"Health Data Governance in the Age of Digital Health: Legal Models of the EU and China"

Z h i c h e n g   H e

The Swedish Law and Informatics Research Institute

Stockholm University

21 April 2023

03

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Second visuAAL

PhD Seminar

01

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01 PhD Project Overview

The aim of **visuAAL** is to bridge the knowledge gap between users' requirements and the appropriate and secure use of video-based AAL technologies to deliver effective and supportive care to older adults managing their health and wellbeing.

visuAAL will seek to increase awareness and understanding of the context-specific ethical, legal, privacy and societal issues necessary to implement visual system across hospital, home and community settings, in a manner that protects and reassures users; outputs will stimulate the development of a new research perspective for constructively addressing privacy-aware video-based working solutions for assisted living.

Various Legal Aspects in Play

4. Legal aspects

State of the art on ethical, legal, and social issues linked to audio- and video-based AAL solutions

Working Group 1.
Social responsibility: Ethical, legal, social, data protection and privacy issues

December 2021

cost
EUROPEAN COOPERATION
IN SCIENCE & TECHNOLOGY

goodbrother

A taxonomy for descriptive legal research in law and technology

Step 2

To analyse whether and to what extent these norms apply to the technologies at issue

Step 1

To identify relevant norms.

(Koops, 2013)

Step 3

To put the norms in perspective, describe their context and purpose for further interpretation.

Step 4

To analyse diverse aspects of the norms to achieve a 'thick description'.

Wider considerations
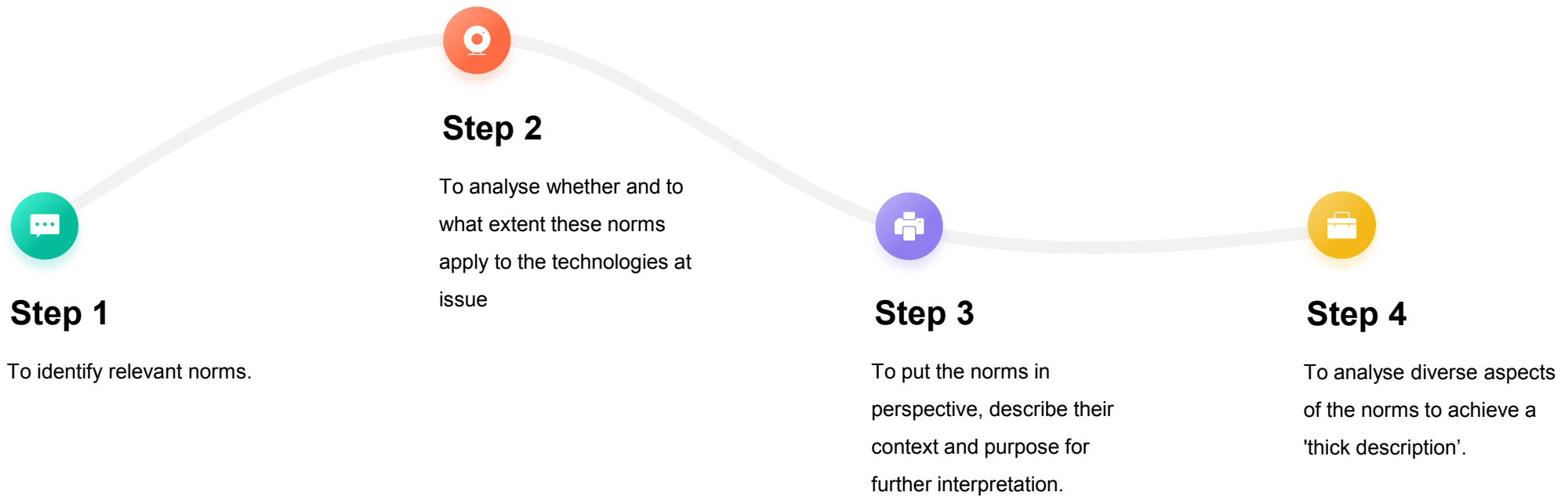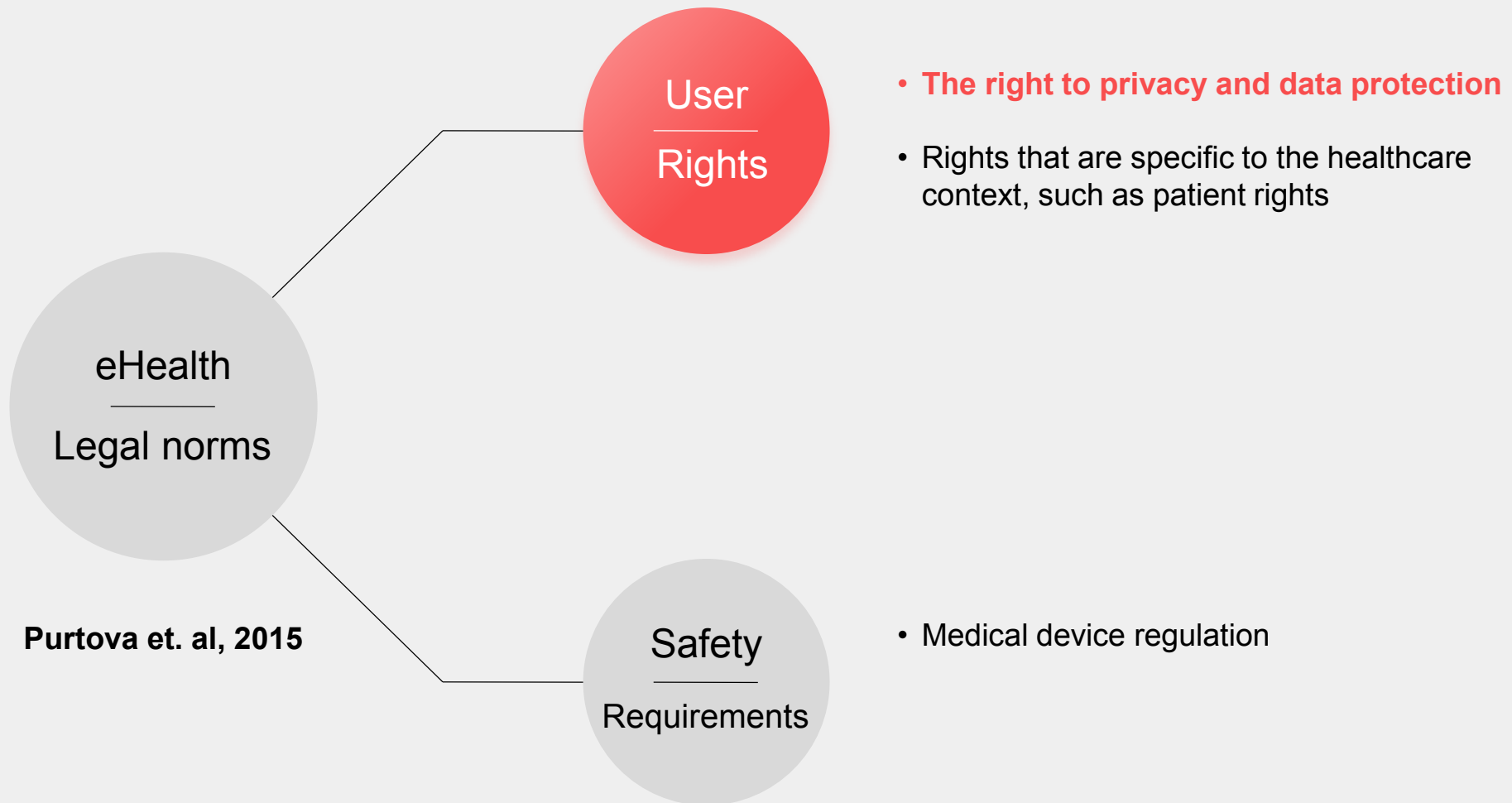
End-users

- Raise awareness.

- Help users understand their legal rights better.

Technology companies and developers

- Enhance awareness of legal issues.

- Build knowledge regarding complex regulatory compliance works.

Policy makers

- Provide insights on the 'state-of-the-art' of the current regulatory frameworks.

- Inform possible policy changes, legislative updates and revisions.

- Make connections and promote better understanding.

02

"Progress Recap"

Main research method

Comparative legal study between the EU and China

Source: China Briefings

Comparative law

- Comparative law is the study of differences and similarities between the law (legal systems) of different countries.

Why comparative law

- Legislation.
- Enforcement.
- Globalisation.

How

- Macro comparison v Micro comparison
- Function comparison v Concept comparison
- Cultural comparison
- Static comparison v Dynamic comparison

Plans - Training and Development (May 2022)

Trainings and courses

- To attend visuAAL training school on "Innovation in health and integrated care", 1-3 June 2022, Trinity College Dublin, Ireland.

- To attend the 2nd visuAAL doctoral seminar, 2023, Stockholm University, Sweden.

- Courses at Stockholm University.

Conferences

- To attend and present in the 2022 Global Meeting on Law and Society, July 2022, Lisbon.

- GoodBrother International Conference on Privacy-friendly and Trustworthy Technology for Society, Zagreb, June 2022

- PETRA 2022, PrivAw – GoodBrother Workshop on Privacy aware and acceptable solutions for AAL, 29 June – 1 July 2022

Network

- To complete courses from WASP-HS Doctoral school.

- To participate in activities within the WASP-HS.

visuAAL

03

"Progress Report"

Conferences

Conference attended with presentation

1. International Conference on Privacy-friendly and Trustworthy Technology for Society, June 2022. Attended and presented.

2. The 15th ACM International Conference on PErvasive Technologies Related to Assistive Environments (PETRA 2022) in Corfu, Greece. June 2022. Presented my paper and received the "Best Workshop Student Paper Award".

3. 2022 Global Meeting on Law and Society, July 2022, Lisbon. Attended and paper presented.

4. 2022 Asian Law and Society Meeting, December 2022, Hanoi. Attended and presented paper.

Publication Journal Article

ELSEVIER

Computer Law & Security Review

Volume 47, November 2022, 105758

When data protection norms meet digital health technology: China's regulatory approaches to health data protection

Zhicheng He ✉

The Swedish Law and Informatics Research Institute, Faculty of Law, Stockholm University, Universitetsvägen 10C, 106 91 Stockholm, Sweden

Publication

- **Presented at PETRA.**

- **Best Student Paper Award.**

Trainings

Completed all visuAAL trainings.

1. visuAAL training school on "Innovation in health and integrated care", 1-3 June 2022, Trinity College Dublin, Ireland.

2. 1st visuAAL doctoral seminar and training school on "Skills 2. Presenting and publishing", 21-25 March 2022, Aachen, Germany.

3. visuAAL training school "Video-based AAL application", 7-10 December 2021, TU Wien, Vienna, Austria.

4. Attended visuAAL seminars on Responsible Research and Innovation, 13-14 October 2021, online.

5. first visuAAL training school on "Responsible research and innovation" and "Research Skills", 27 September to 1 October 2021, University of Alicante, Spain.

Courses

SU Courses

1. Fundamental concepts of law, 7.5 credits, Stockholm University, January 2022, completed.
2. Academic writing, 7.5 credits, Stockholm University, May 2022, completed.
3. Philosophy of Social Sciences, 7.5 credits, August to November 2021, Stockholm University. Completed.
4. Course for newly admitted PhD students on how to manage PhD project, September - December 2021, Stockholm University. Completed.

WASP Courses

1. Introduction to Artificial Intelligence. 2022. 2.5 credits. Completed.
2. Deep Learning. May 2023. 3 credits. Forthcoming.

Swedish Courses

1. Svenska för anställda, B. HT2021. Completed.
2. Svenska för anställda, D. VT2022. Completed.
3. Svenska för anställda, F. VT2023. Ongoing.

03

"**Dissertation**"

Two phases of health data governance **in China.**

O1	**O2**	**?**

Fragmentation.

Various laws and regulations.
No standalone data protection
law before 2021

Harmonisation.

PIPL 2021 harmonised the
protection of health data.
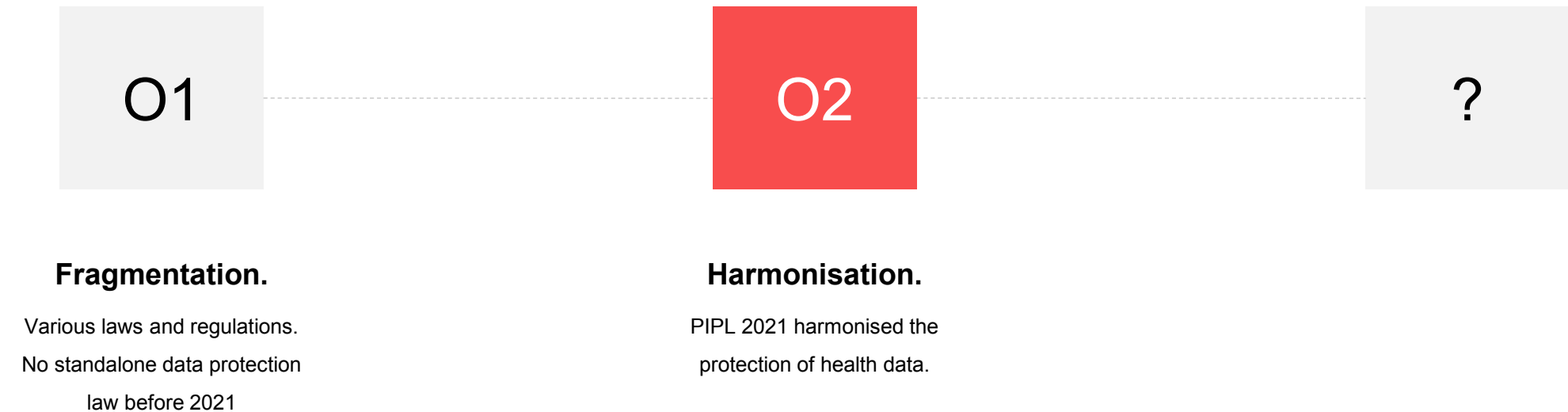
China's data protection legal landscape before 2021
A Patchwork of Regulations

Data protection related regulations		Sectoral laws
2000 **NPCSC Decision**	2013 Ministry of Industry Regulations	Consumer Rights Protection Law
2009 Amendment 7	2015 Amendment 9	Resident Identity Card Law
2012 NPCSC Decision	**2016** **Cybersecurity Law**	Regulations on Credit Information Industry
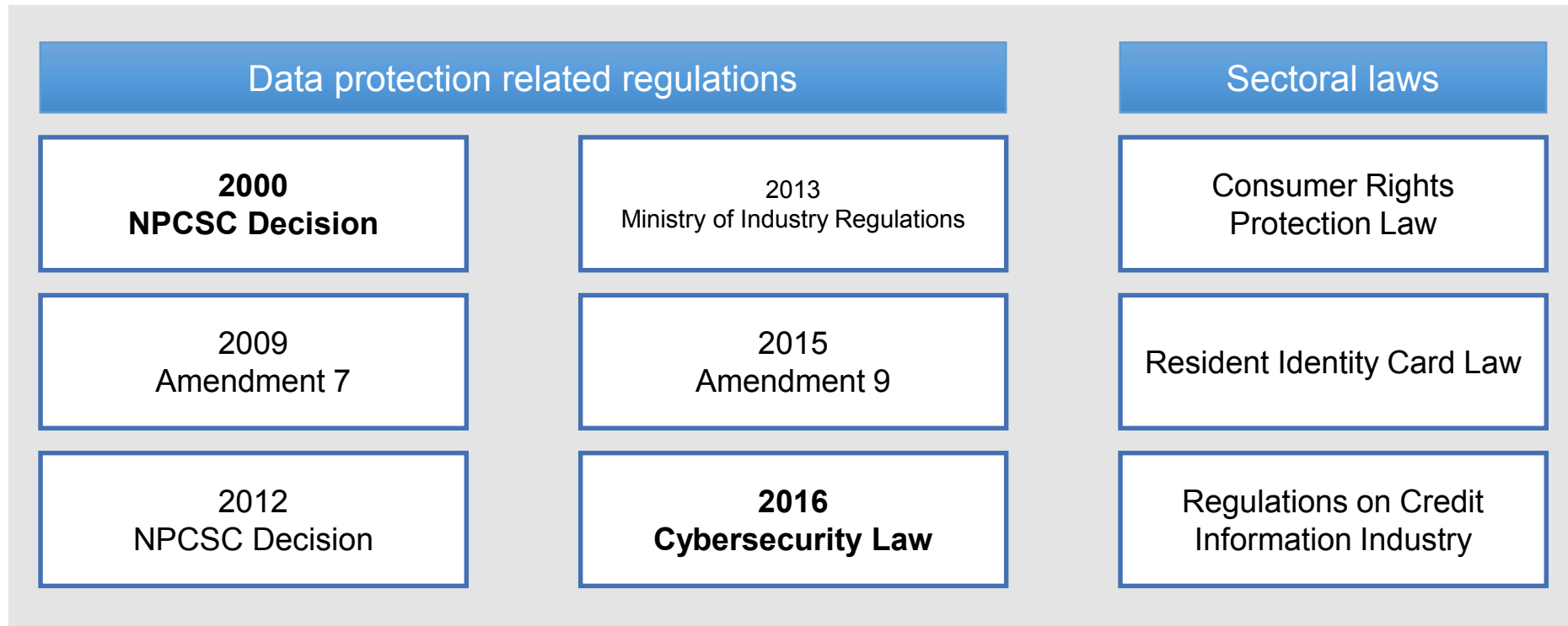
Personal Information Protection Law 2021 (PIPL)

- China's **first ever** standalone data protection law.

- Personal information protection **principles**.

- Strengthened data subject **rights**.

- Data processing requirements for **public authorities**.

- **Public interest lawsuits**.

Legal framework of health data governance in the **European Union law**
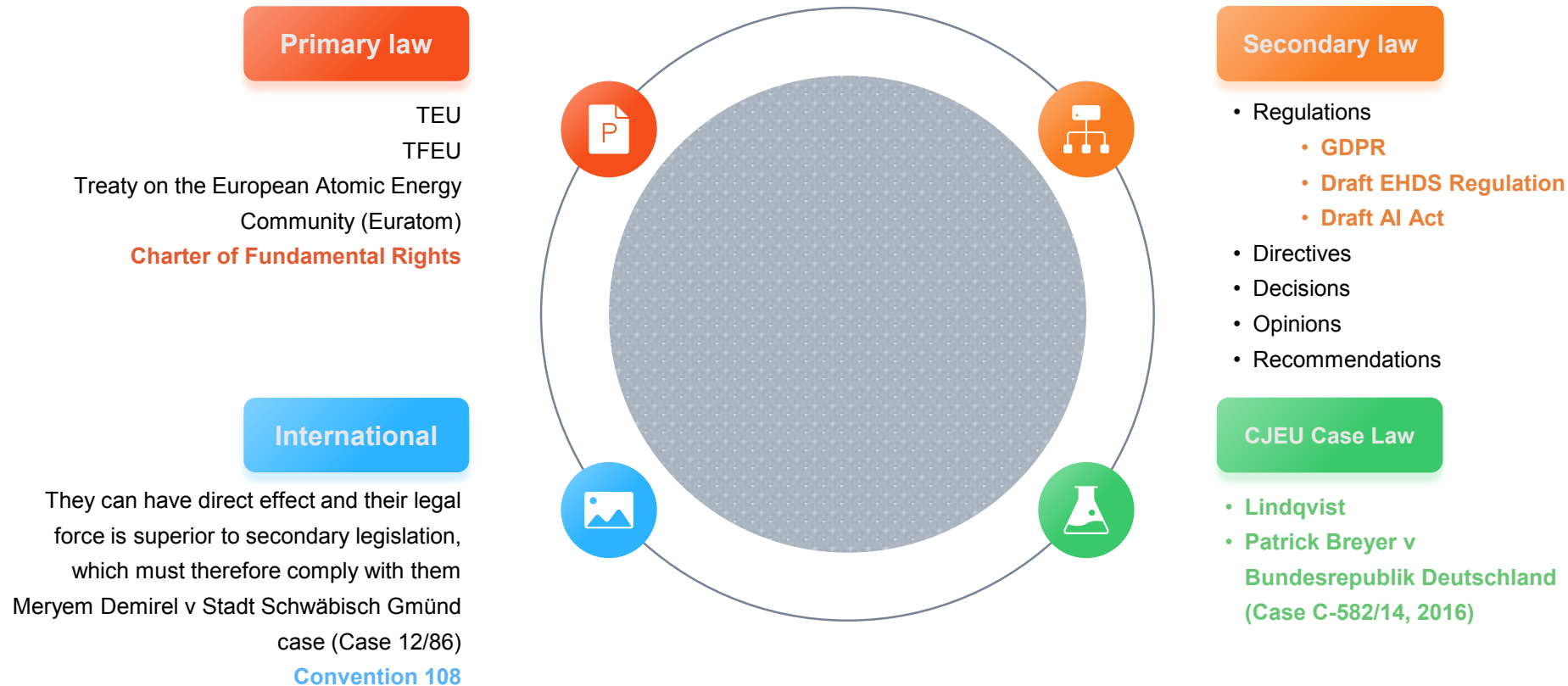
Primary law

TEU
TFEU
Treaty on the European Atomic Energy Community (Euratom)
Charter of Fundamental Rights

International

They can have direct effect and their legal force is superior to secondary legislation, which must therefore comply with them
Meryem Demirel v Stadt Schwäbisch Gmünd case (Case 12/86)
Convention 108

Secondary law

- Regulations
  - **GDPR**
  - **Draft EHDS Regulation**
  - **Draft AI Act**
- Directives
- Decisions
- Opinions
- Recommendations

CJEU Case Law

- **Lindqvist**
- **Patrick Breyer v Bundesrepublik Deutschland (Case C-582/14, 2016)**

The Protection Mechanism of Health Data

Member States may maintain or introduce further conditions, including limitations, with regard to the processing of genetic data, biometric data or data concerning health.
(Article 9(2)(4) GDPR)

- Racial or ethnic origin
- Political opinions
- Religious or philosophical beliefs
- Trade union membership
- Genetic data
- Biometric data
- Data concerning health
- Sex life or sexual orientation

Sensitive data

The processing of sensitive data is in principle prohibited.

- Explicit consent
- Employment (MS law)
- Vital interests
- Political, philosophical, religious
- Made public
- Substantial public interest (Union or MS law)
- Medical, health, social care (Union or MS law)
- Public health (Union or MS law)
- Research (Union or MS law)

Exceptions

Sensitive data can only be processed according to these legal grounds.

EUROPEAN HEALTH DATA SPACE

#EUDigitalHealth

OBJECTIVES

✓ Empower individuals through better digital access to their personal health data; support free movement by ensuring that health data follow people;

✓ Unleash the data economy by fostering a genuine single market for digital health services and products;

✓ Set up strict rules for the use of individual's non-identifiable health data for research, innovation, policy-making and regulatory activities.

Thank you.