



CDDF WORKSHOP

14 -15 November 2022

AMSTERDAM (NL)

*Histology independent drug development
– is this the future for cancer drugs?*

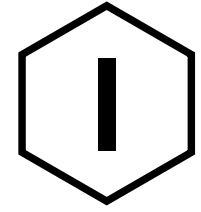


Distributed Data Governance Addressing the “Precision Public Health” dilemma

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The role of digital transformation

to ensure equity access to diagnostics and treatments to patients

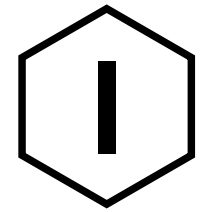
“Beauty is
in the eyes
of the
beholder”

I ▶ **Decision making. ALL stakeholders impacted by digital transformation**
Traditional human instincts to assess the veracity & risks can be misleading in digital space

II ▶ **Governing data usage across domains is the hard problem**
Technology limitations generate mistrust and slow down innovation

III ▶ **Dealing with the extrinsic properties of data is not only about technology**
Distributed Governance leverages advances in decentralised software technologies





Precision Public Health (PPH) -equity access to data

Keeping an unstable information equilibrium

Digital transformation across domains is necessary

Precision/Personalised Medicine

Defined as

the ability to tailor

- treatments,
- prevention strategies

to the

unique characteristics of each person

Public Health

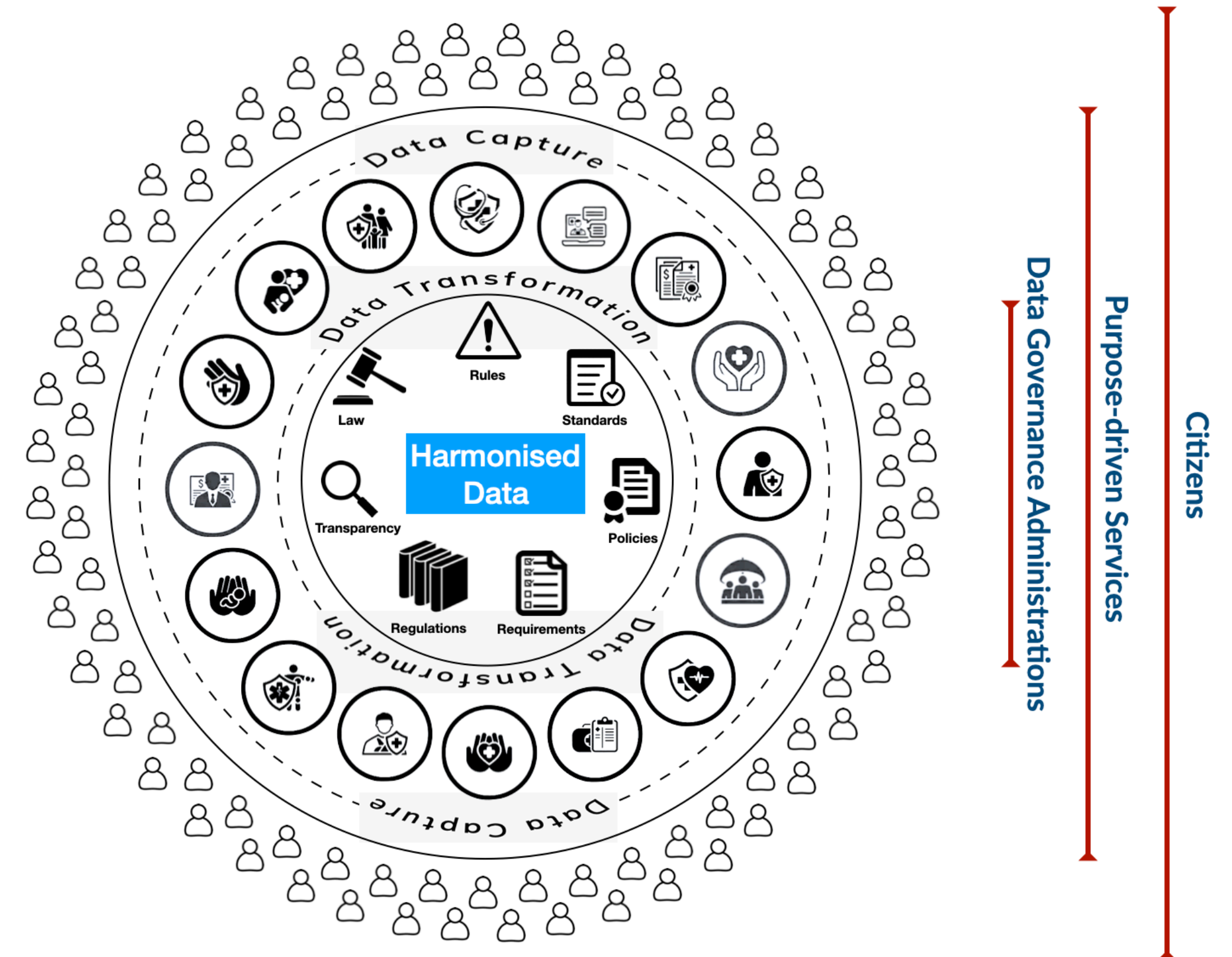
Demands

contextual data to

- enforce health policies,
- boost drug developments,

for the benefit of

the whole community



Precision Public Health captures the essence of today's digital problems

PPH requires *technological & regulatory capacity* to operationalise data sharing



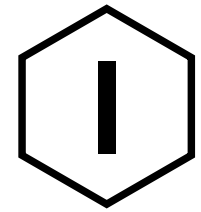
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Precision Public Health (PPH) -equity access to data

Sharing data across ecosystems

May 2022 - creating a digital space for information exchange

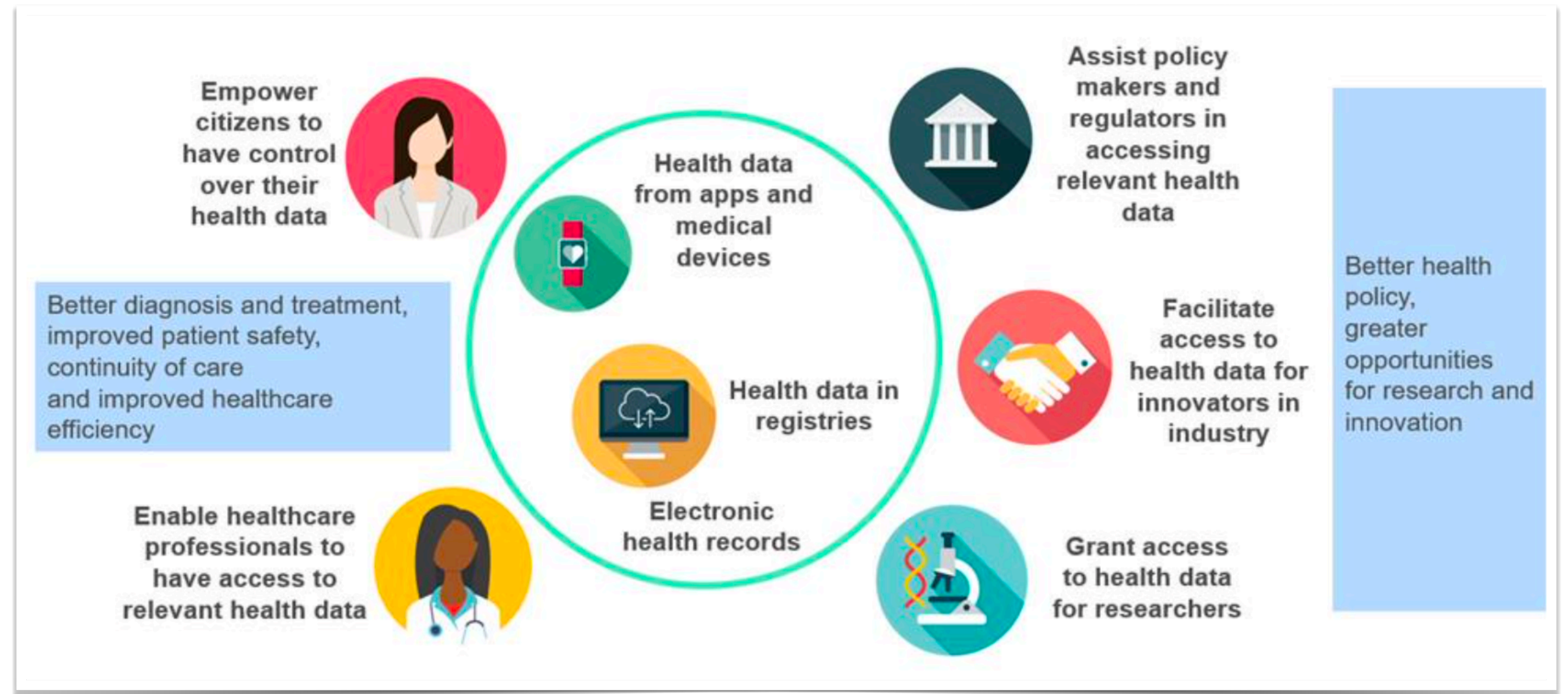
EU Health Data Space

Primary usage of data

Availability - Sharing - Harmonised -
Health professionals - Certifications -
Cross border

Secondary usage of data

Decentralised EU Infrastructure -
Health Data Governance



Source: May 2022, Communication from the EU commission to the parliament and the council



Decision making is impacted by digital transformation for **ALL stakeholders**

Traditional human instincts to assess the veracity & risks can be misleading in digital space



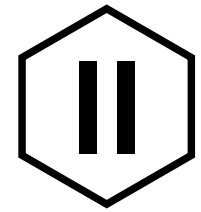
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Technology is pushed beyond its current capacity

Two network designs did not scale fast enough

>500k profile hacked



Highest Security could not protect vulnerable populations

0



globally interoperable health pass

Precision Public Health



Authentic Data Authentication



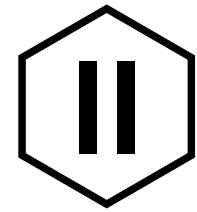
Deterministic Data Semantics



Data "Platforms" reach their limits

We need to secure the *data itself*, not only the location

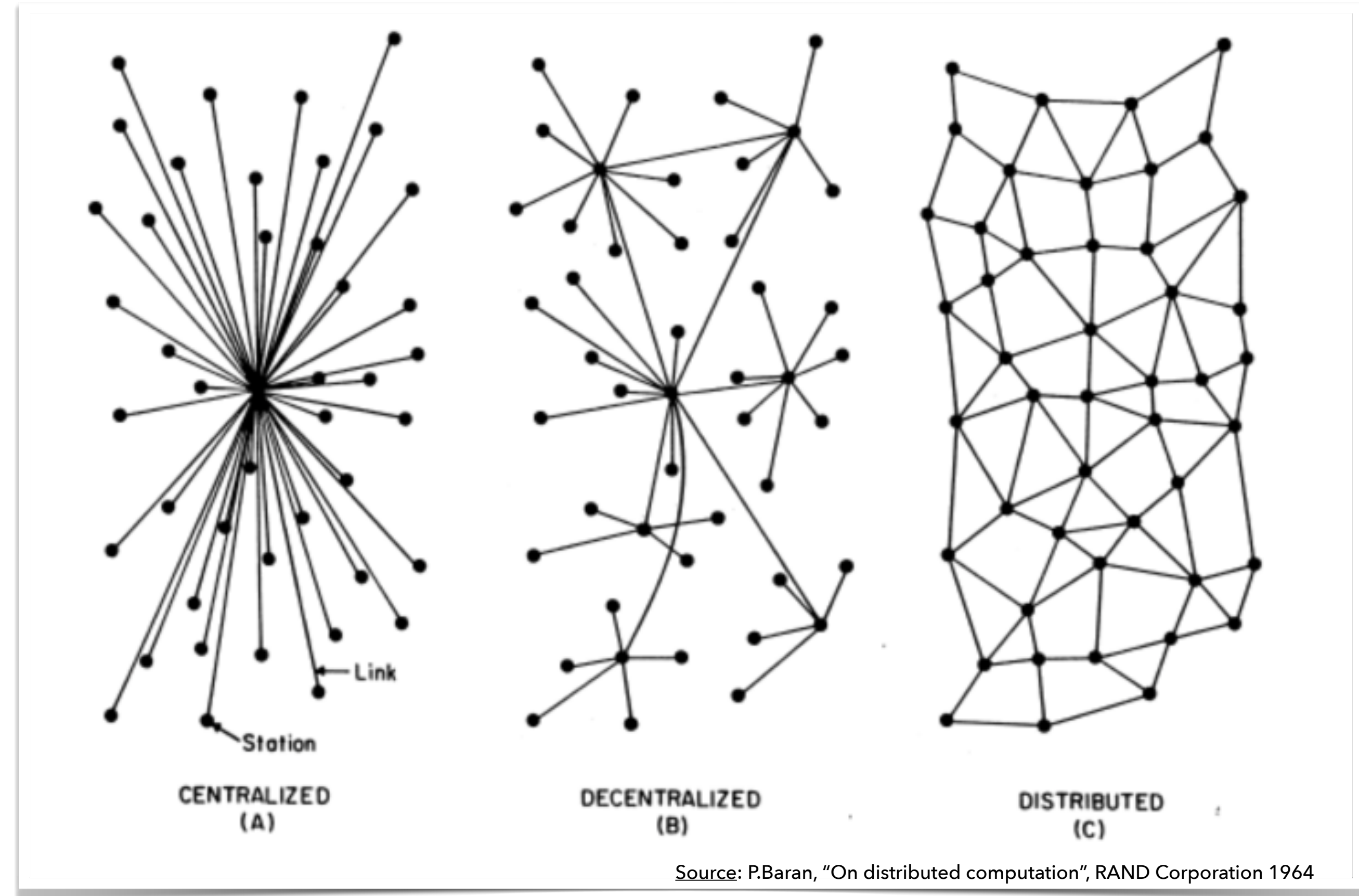
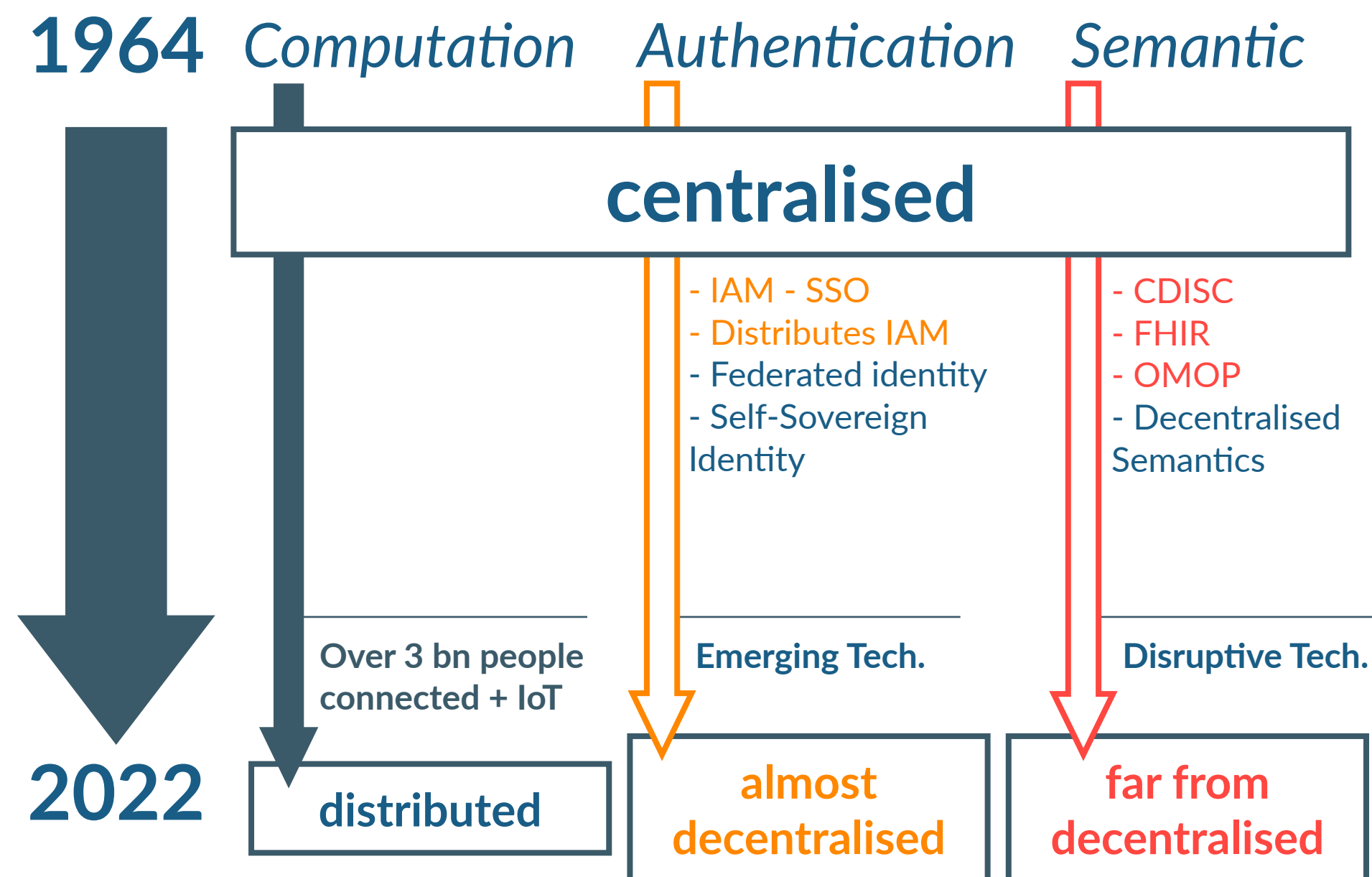




Governing data usage across domains

The natural drive toward decentralisation

Driven by security & safety



Governing data usage across domains is the hard problem
 Technology limitations generate mistrust and slow down innovation



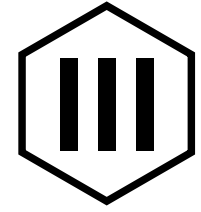
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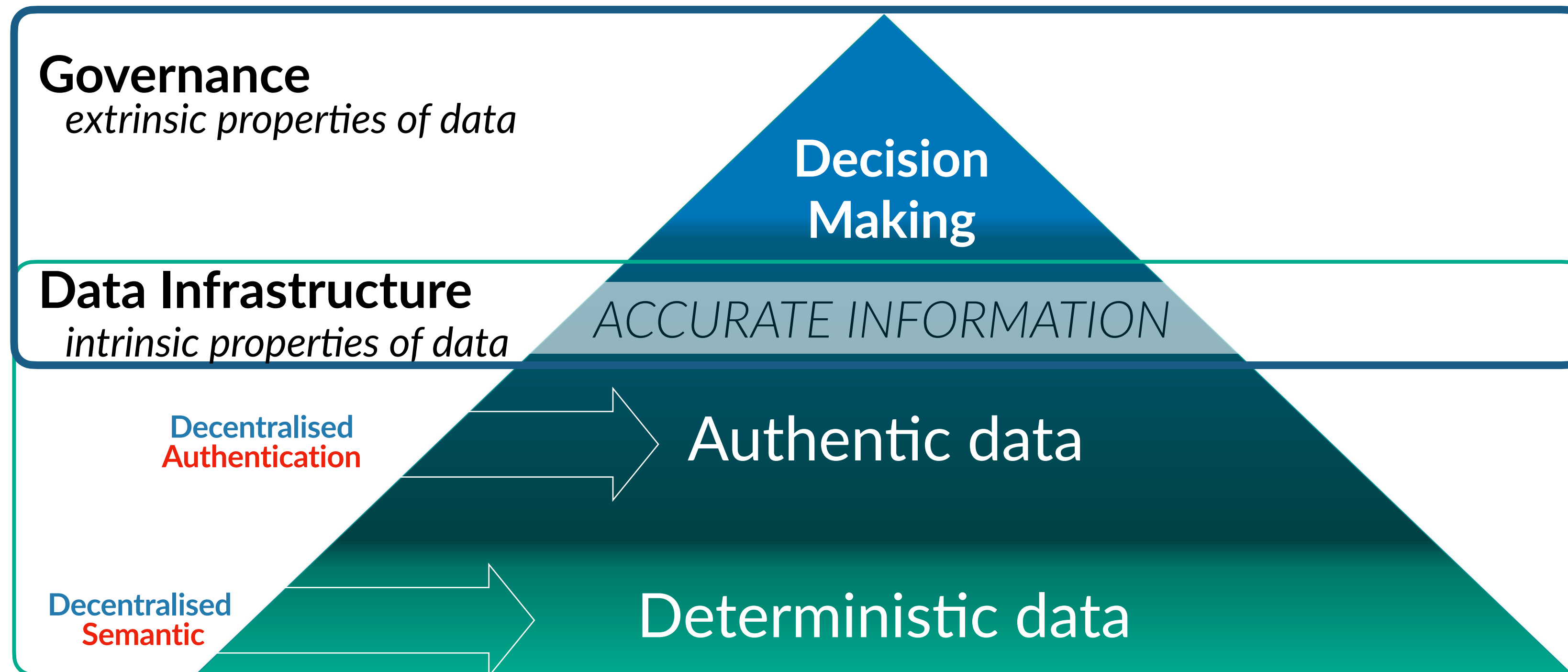
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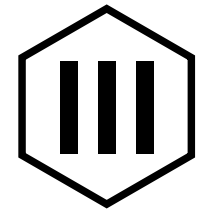
Operationalise Data Sharing at scale

Step 1 *Securing & Harmonising* data



► **Current concept of “platform” is replaced by traceable data (*data lineage*)**
Decentralisation facilitates cross domain data sharing





The road to distributed governance

Sharing data across ecosystems

Step 2 A decentralised infrastructure for *Purpose driven* data usage

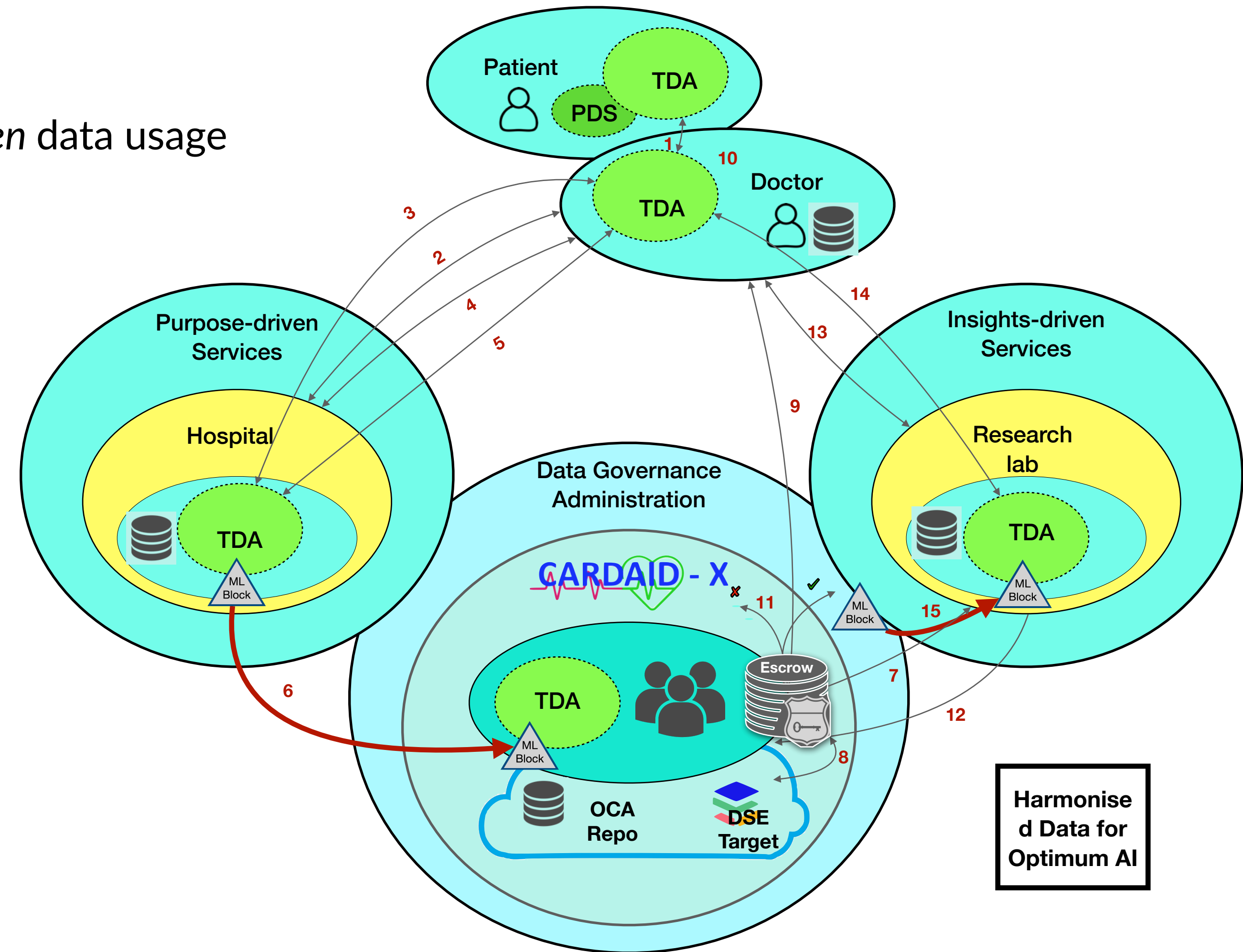
Ecosystem driven Data Space

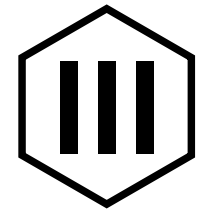
Primary usage of data

“Peer”-to-“peer” interactions
Data Harmonisation at capture level
Purpose & Insights driven services
User-centric decentralised data governance administration

Secondary usage of data

Registries - Dynamic Searches -
Consent management





Exchanging data across domains

Decentralised technologies & Ecosystems

Ecosystems = Domains with a governance

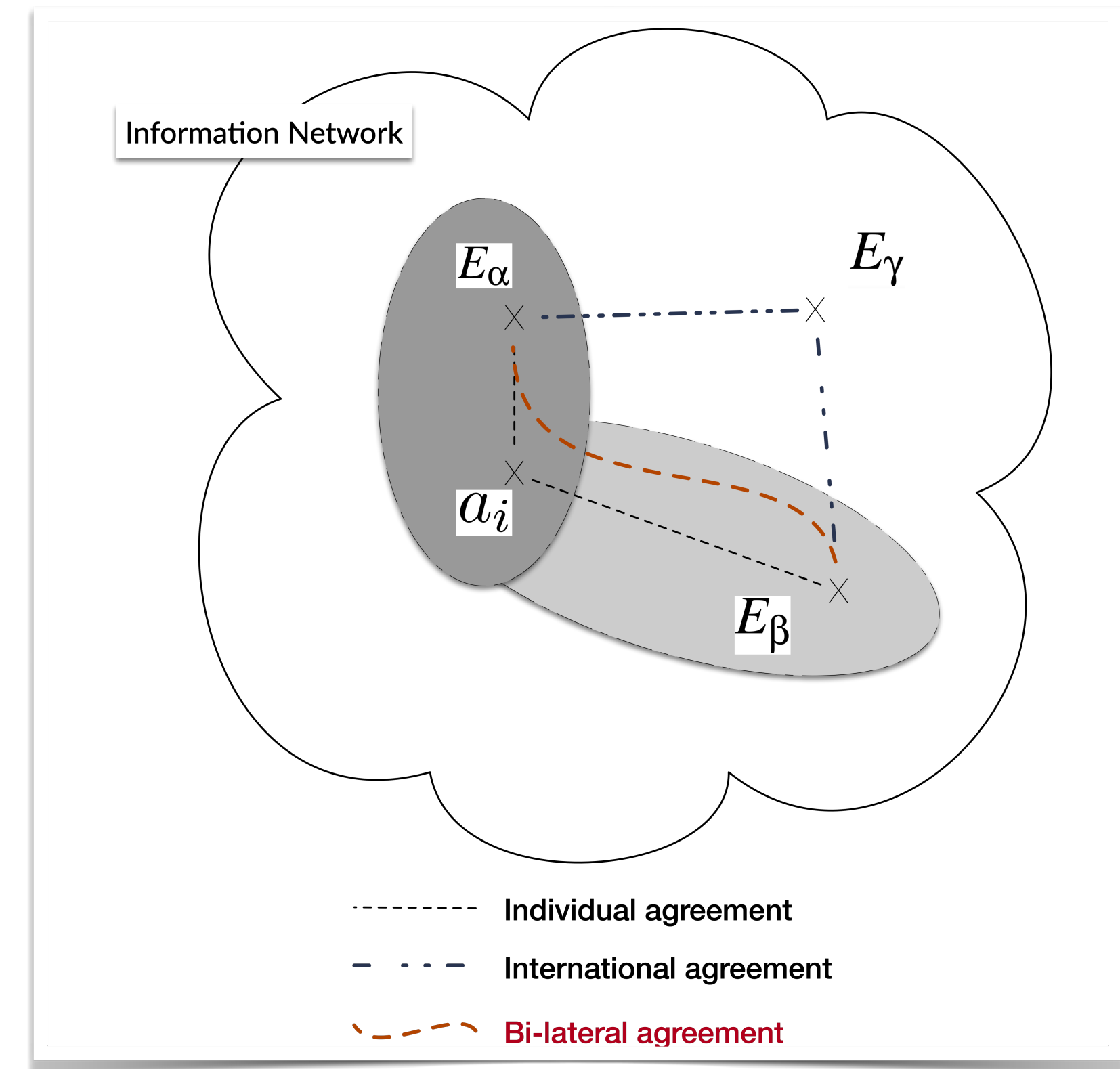
with their own rules & constraints

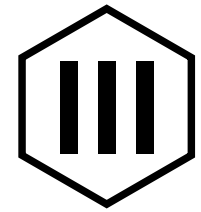
Users as *Autonomous Principals*

interact with multiple ecosystems

Ecosystems are interacting

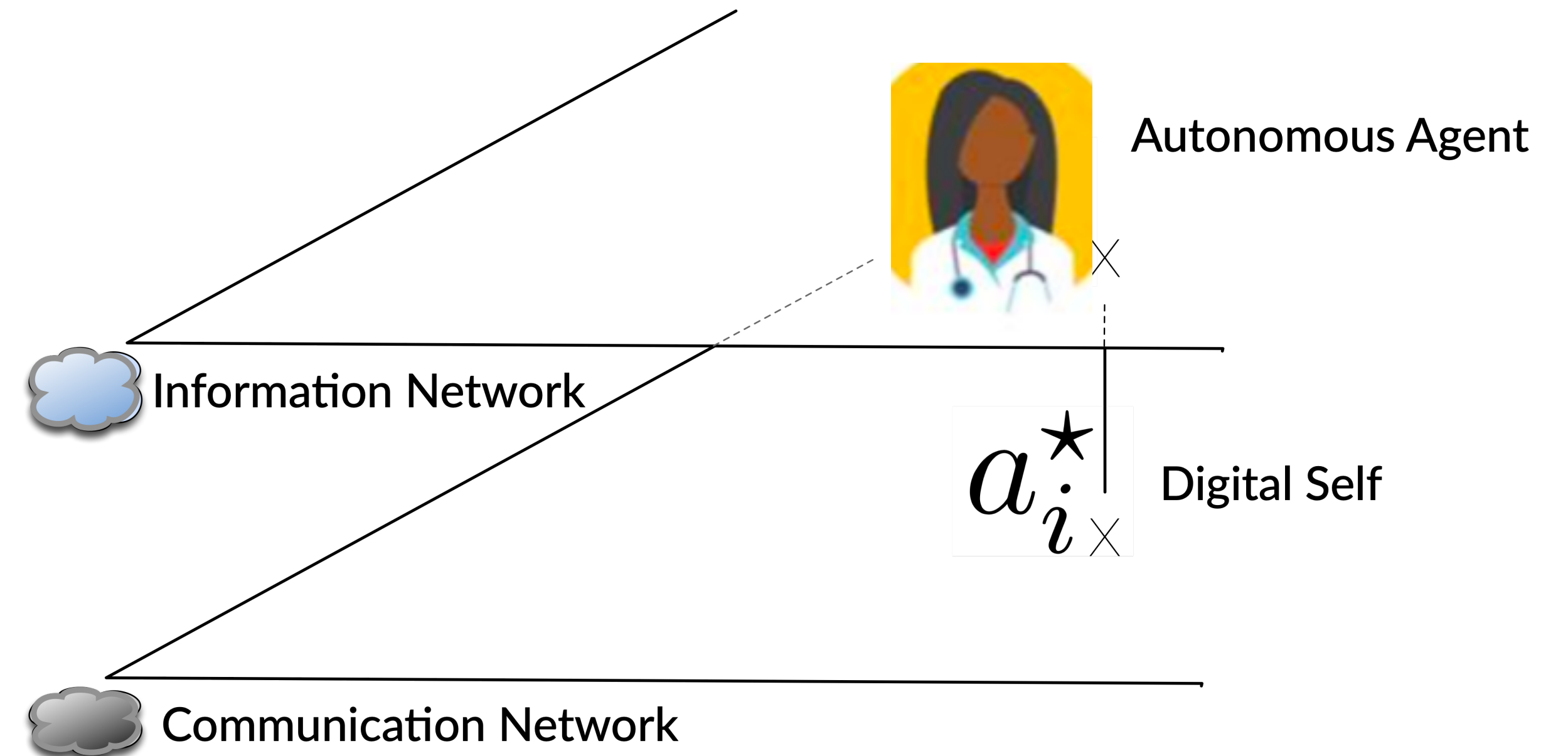
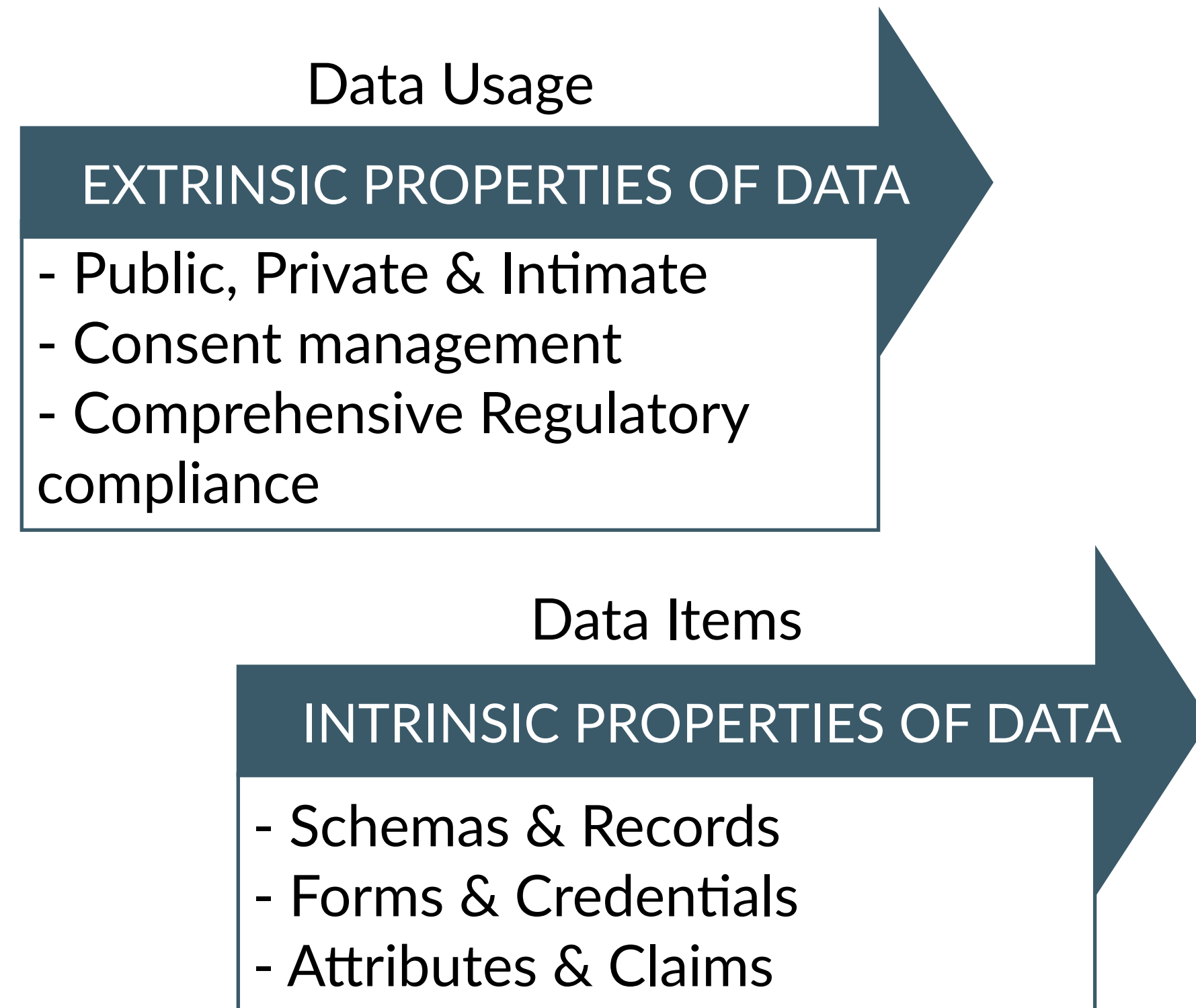
through agreements





Dealing with extrinsic properties of data

A dual approach to data governance



Dealing with the **extrinsic properties** of data is not only about technology
 Distributed Governance leverages advances in decentralised software technologies





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- Distributed Data Governance provides a framework for**
- data-centric exchange between **governed domains**
 - human-centric choice & accountability in the digital space

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