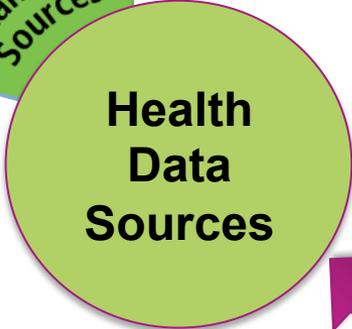
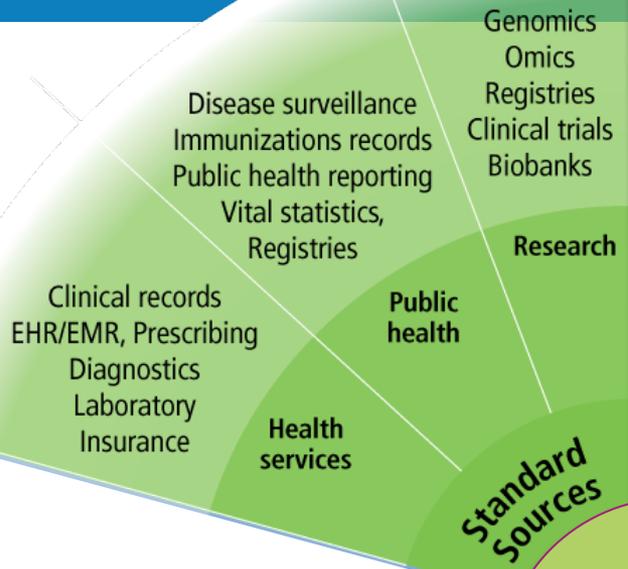


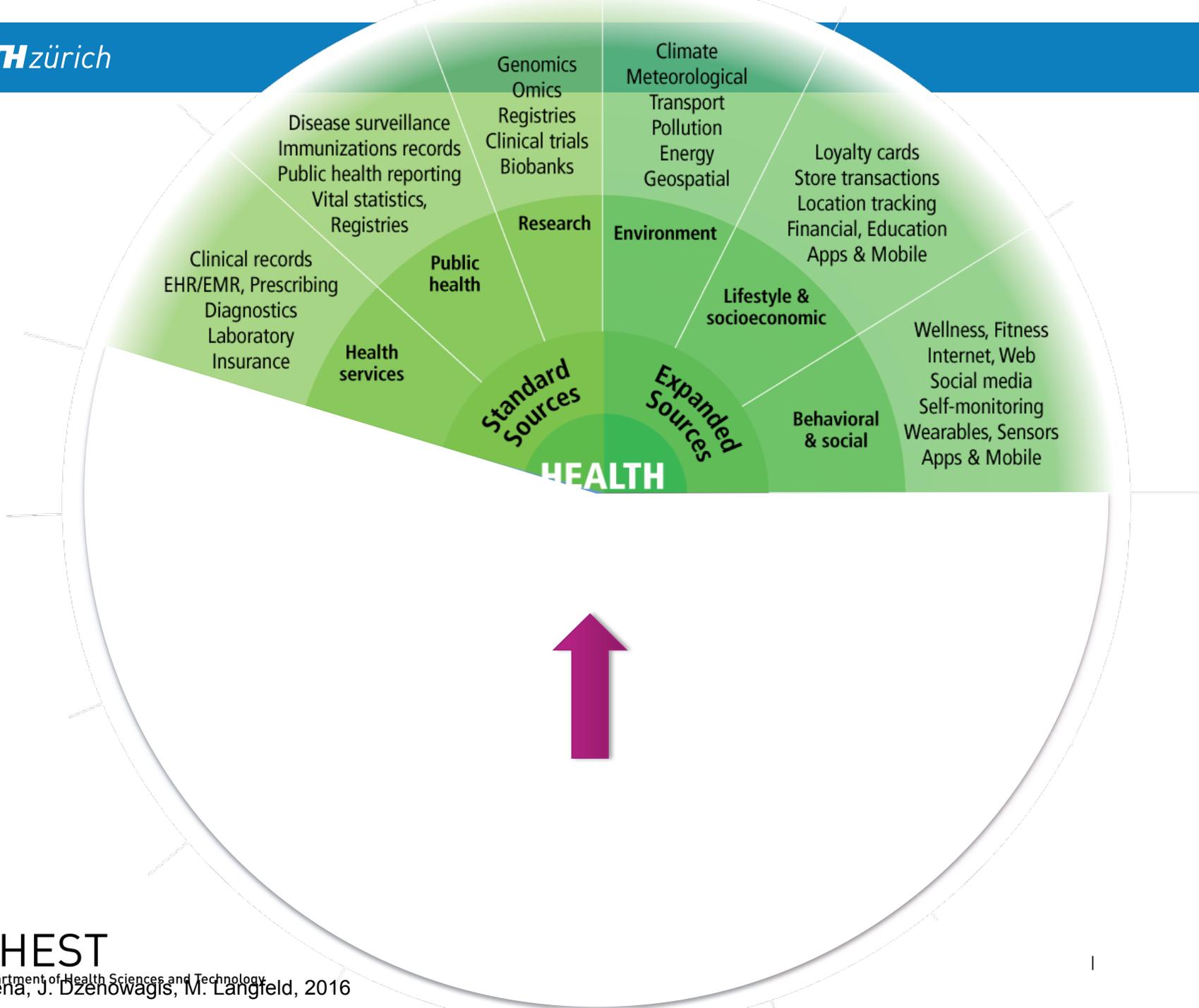


Individual control of health data in the big data environment

Professor EFFY VAYENA
Health Ethics and Policy Lab
@effyvayena

Chair SPHN ELSlag

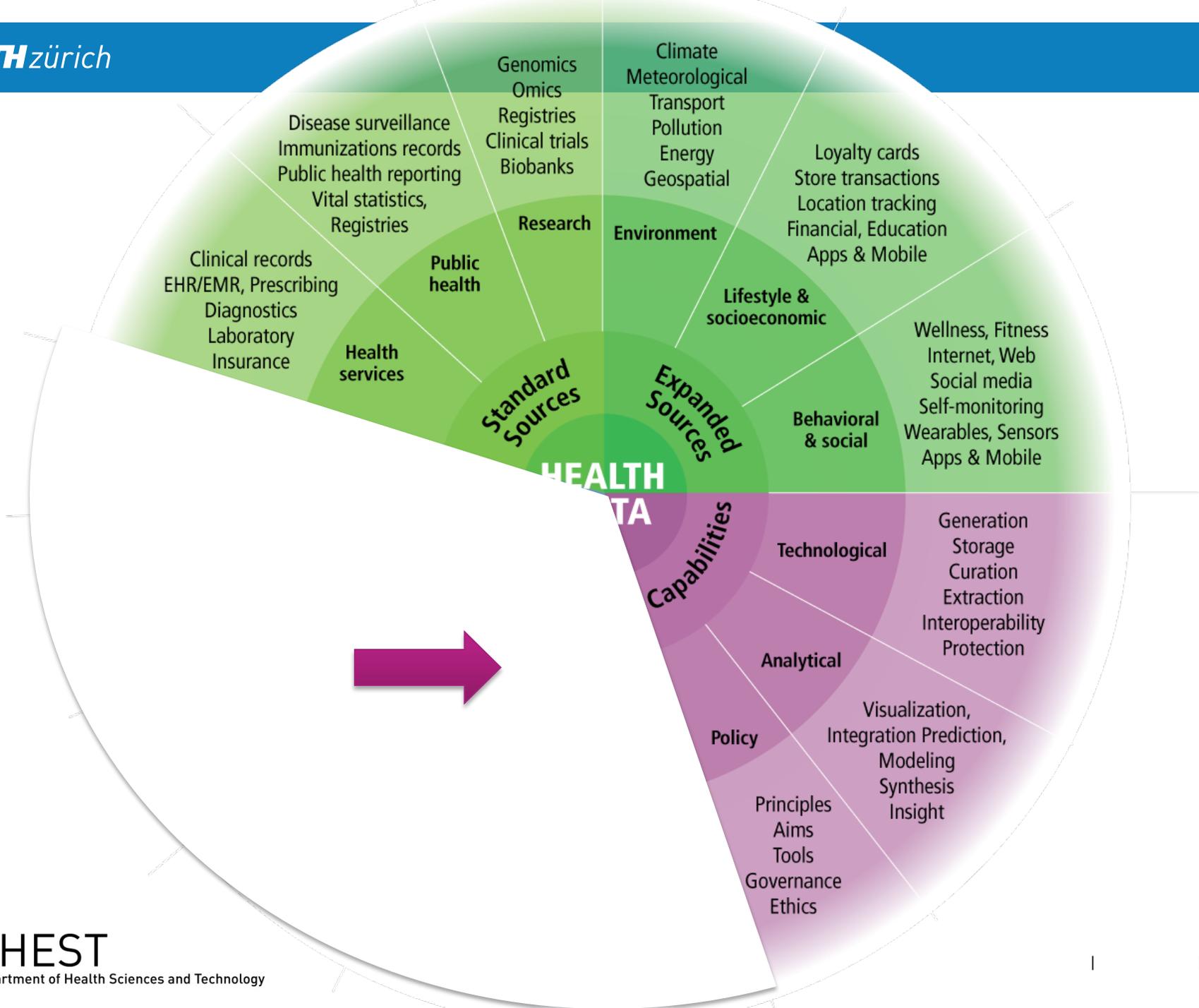


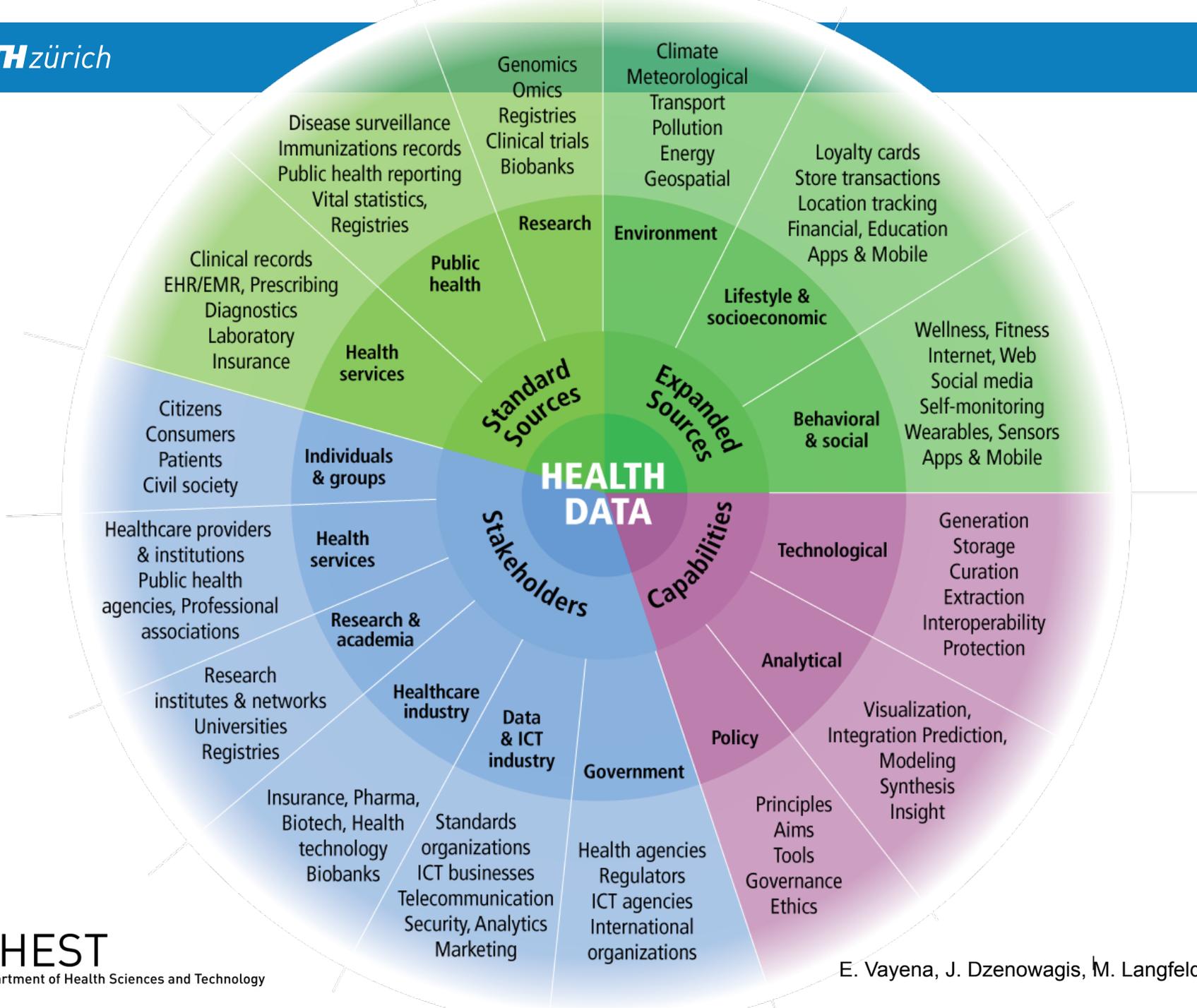


2017 This Is What Happens In An Internet Minute

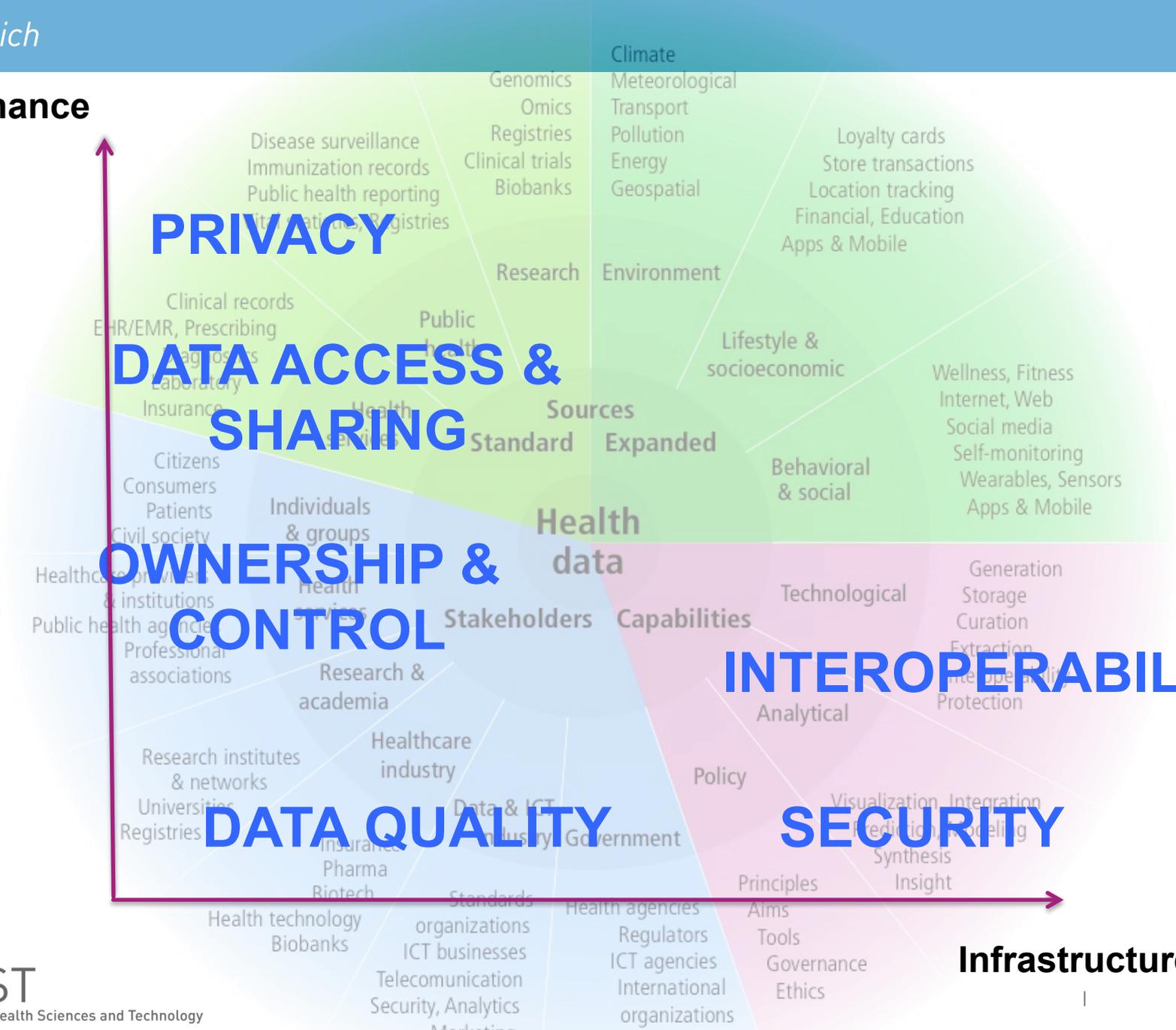


Created By:
 @LoriLewis
 @OfficiallyChadd





Governance



PRIVACY

DATA ACCESS & SHARING

OWNERSHIP & CONTROL

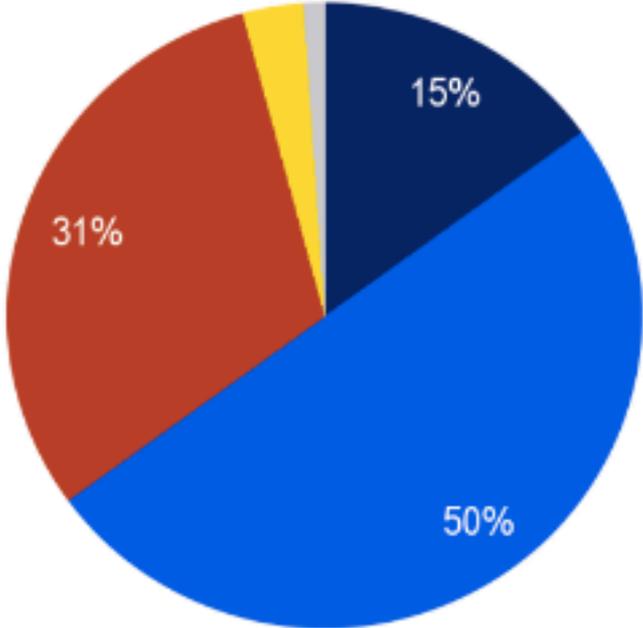
DATA QUALITY

INTEROPERABILITY

SECURITY

Infrastructure

QB4. How much control do you feel you have over the information you provide online, e.g. the ability to correct, change or delete this information?

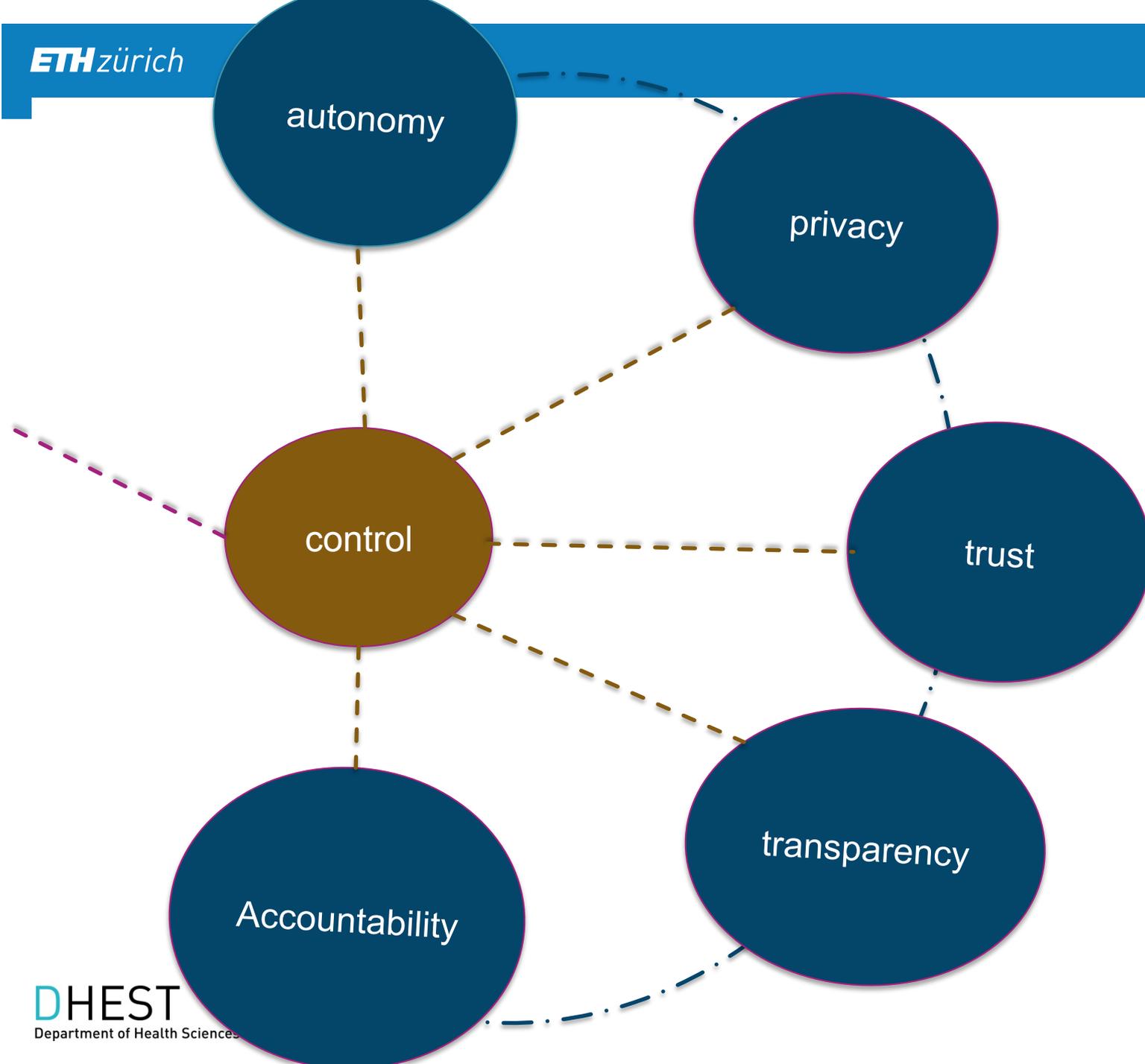


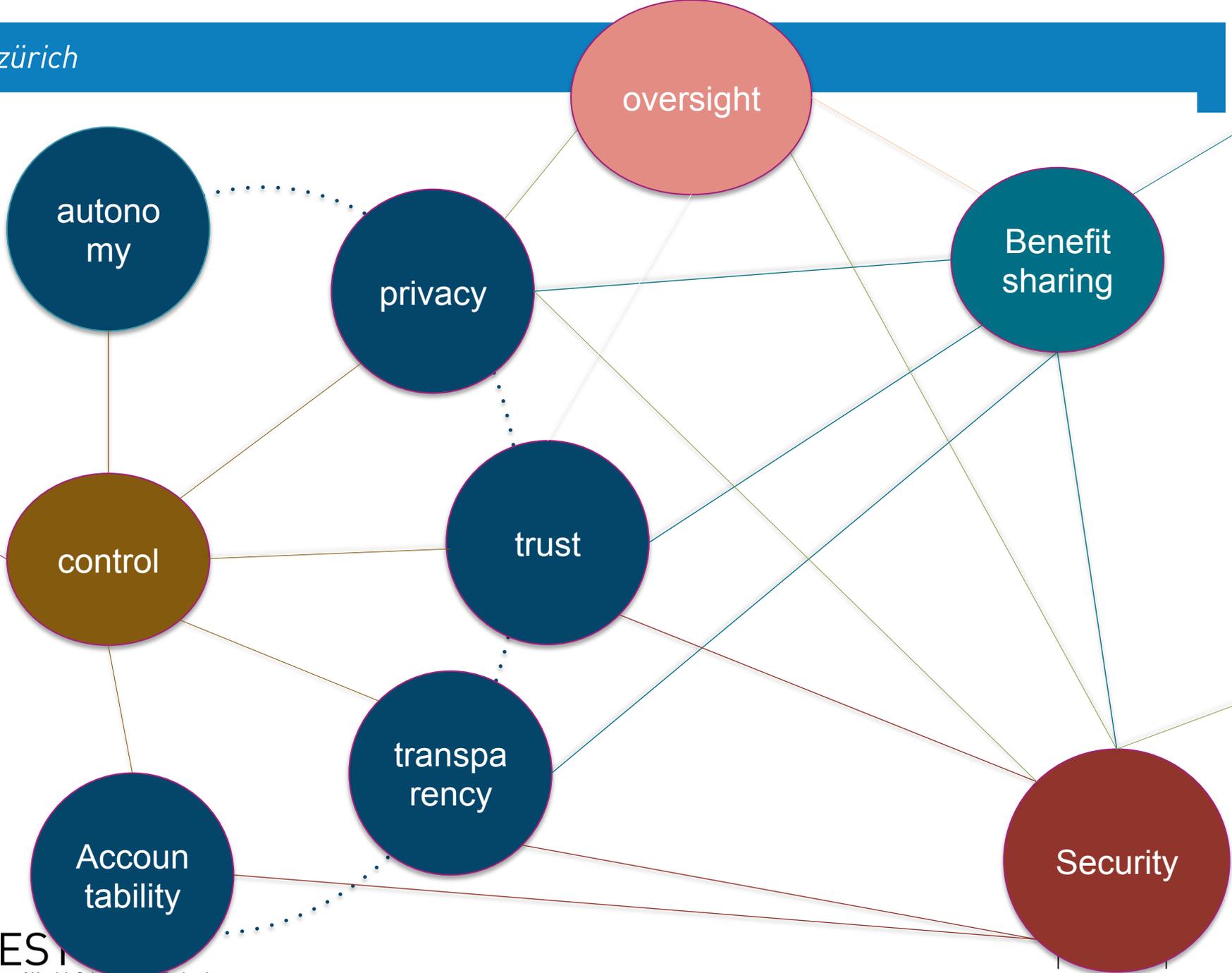
- Complete control
- Partial control
- No control at all
- It depends on the website or application (SPONTANEOUS)
- Don't know

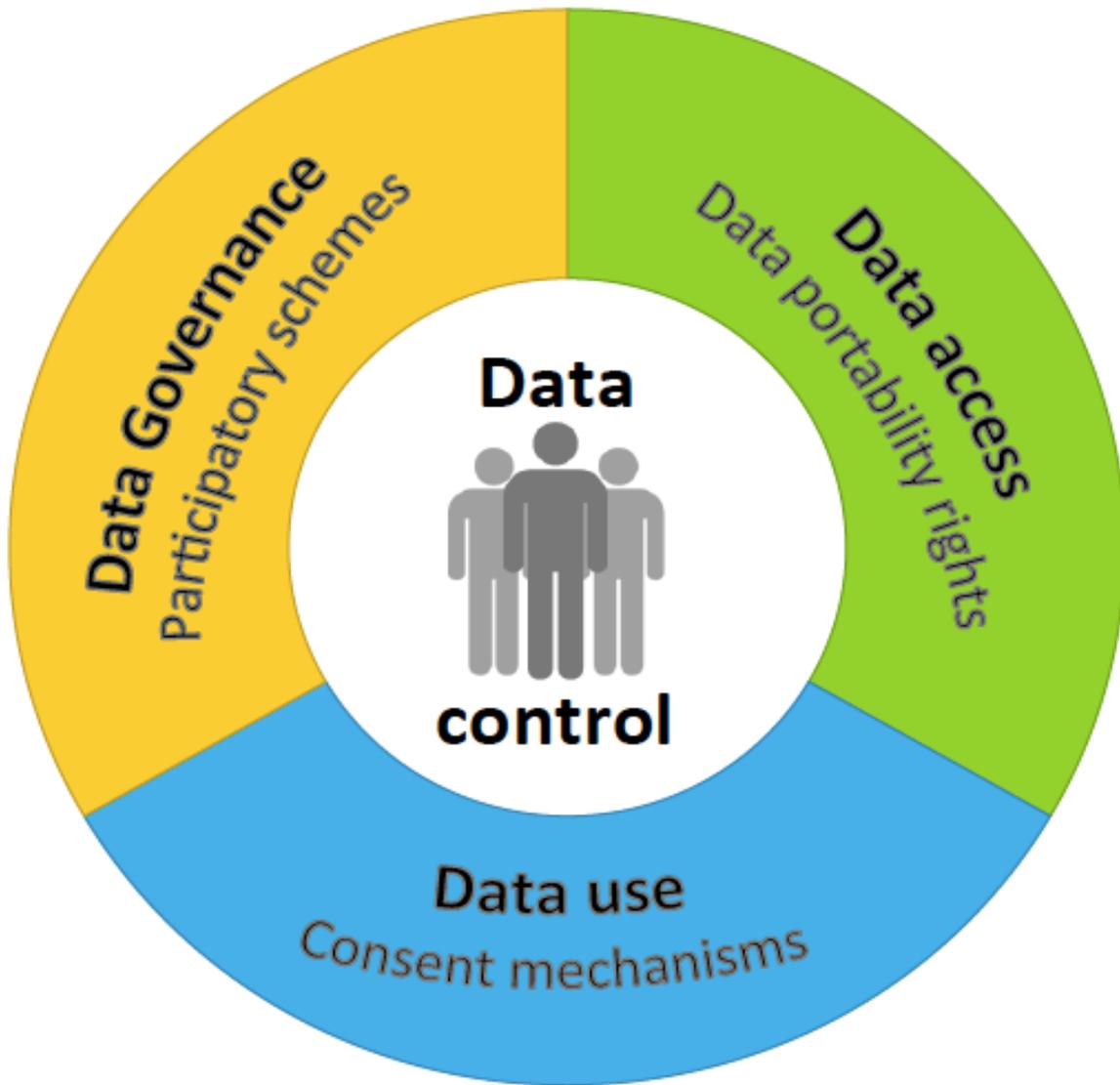
EU28

Base: Respondents who provide personal information online (n=19,430 in EU28)

- 69% of people say that their **explicit approval** should be required in all cases before their data is collected and processed.
- Roughly seven out of ten people are concerned about their information being used for **a different purpose** from the one it was collected for.







Conceptual shifts

- Data subjects become data distributors
- Consent becomes a monitoring tool
- Governance becomes more democratic

ACCESS

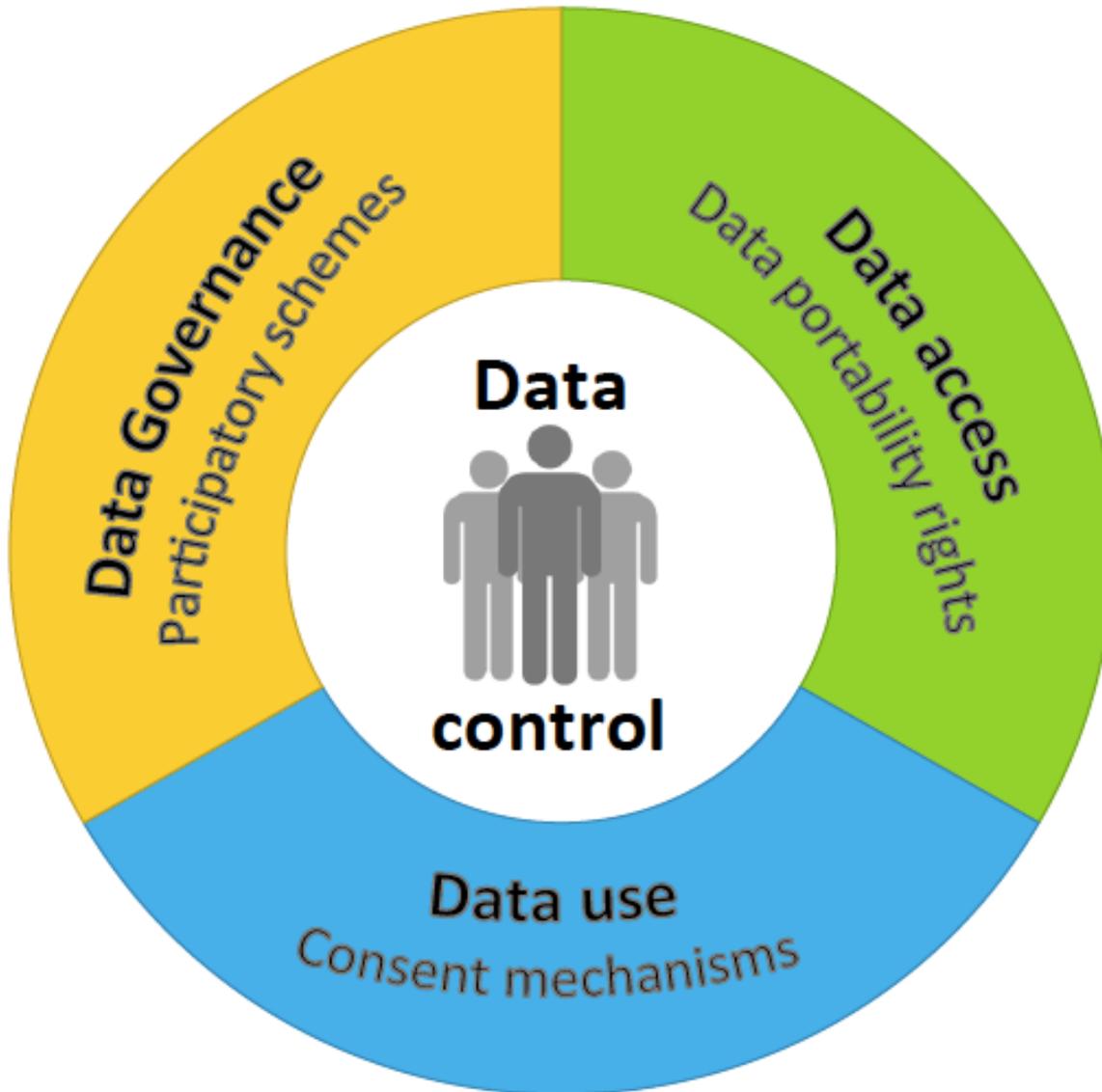
Data portability right

General Data Protection Regulation

Article 20. **Data portability right**

*“[the] data subject shall have the right to **receive the personal data concerning him or her**, which he or she has provided to a controller, in a structured, commonly used and machine-readable format and have the right **to transmit** those data to another controller without hindrance from the controller to which the personal data have been provided”.*

- *This includes all data observed about the data subject during the activities for the purpose of which the data are collected, such as a transaction history or access log. Data collected through the tracking and recording of the data subject (such as an app recording heartbeat or technology used to track browsing behavior) should also be considered as “provided by” him or her even if the data are not actively or consciously transmitted*



- Shift:
- Individual (data subject) acquires power to **distribute**

USE

Consent models Information tools

- Migration from paper to the digital
 - eIC tools
 - Online consent management
 - Dynamic consent

From analog to digital?

Table 1. Components and Challenges of Informed Consent with Traditional Paper Forms and Electronic Methods.

Component	Traditional Paper Informed Consent	Electronic and Digital Informed Consent	Challenges and Areas for Research
Disclosure	Information is written, usually on paper Discussion with investigator takes place, usually face to face	Consent can involve electronic information, multimedia information, video graphics, and interactive computer interfaces Investigator can be remote in time or place from participant	All types of disclosure require determining the appropriate content (amount and complexity of information) for disclosure User-friendly disclosure is needed Amount and style of information tailored to electronic platforms need to be determined
Understanding	Investigator and participant discuss information Participant asks questions Investigator assesses understanding, in some cases using questions, structured quizzes, other methods	Interaction can take place during disclosure Questions and assessment of understanding are easily built in Ongoing engagement is enabled Links to additional information can be included	Evidence indicates that people do not read click-through agreements on computers and mobile devices Information should be engaging and user-friendly to promote reading and understanding It may be difficult to assess capacity and understanding Empirical evidence to date indicates that video and multimedia consent strategies have not resulted in consistent advantages or disadvantages with regard to participant understanding ⁴⁷
Voluntariness	Investigator asks participant to make a choice in a setting free from coercion and undue influence Research team observes participant's body language and any hesitation	Some electronic systems facilitate participant control Participant can easily sign off or disengage Participant can decline	It may be difficult to assess voluntary choice without the clues of body language and tone It may be difficult to verify the identity of the person consenting Some data collection is passive In some cases, contributing data is a required part of the arrangement
Authorization	Paper consent document is signed Copies of document are kept in records	Options might include clicking agreement or an electronic signature Records of agreement are kept electronically	It may be difficult to verify the identity of the authorizing person

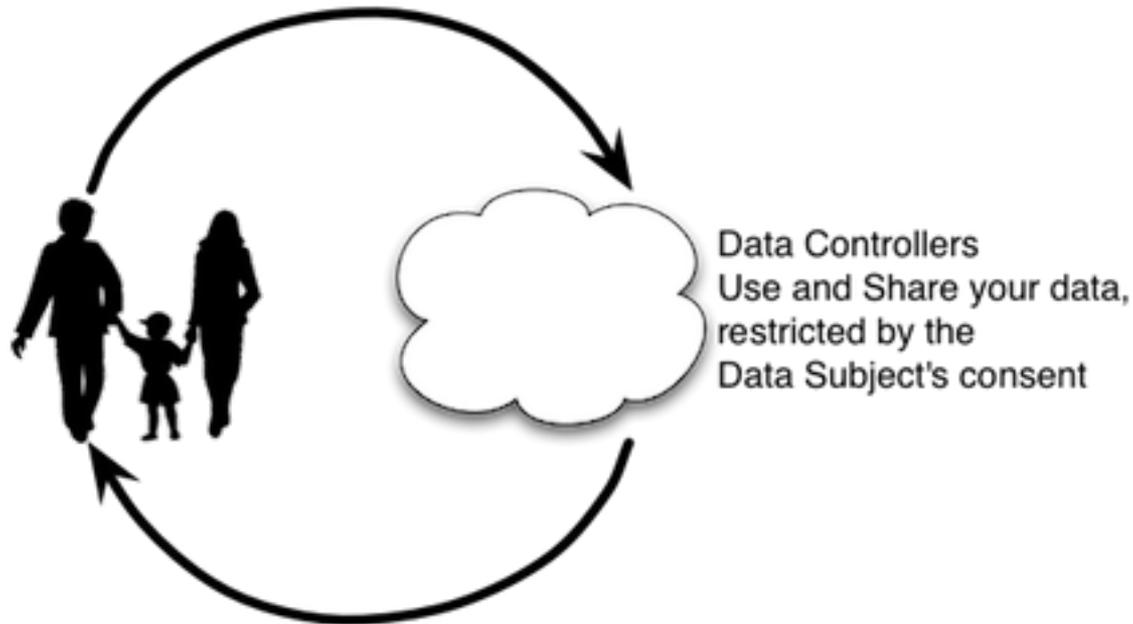
Participant Centered Consent Toolkit



Sage Bionetworks developed and maintains the *Participant-Centered Consent (PCC) toolkit*.

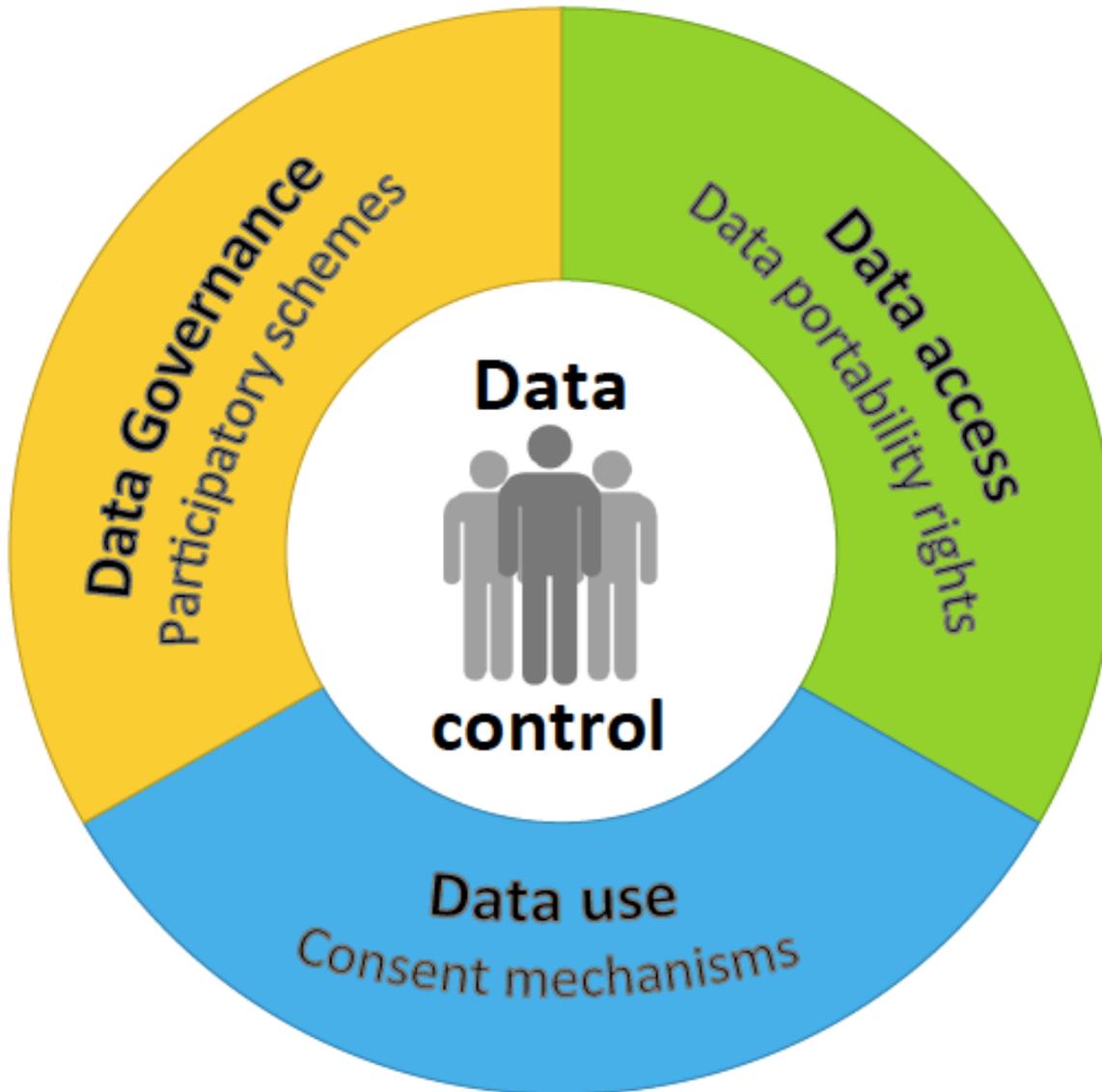
Dynamic consent

Data Subjects can change their consent preferences



Data Subjects are Notified and kept Informed
of where and when their data was used.

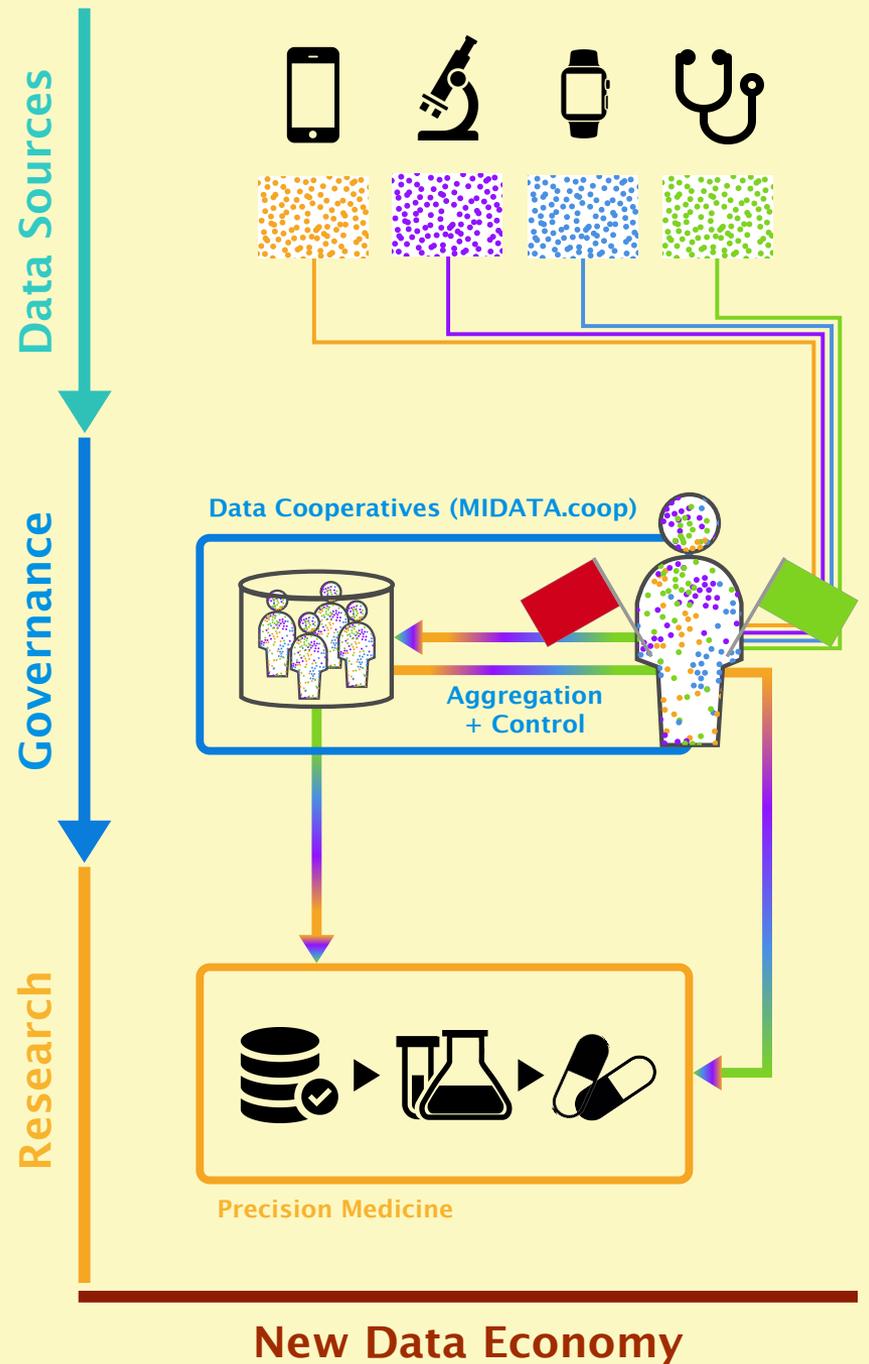
<https://www.hwcomms.com/DynamicConsent>

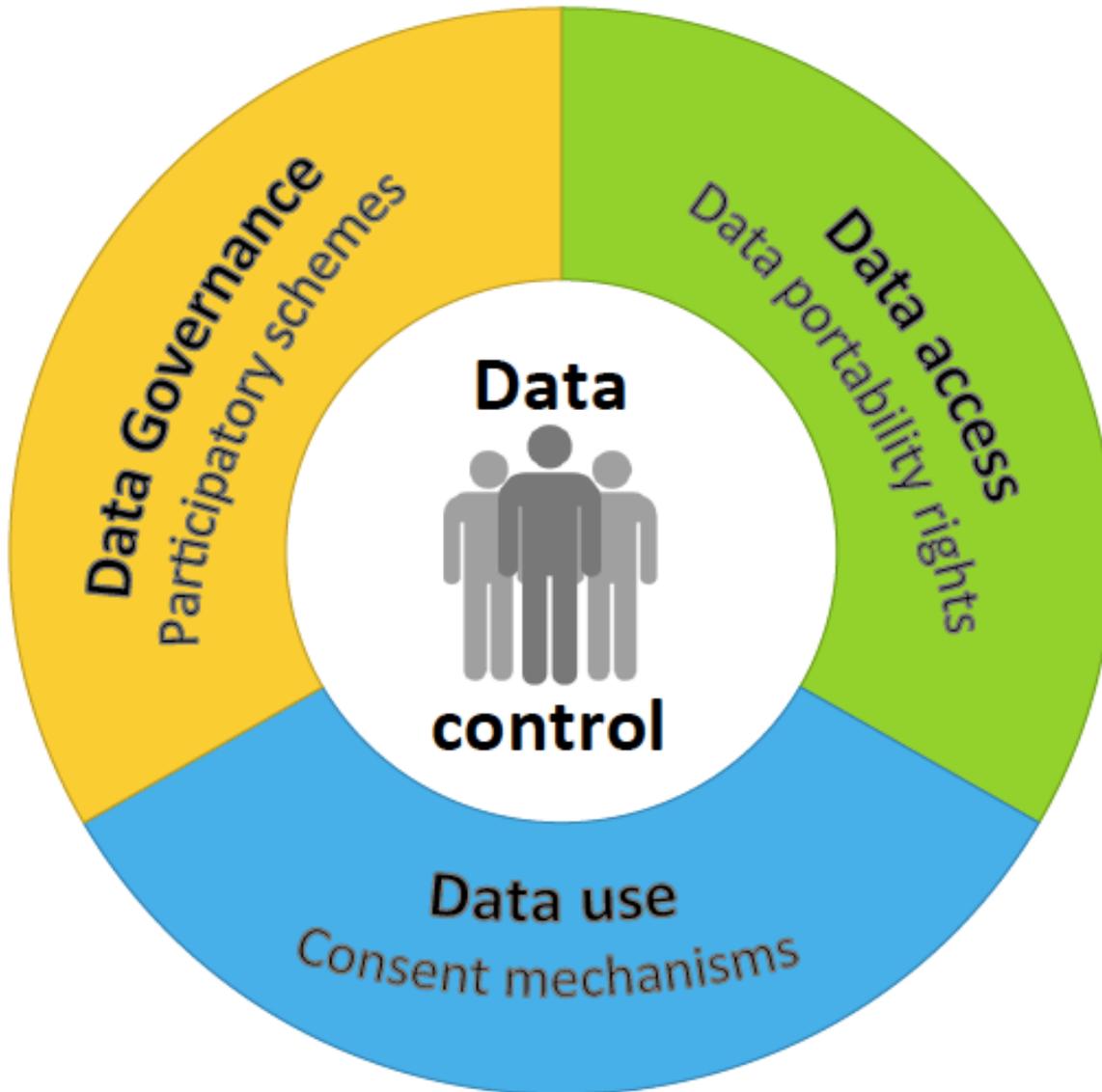


- Shift:
- Increased granularity
- Meaningful disclosure
- **Monitoring** of data uses

GOVERNANCE

Participatory schemes





- Shifts
- Citizen owned
- Federated system
- Augmented control

- Trend towards more individual control (not just in rhetoric)
- Innovative models face challenges
- More synergy in innovation around control could be more effective
- Meaningful individual control will be crucial for data access and sharing

“Big Data is not about the Data”
Gary King

