

# Common European Data Spaces

and Official Statistics

## UNECE/EFTA Workshop on Modernizing Statistical Legislation

Barteld Braaksma, Eko Rahmadian, Anastasija Spajic

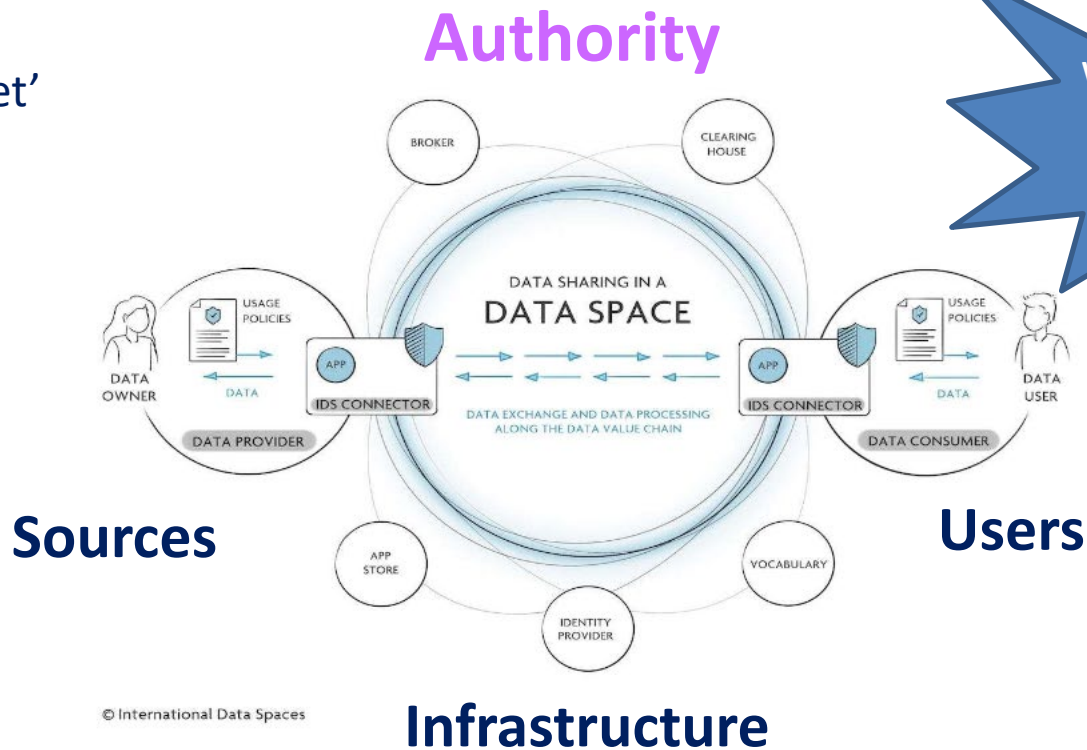
Tirana, 30 May 2024

# Contents

- ❖ Introduction of Common European Data Spaces
- ❖ Governance framework (Eko Rahmadian)
- ❖ Legal aspects of HDAB (Anastasija Spajic)
- ❖ Take-away messages

Interoperability  
Control  
'Data Market'

STAKEHOLDER

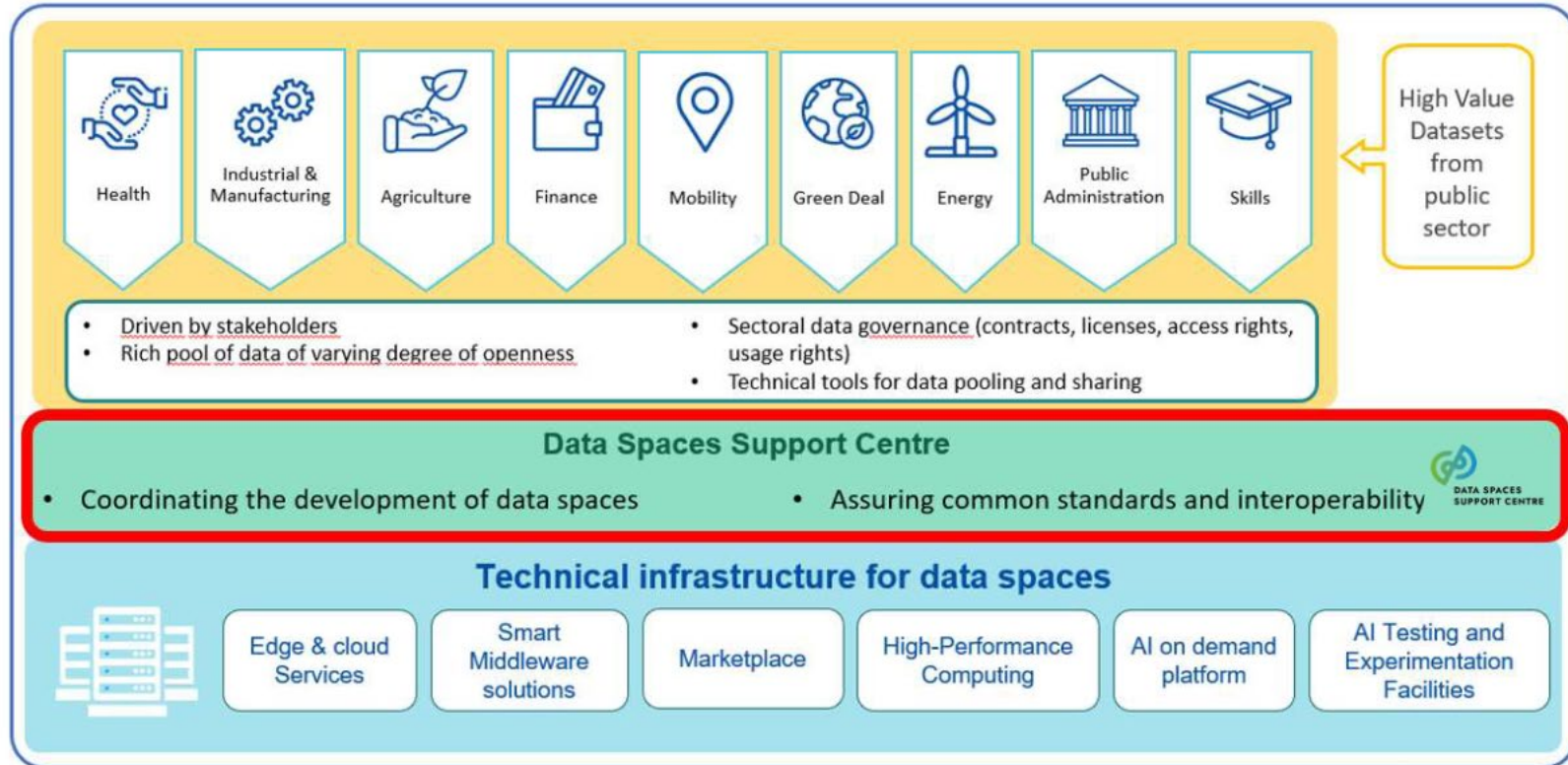


© International Data Spaces

Four-corner principle of data space concept (International Data Spaces)



# Domain-Centered Approach (including laws)



# Many aspects to take into consideration...



## Stakeholder Engagement

Comprehending the needs and concerns of both internal and external stakeholders.



## Sector and domain-specific applications

Customize initiatives and policies to tackle the distinctive challenges and prospects within each realm.



## Governance

Establishing a robust governance and regulatory framework is essential for effectively overseeing the operations of CEDS.



## Interoperability and data sharing

Enabling seamless data exchange and collaboration within CEDS and across other data spaces.



## Organizational Capabilities

Building the capacity of stakeholders (particularly internal stakeholders and close partners) to effectively participate in CEDS.



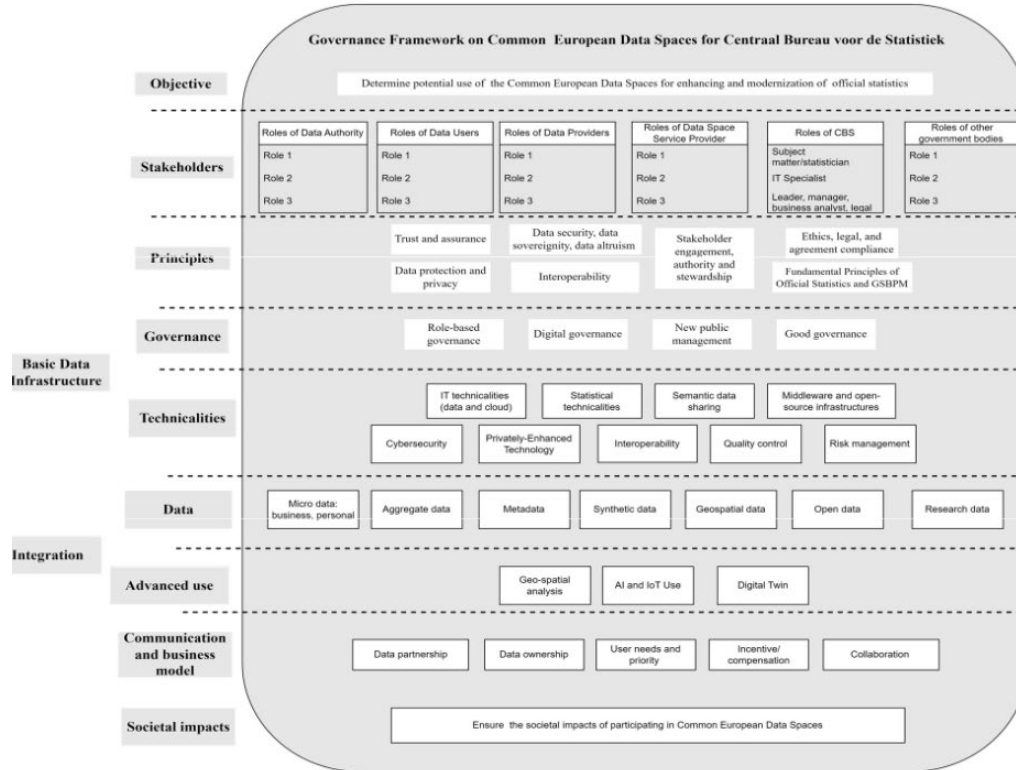
## Collaboration

Collaboration with national and international partners and organizations is essential to align policies, share best practices, and address common challenges

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March 2024



# How to make choices?



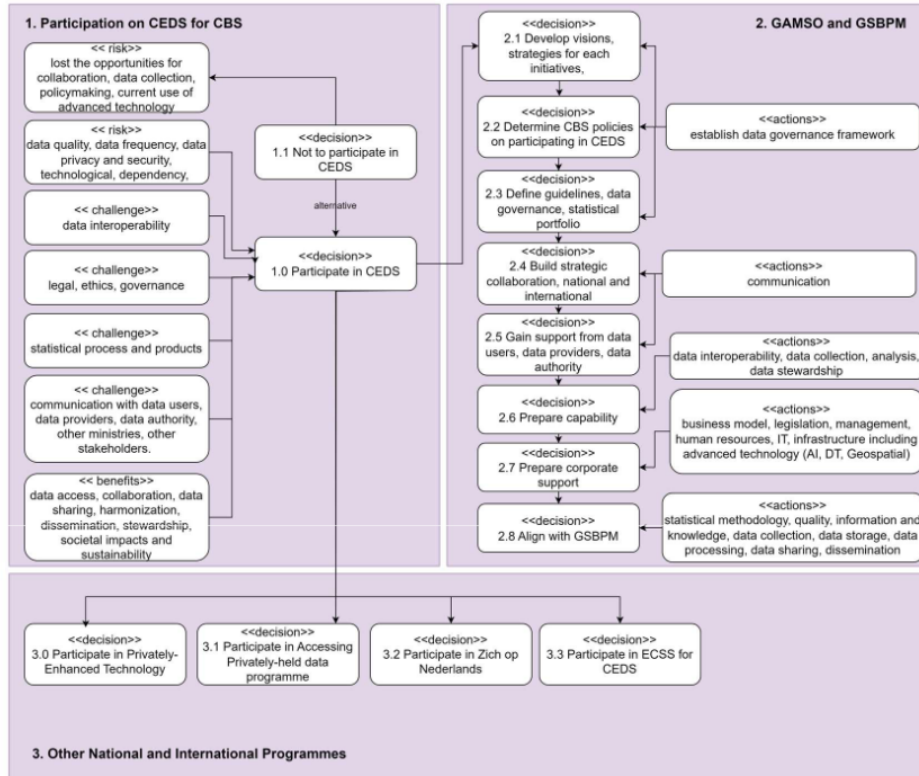
## PROPOSED GOVERNANCE FRAMEWORK FOR CBS

Set of policies, guidelines, rules, actions on data governance; to provide comprehensive overview, ensure the benefits, and mitigate the risks.

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# Questions and decision trees



**How to implement?**

## DECISION RELATIONSHIP VIEWPOINT

Describe the relationship of each decisions on participating on CEDS for CBS with GAMSO, GSBPM, and other programmes.

It helps CBS to track decisions for transparency, accountability and clarity.

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● Council of the EU | Press release | 15 March 2024 01:10

## European Health Data Space: Council and Parliament strike deal

*This press release was updated on 22 March 2024 to include the link to the compromise text*

The Council of the EU and the European Parliament have reached a provisional agreement on a new law making it easier to **exchange and access health data** at the individual level. The agreement will now need to be endorsed by both the Council and the Parliament.

The proposed regulation for a **European Health Data Space (EHDS)** aims to improve individuals' access to and control over their personal electronic health data,

After months of hard work and dedication, we have a deal that will strongly support patient care and scientific research in the EU. The new law agreed on today will allow patients to access their health data wherever they are in the EU. It will also provide for easier access to electronic health data for individuals, while also providing scientific researchers with easier access to health data for reasons of public interest. The new law will also ensure that individuals have greater control over their health data that will greatly support the implementation of digital health policies.

— Frank Vandenbroucke, Belgian Deputy Prime Minister  
Minister of Health



Health Data  
Access Body

### Easier access to health data for individuals

Under the new rules, individuals will have **faster and easier access to electronic health data**, regardless of whether they are in their home country or another member state. They will also have **greater control over how that data is used**. EU countries will be required to set up a **digital health authority** to implement the new provisions.

### Greater research potential

[Provisional agreement on a new law](#)





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 groningen



Centraal Bureau  
 voor de Statistiek

# Granting access to health data for secondary purposes – ‘Good governance’ assessment of legal schemes for Dutch Health Data Access Body

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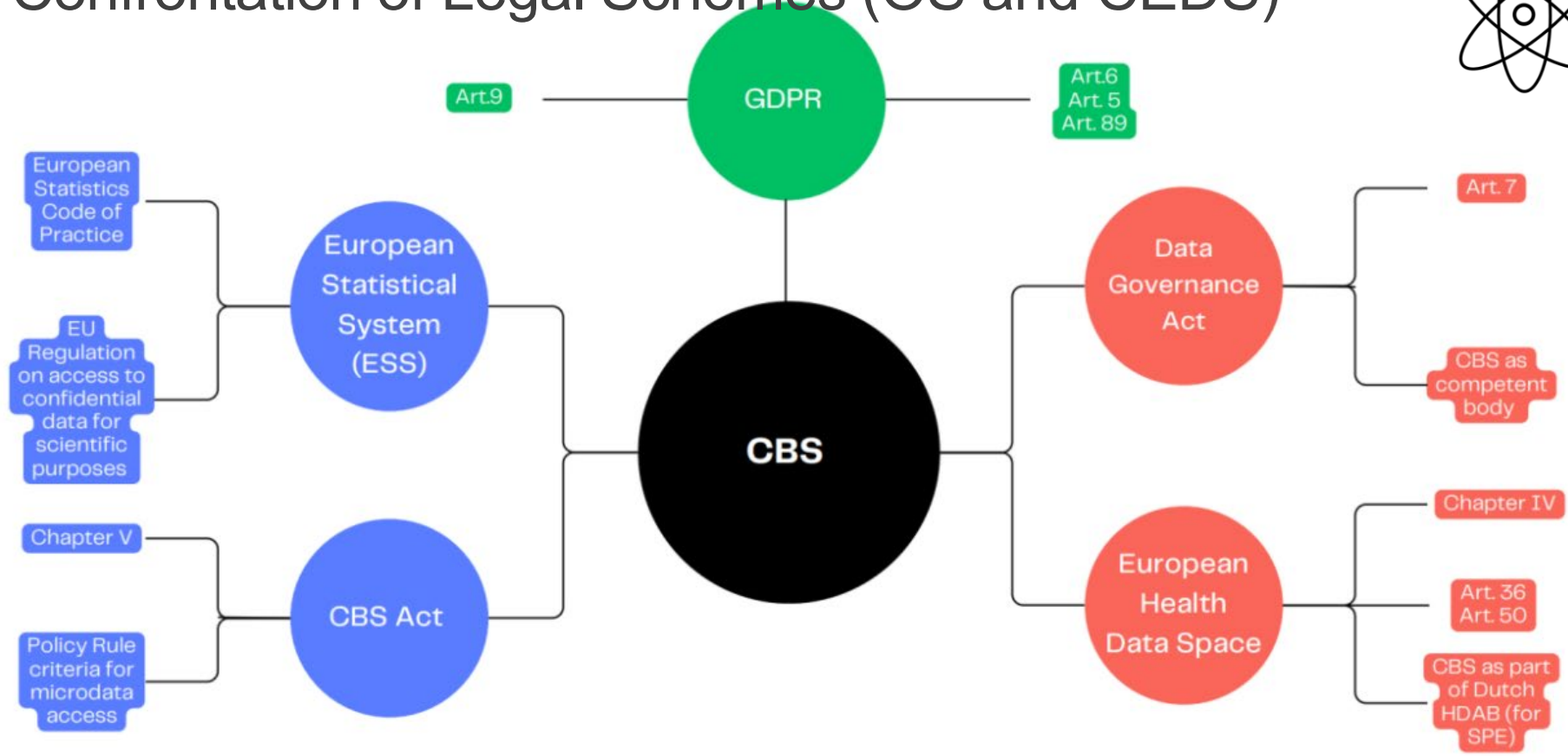
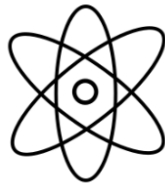
*MASTER THESIS PROJECT WITHIN RESEARCH INTERNSHIP AT CBS*

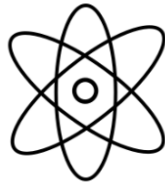
*ANASTASIJA SPAJIC*

*A.SPAJIC@STUDENT.RUG.NL*

*28.08.2023*

# Confrontation of Legal Schemes (OS and CEDS)





# Research Question and Methodology

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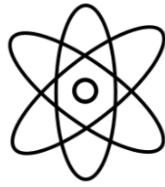
## RESEARCH QUESTION

**How do the possible legislative frameworks for the establishment of the secure processing environment of the Dutch HDAB adhere to good governance principles and how do they affect access to health data by the pharma industry?**

## METHODOLOGY

**Evaluative framework for Good Governance, based on seven principles:**

**1) Transparency; 2) Responsibility and Accountability; 3) Participation, Engagement and Collaboration; 4) Effectiveness and Efficiency; 5) Privacy and Data Protection; 6) Security; 7) Trust**

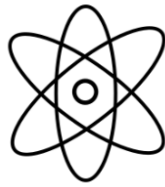


# Rules of legislative schemes for secondary use of data (II)

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## Consequences for pharma industry as health data users

- EHDS Proposal: broad opportunities for secondary use of health data
  - Various purposes, i.e. develop products that contribute to public health or evaluate medicinal products
  - Apply for access via application form and state for instance intention of health data reuse and measures taken to safeguard data
- CBS Act: restrictive conditions for the secondary use of health data
  - Only authorized for data access if conducting statistical or academic research (follow strict research design)
  - 60% of workforce is solemnly dedicated to conducting research or there is a separate research department



# Conclusions

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- **Both legal schemes fulfill good governance.** Decision on the most apt framework depends on interests of decision-makers and weighing the challenges.
- **Lack of adequate, pre-established EU principles** that would guide data governance frameworks
- **Complexity of the interplay of legal frameworks:**
  - EU level ambiguity between EHDS and DGA.
  - New legal initiatives implemented without resolving issues with existing frameworks like the GDPR.
  - Interplay between ESS and DGA underexplored.
  - Extensive research conducted on the GDPR given its revolutionary nature but little attention has been given to the ESS and pre-existing frameworks that also govern access to data for research purposes.

# Another case: The Green Deal Data Space

HOME PRAC

The Green Deal Data Space specifically, will link with other EU programmes such as [Horizon Europe](#), [Galileo](#), and [Copernicus](#) to provide large amounts of real-time data to:



Home ▶ News ▶

## Digital Deal

- Provide relevant high-quality data from the activities related to high-value datasets; and
- Interlink to data from other sectoral data spaces where relevant; and
- Contribute to the [Destination Earth initiative](#), a very high precision digital model of the Earth to enable visualising, monitoring and forecasting natural and human activity on the planet in support of sustainable development.

25.11.2021

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The Green Deal Copernicus to p

Ultimately, this data space is to develop into a user-driven pan-European Green Deal data space by connecting EU programmes, national, regional and local data ecosystems at the EU level. To achieve this, the Commission established a number of deliverables:

1. A sustainable data governance scheme and blueprint that connects national, regional and local data ecosystems and enables public and private stakeholders to access relevant data and to develop cross-sector data services;
2. A priority list of datasets relevant to the European Green Deal Strategy;
3. A roadmap towards the common European Green Deal Data Space.

This roadmap should ensure that relevant users, such as climate and environmental scientists, are able to access and make use of the opportunities offered by Green Deal Data Space.



# Not only in Europe 😊

The screenshot shows the homepage of the SATU DATA INDONESIA portal. At the top left is the logo 'SATU DATA INDONESIA'. The top right navigation bar includes links for 'Dataset', 'Data Insight', 'Publication', 'About', 'SDI Regulations', and an 'Enter' button. The main heading reads 'Access Data Indonesia in One Portal' with a subtext '391797 DATASETS AVAILABLE'. Below this is a search bar with a dropdown menu set to 'All Data' and a search input field containing 'Search Indonesian Public Data'. A central illustration depicts various Indonesian landmarks and the national flag. At the bottom, a 'Data Topics' section features ten categories, each with an icon and a title: Economy and Industry, Environment and Natural Resources, Culture And Religion, Social and Health Protection, Regional development, Education And Workforce, General Government, General Supporter, Public Order and Safety, and Defense And Foreign Affairs.

A data governance policy to produce data that is accurate, up-to-date, integrated and accountable, as well as accessible and easy to share between government agencies in national level and regional agencies in sub-national levels, through compliance of the principles: standard data, metadata, data interoperability, and using reference code and master data.

**One Data Indonesia**



# Take-aways

- A lot of activity, often domain-specific
- Many stakeholders involved
- What's in it for us?
- **Data spaces lead to broader strategic questions**
- When modernizing statistical legislation, need to consider broader developments like data spaces
- Not just Europe!







**Facts that matter**