# Data governance guidebook for innovators

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http://ec.europa.eu/digital-single-market/ehealth

# Reference: case studies on data sharing practices



Countries that responded to the survey

Based on collected case studies and identified barriers to cross-border data sharing,

- more than half were legal-related barriers
- **30% were caused by data management**
- 13% were technical issues
- 5% were trust-/transparency-related barriers.

Source: *Report on secondary use of health data through European case studies* (TEHDAS, 2022)
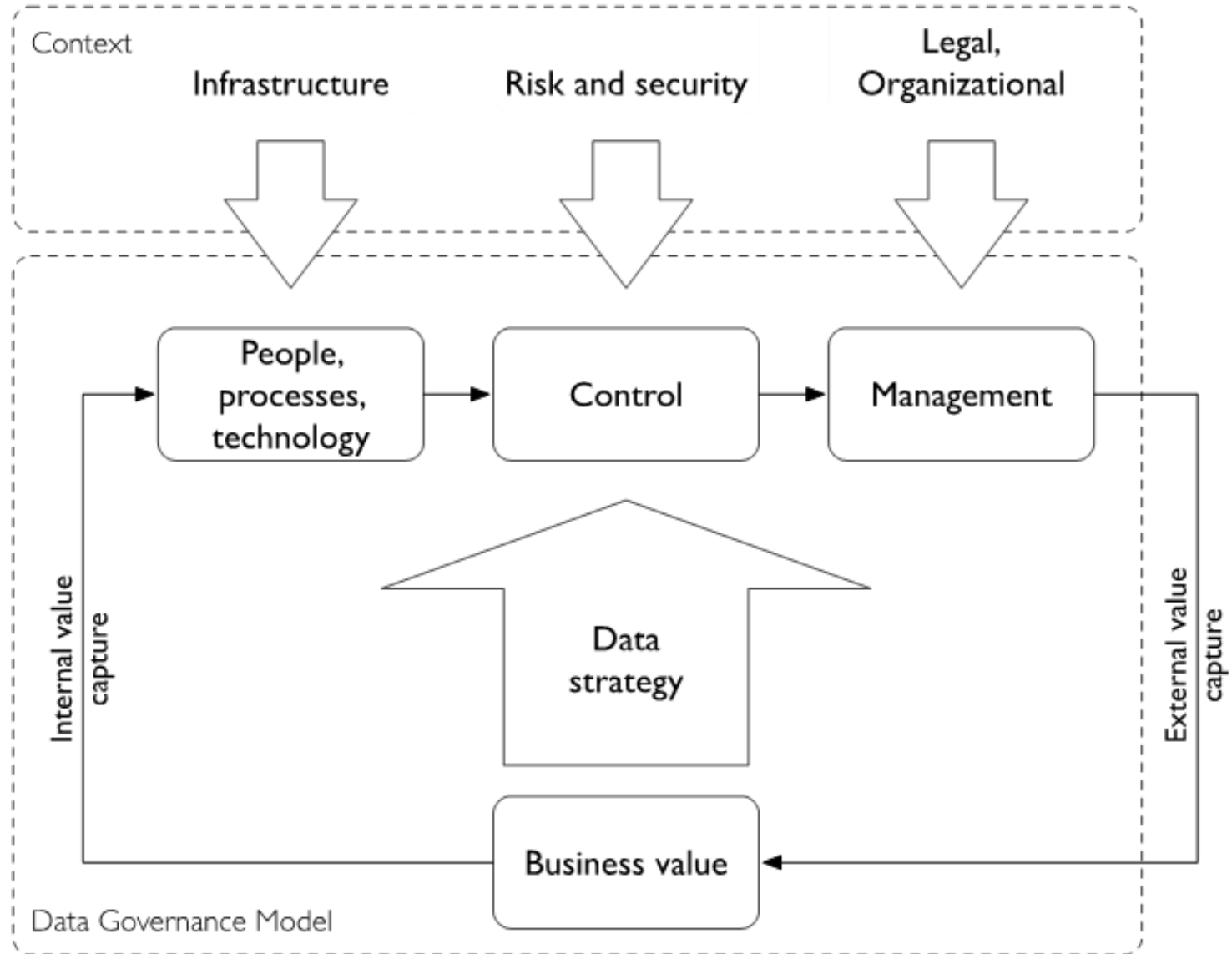
# Data governance guidelines for innovators

Data governance is seen as a feedback loop  to create value for the organisation through gaining control over the data.  The control is enabled by

**PEOPLE, PROCESSES, TECHNOLOGY**

The guidelines describe key elements of **context** that support the data governance:

• infrastructure that provides basic information technology tooling for handling, storing, and transferring data;

• risk and security that links the data model with the safety requirements as well as dangers linked to data processing;

• legal and organisational context that enables and supports the data model.

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Context

Infrastructure          Risk and security          Legal,
                                                   Organizational

People,
processes,          Control          Management
technology

Internal value capture                                    External value capture

Data
strategy

Business value

Data Governance Model

# PEOPLE

## RECOMMENDATIONS:

- Combining regulatory requirements with best practice and practical needs of data governance, we describes list of roles to cover the needed tasks and functions. As data moves through its lifecycle, it requires different competences.

- The capacities need to be developed continuously to meet the challenges coming from external context.

# PROCESSES

**RECOMMENDATIONS** are given according to each specific process:

- Risk management process

- Data architecture management

- Metadata management, including data quality management

- Information security, incl data protection

# REGULATIONS

New EC regulations, such as EHDS bring changes that need to be addressed by data governance. EHDS grants individuals the right to access their personal electronic health data, to control who accesses their data and for which uses, to restrict access, and to transmit information from one health care provider to another.

## RECOMMENDATIONS

- For service providers, there is need to address these aspects in **the internal data policies**. There is need to raise competences as well as make significant investments to enable user´s control, for example by consent management or automating data portability.

# Practical tips and tools

## Toolbox on impact evaluation and data governance

- Toolbox is a collection of practical tools how to apply data governance in practice. It includes guiding principles and checklists to assess your company:

- how to abide by ethical standards;

- how to set up and demonstrate systematic data collection process;

- ensure data protection compliance;

- align with standards to enable data quality and interoperability

- generate evidence that the product achieves clinical, social, economic or behavioural benefits: impact!

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# Please comment and reflect from your experience

https://innovation4ageing.tehnopol.ee/

Looking forward to further exchange:

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