosis. Occupational health care providers change when individuals change jobs. There is no convenient way to organize data logistics between different occupation health care providers. Furthermore, getting more data about individuals would significantly help personalize and optimize health and wellbeing services and provide alternative means for diagnosis. The MyData infrastructure can provide standardized methods for managing data logistics between different professional and public health organizations and sources of behavioral data in robust ways across organizations.



MyData shifts

What needs to change

Formal Rights

In many countries, individuals have enjoyed **legal** data protection for decades, yet their **rights** have remained mostly **formal**: little known, hard to enforce, and often obscured by corporate practices.

Actionable Rights

We want **true transparency** and **truly informed consent** to become the new normal for when people and organizations interact. We intend access and redress, portability, and the right to be forgotten, to become "**one-click rights**": **rights** that are as simple and efficient to use as today's and tomorrow's best online services.

Data Protection

Data protection regulation and corporate ethics codes are designed to **protect** people from abuse and misuse of their personal data by organizations.

Data Empowerment

We intend to change common practices towards a situation where individuals are both **protected** and **empowered** to use the data that organizations hold about them. Examples of such uses include simplifying administrative paperwork, processing data from multiple sources to improve one's self-knowledge, personalized AI assistants, decision-making, and data sharing under the individual's own terms

Closed Ecosystems

Today's data economy creates network effects favoring **a few platforms** able to collect and process the largest masses of personal data. These platforms are **locking up markets**, not just for their competitors, but also for most businesses who risk losing direct access to their customers.

Open Ecosystems

By letting individuals control what happens to their data, we intend to create **a truly free flow of data** – **freely decided by individuals**, free from global choke points - and to create balance, fairness, diversity and **competition** in the digital economy.



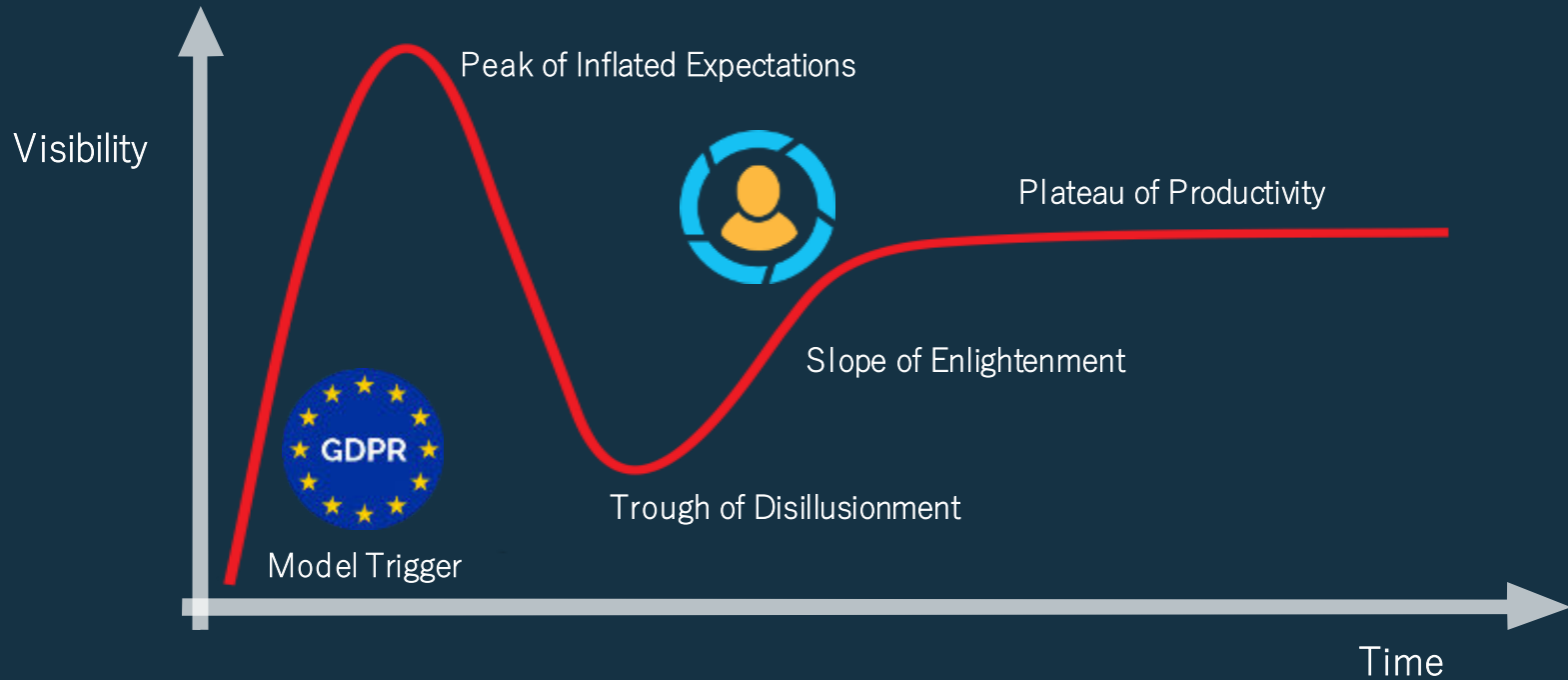
A glance to the future of design

MyData. A Nordic Model for human-centered personal data management and processing



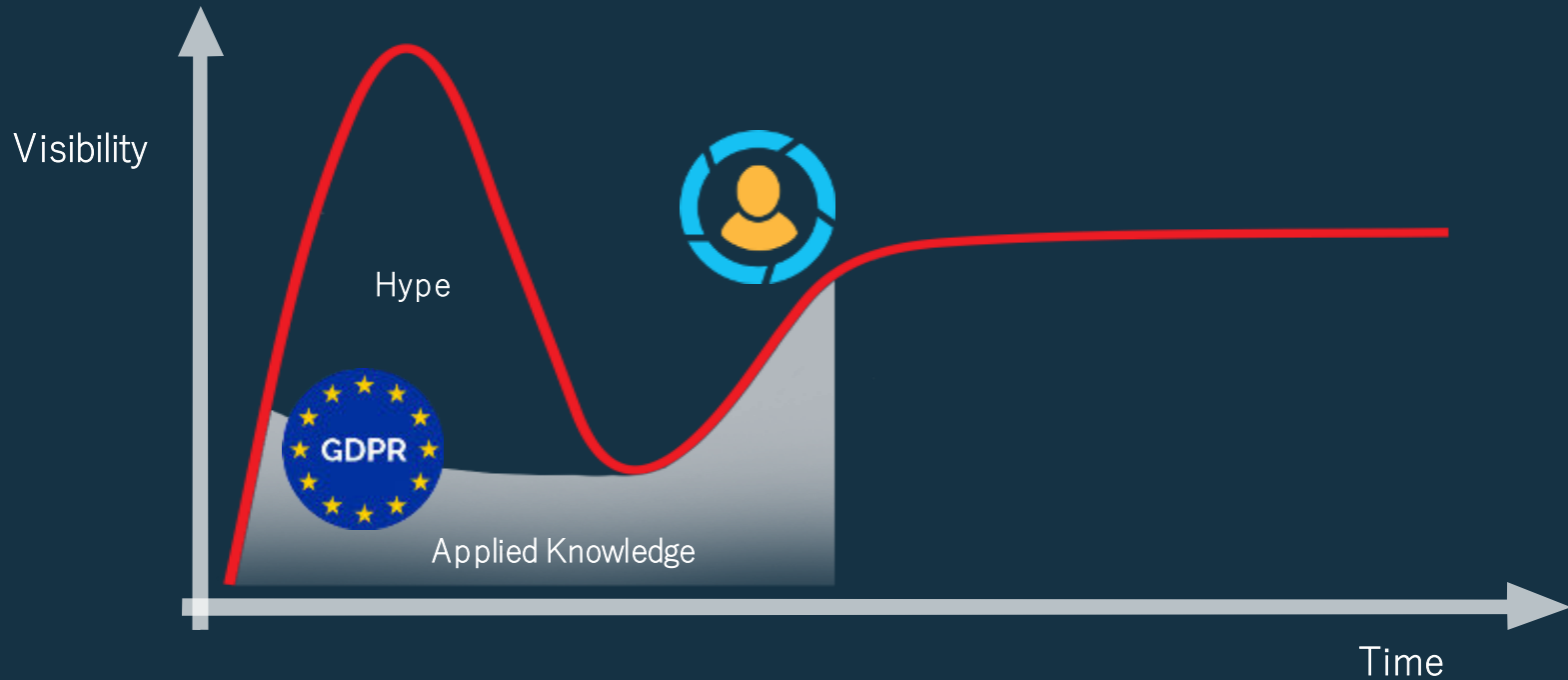
Positioning: Amara's law

We tend to overestimate the effect of a model in the short run and underestimate the effect in the long run



MyData in Amara's Law

It takes a lot of time to apply knowledge in a productive way, beyond the initial hype



Final thoughts



Big opportunities for business

Trust is required!



Create a “data civilization” to grasp the opportunities and transcend society/individual disciplines



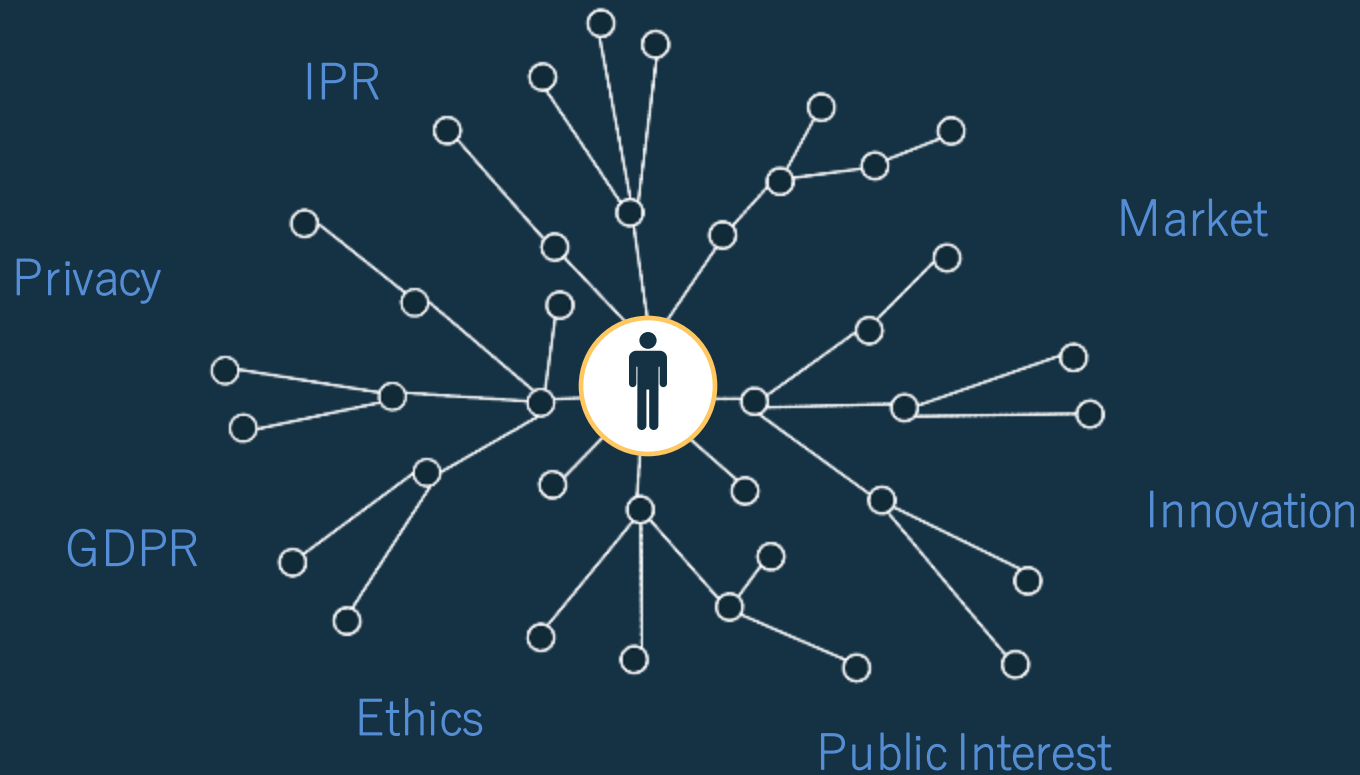
From sick care to preventive health care by individual involvement



Data guardians

- People
- Parties
- Operators

Digital Health Ecosystem open – ethical – trustworthy



MyData Global

Local Hub is a group of MyData Global members in a certain geographic area



MyData Local hubs are the locus of MyData Global's activity, and an important means to realise its purpose

MyData Thematic Groups

Thematic groups are officially recognised subcommunities facilitated and sanctioned by MyData Global that are interested in a particular theme

Design

Health

MyData Operators

MyData4Pandemics

Skills data

Data Literacy

MyData Thematic Groups are the locus of MyData Global's activity and a driving force for MyData Global's thought leadership



Thank You

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