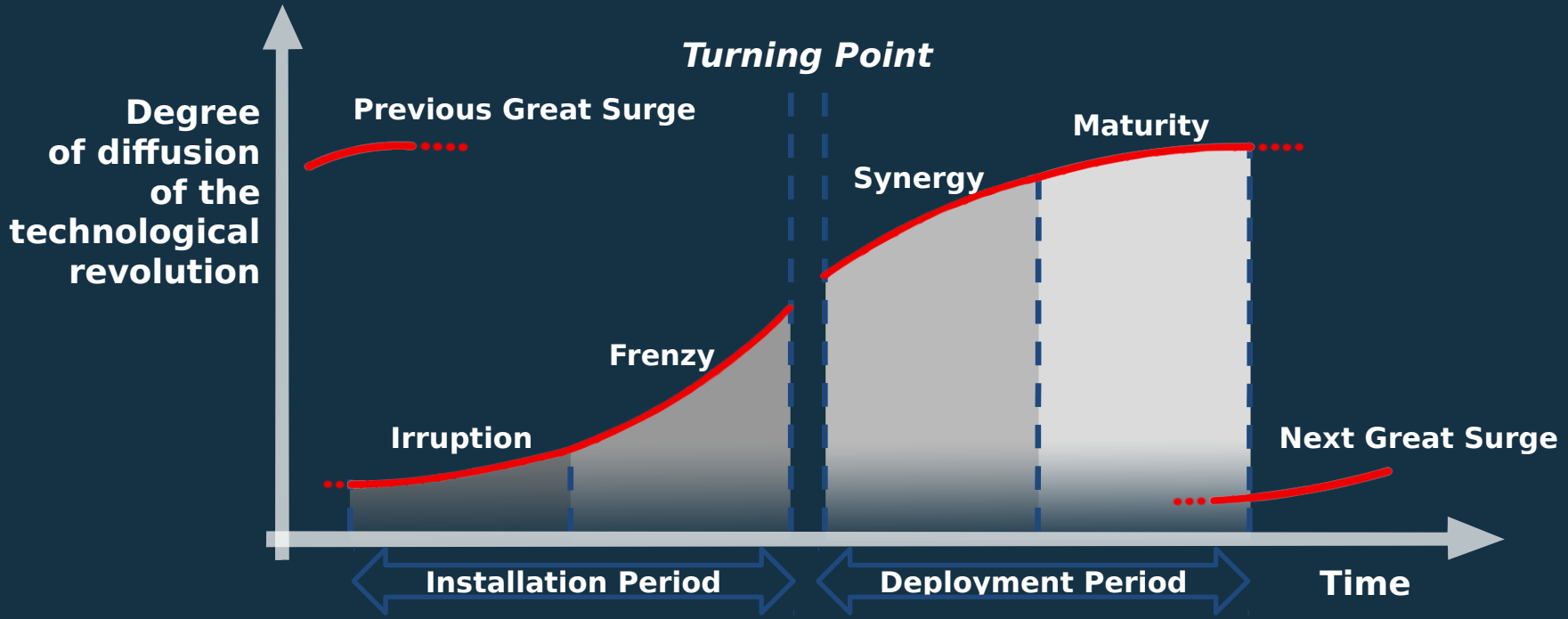
Towards a Fair (My)Data Economy

Alexandros Nousias, MyData Greece

The techno-economic paradigm (TEP)

TEP is a recurring pattern of cyclical movement: from an initial installation period, through a collapse and recession which signify the turning point, to a full deployment period.



source: Carlota Perez: The techno-economic paradigm shift

Health data analysis

Do we need it?

81%

Should we analyze?

81% of NHS + private healthcare sector support the analysis of anonymized data

87%

Should benefit NHS?

87% support NHS should receive a fair share of gains following medical discoveries

87%

Should benefit taxpayer?

87% support taxpayers should also benefit from gains resulting from any analysis

Health data analysis

Who should do it, and for whom?

Multinationals?

12% would be comfortable with a multinational carrying out the analysis

Confidentiality

17% believe that the data will be processed in a confidential manner

Recommend to patients?

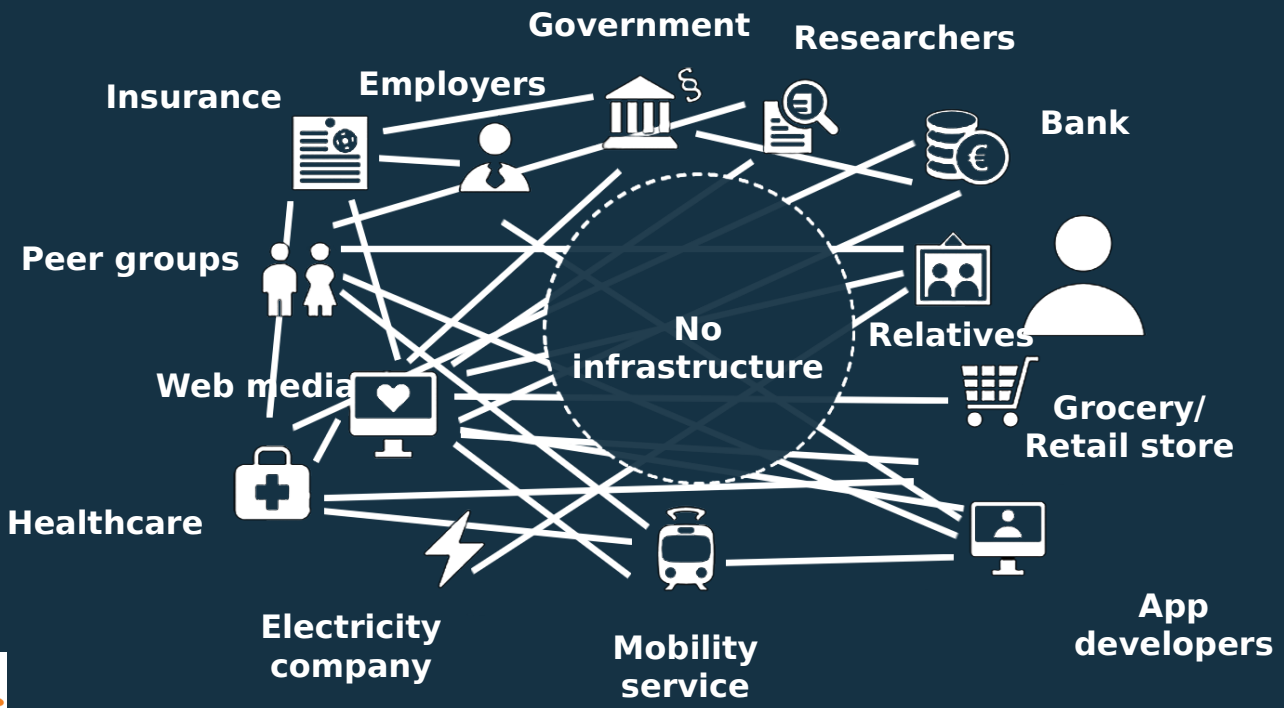
73% of doctors/nurses would recommend their patients use data driven technology

Existing patient use?

36% said their patients made use of existing health care digital services

API ecosystem

In the current structureless API economy, if the number of services grow, then the number of connections between them grow at a faster rate



Aggregator Model

Aggregating data control is easier, but different aggregators do not have a built-in incentive to develop interoperability between them

Exclusion

Human exclusion

Exclusion is the usual game humans play

Data exclusion

Today it feels like 99% of humans are excluded from their own data

Exclusion ---> Inclusion

Exclusion is not inherent. It’s a human invention

Trust is broken

Data exclusion creates a
form of apathy against forces that seem too big to control

Trust must be rebuilt

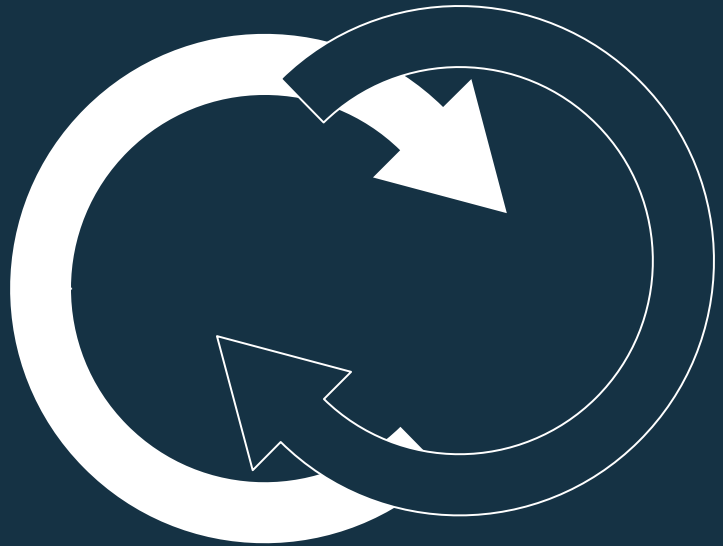
To rebuild trust we need to put humans in control of
the data about them

Privacy vs. Innovation

Building dynamically in one another

Privacy

the right to be free from secret surveillance and to determine whether, when, how, and to whom, one's personal or organizational information is to be revealed



Innovation

The process of translating an idea or invention into a good or service that creates value or for which customers will pay

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Trust by Design

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

1. Human centric control and privacy

Individuals are empowered actors, not
passive targets, in the management of
their personal lives

2. Usable data

It is essential that personal data is technically easy to access and use – it is accessible in machine readable open
formats via secure, standardized APIs

3. Open business environment

Shared MyData infrastructure enables
decentralized management of personal
data, improves interoperability, makes it
easier for companies to comply with tightening data protection regulations, and allows individuals to change service
providers without proprietary data lock-ins

MyData Model

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.

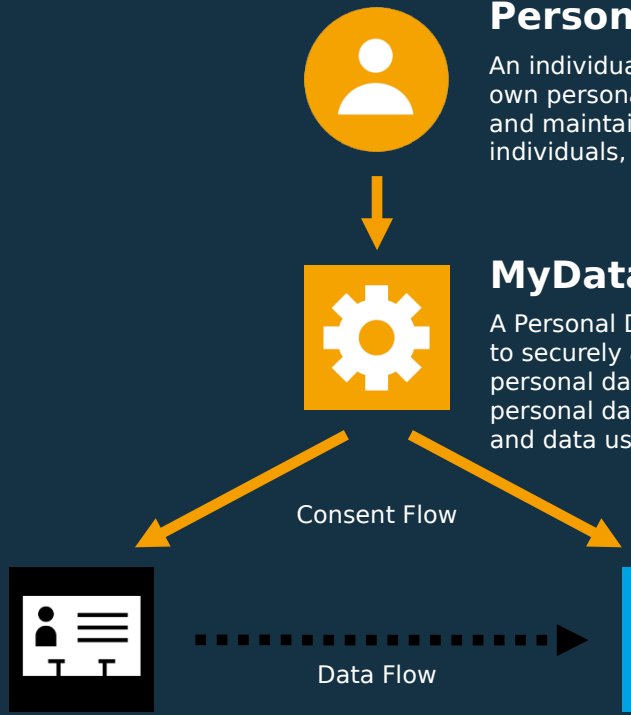
For individuals: The account model provides individuals with an easy way to control their personal data from one place even while the data is created, stored, and processed by hundreds of different services.

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

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

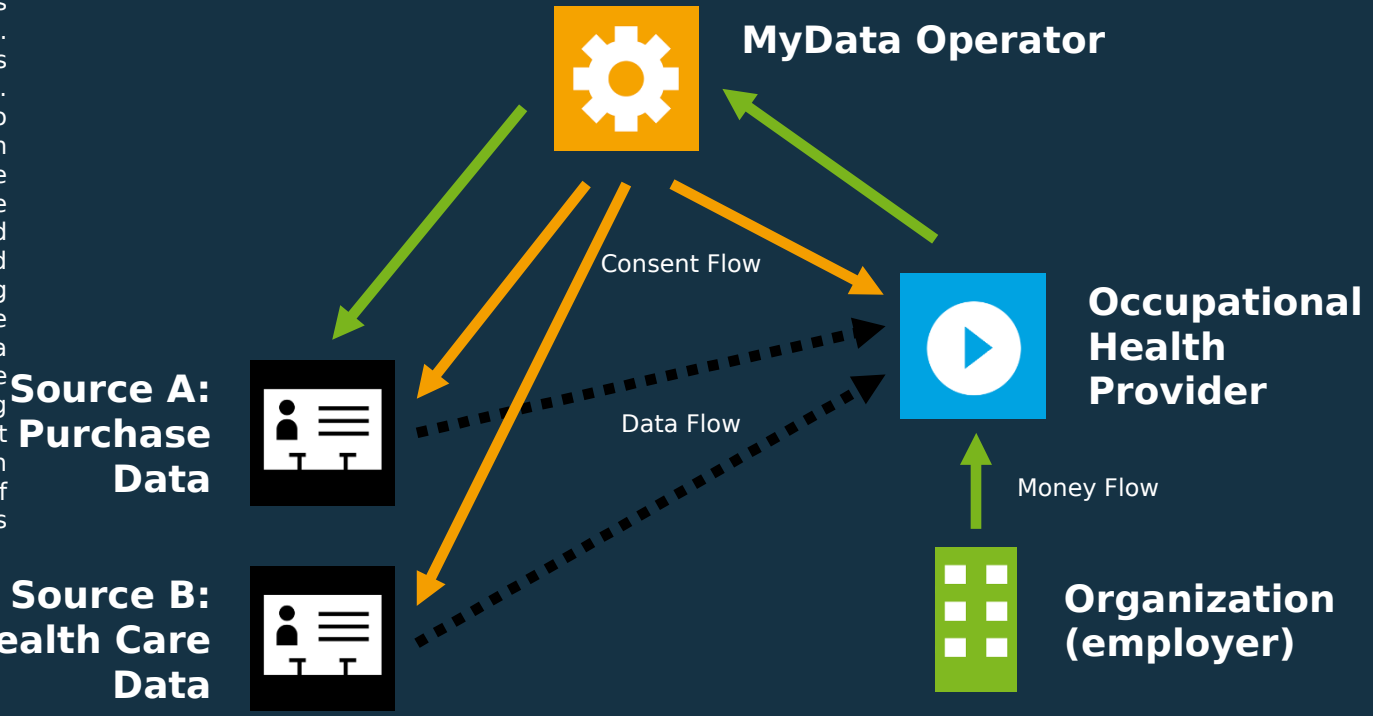
Data using service

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

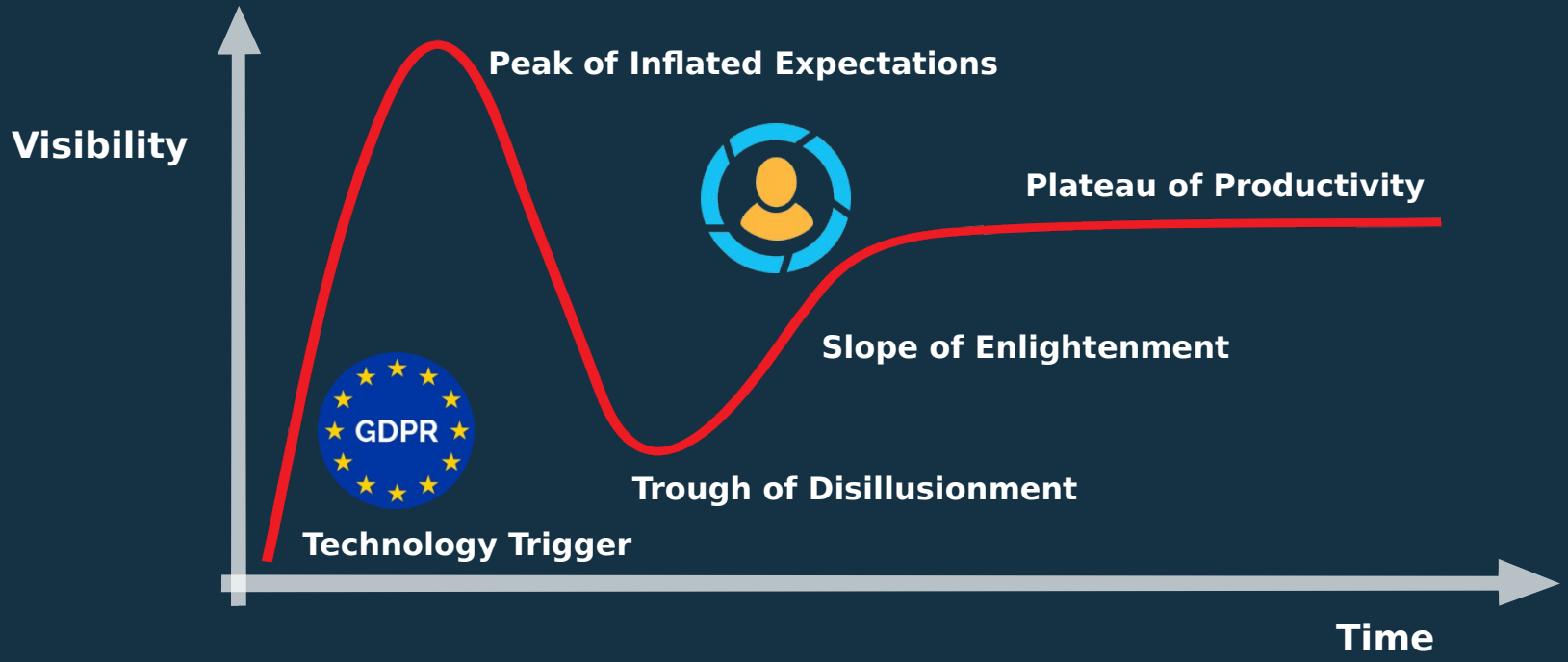
By letting individuals control what happens to their data, we intend to create **a truly free flow of data – freely decided by individuals**, free from global choke points - and to create balance, fairness, diversity and **competition** in the digital economy.

A glance to the future of design

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

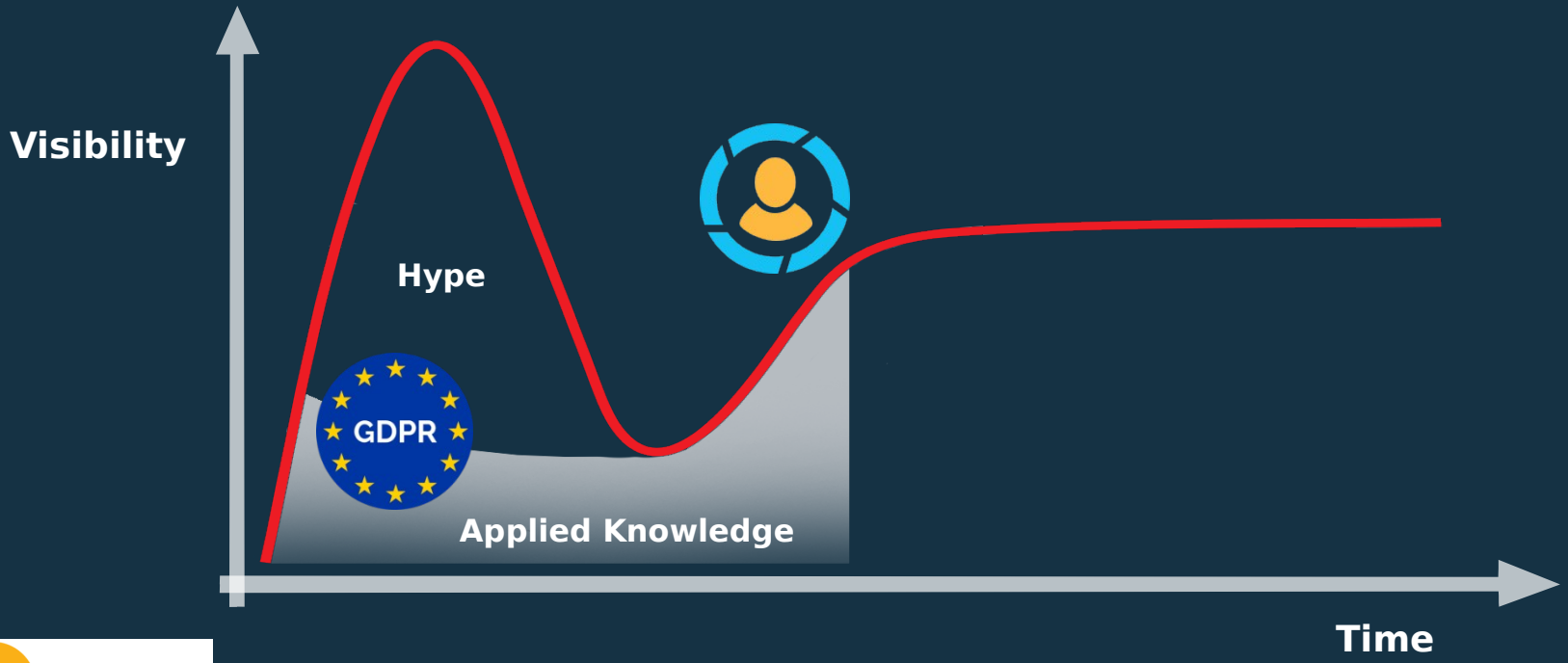
Positioning: Amara's law

We tend to overestimate the effect of a technology 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



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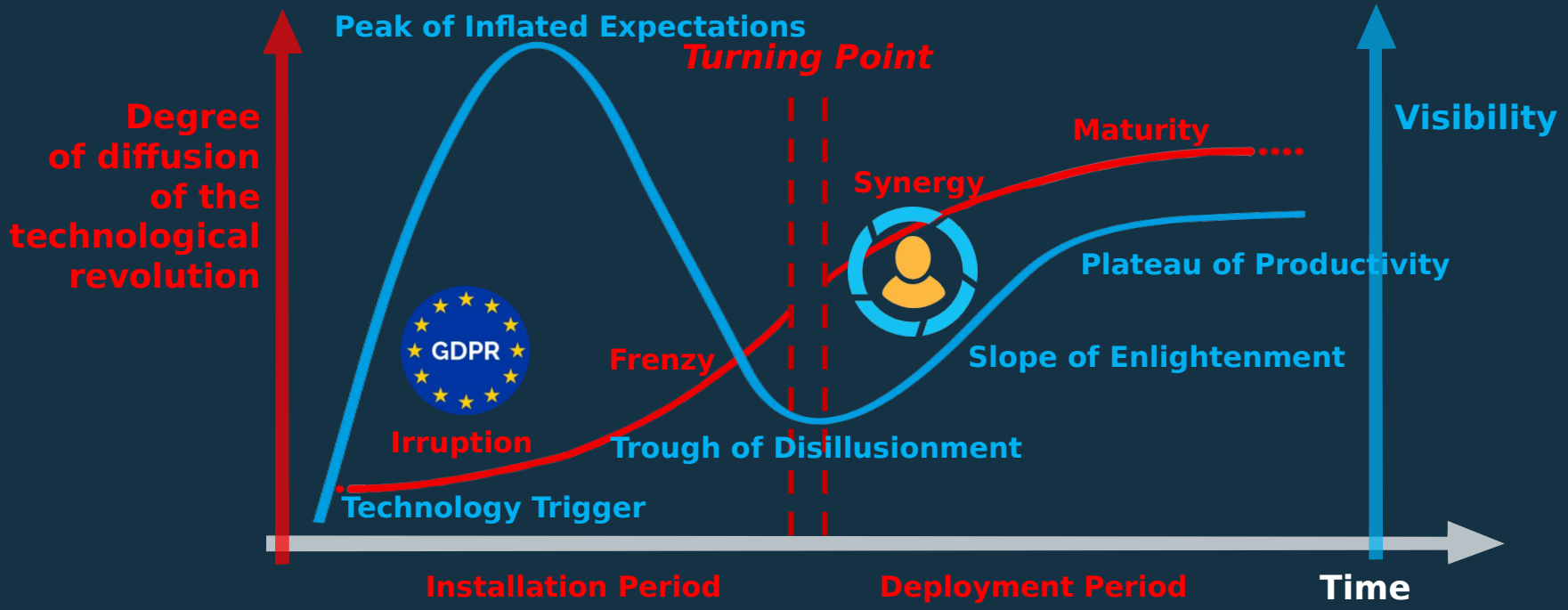
TEP and Amara’s law

The recurring pattern of cyclical movement described by TEP and Amara's law, describing how we overestimate the effect of a technology in the short run and underestimate the effect in the long run.



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

Thank You

Alexandros Nousias

Alexandros Nousias

NCSR-Demokritos
MyData Greece
GFOSS

@alexnousias

https://www.linkedin.com/in/alexandrosnoussias/

alexandros.nousias@gmail.com