

“Bridging Science and Privacy: Legal Approaches to Health Data Governance in the EU and China”

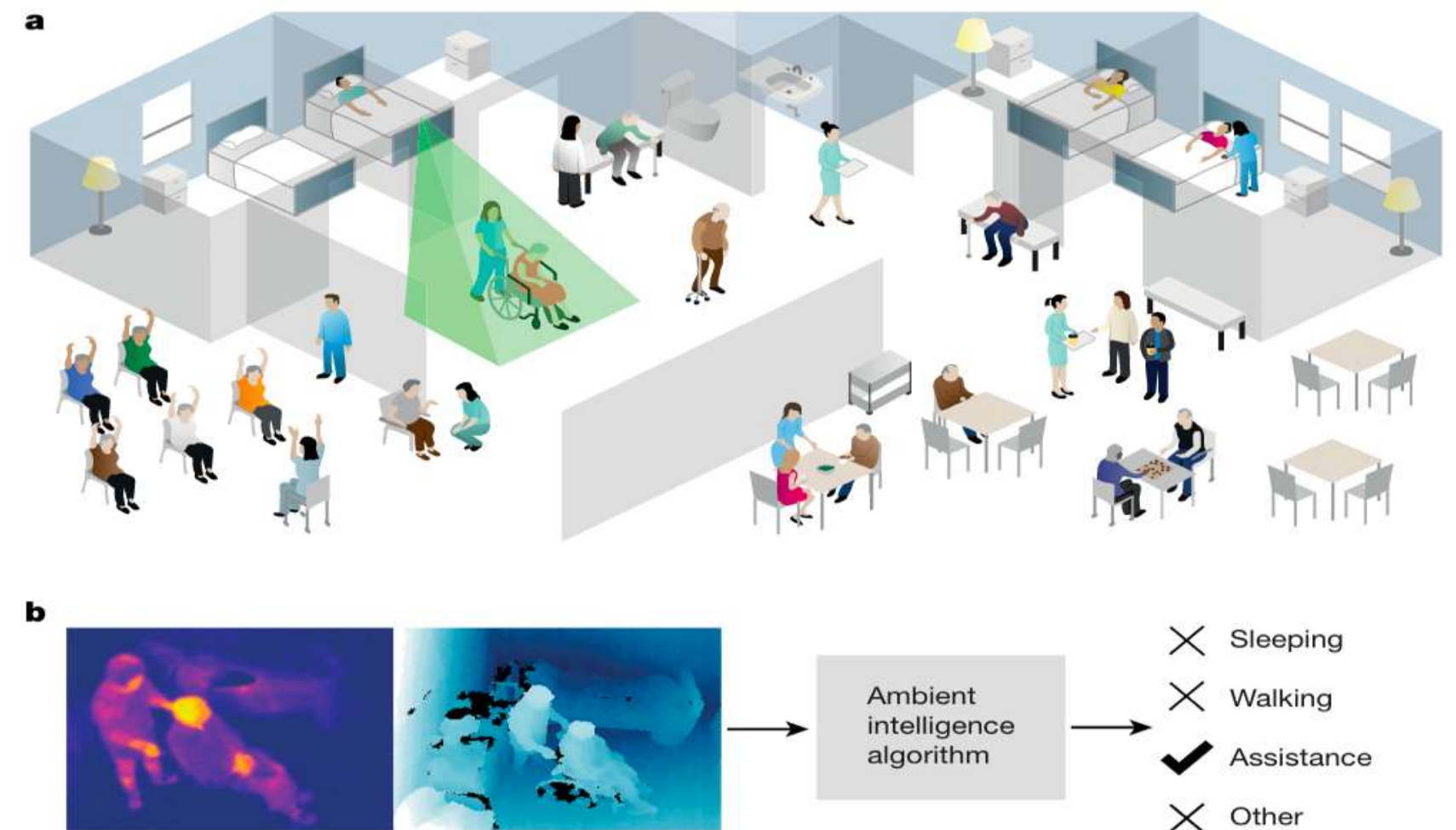
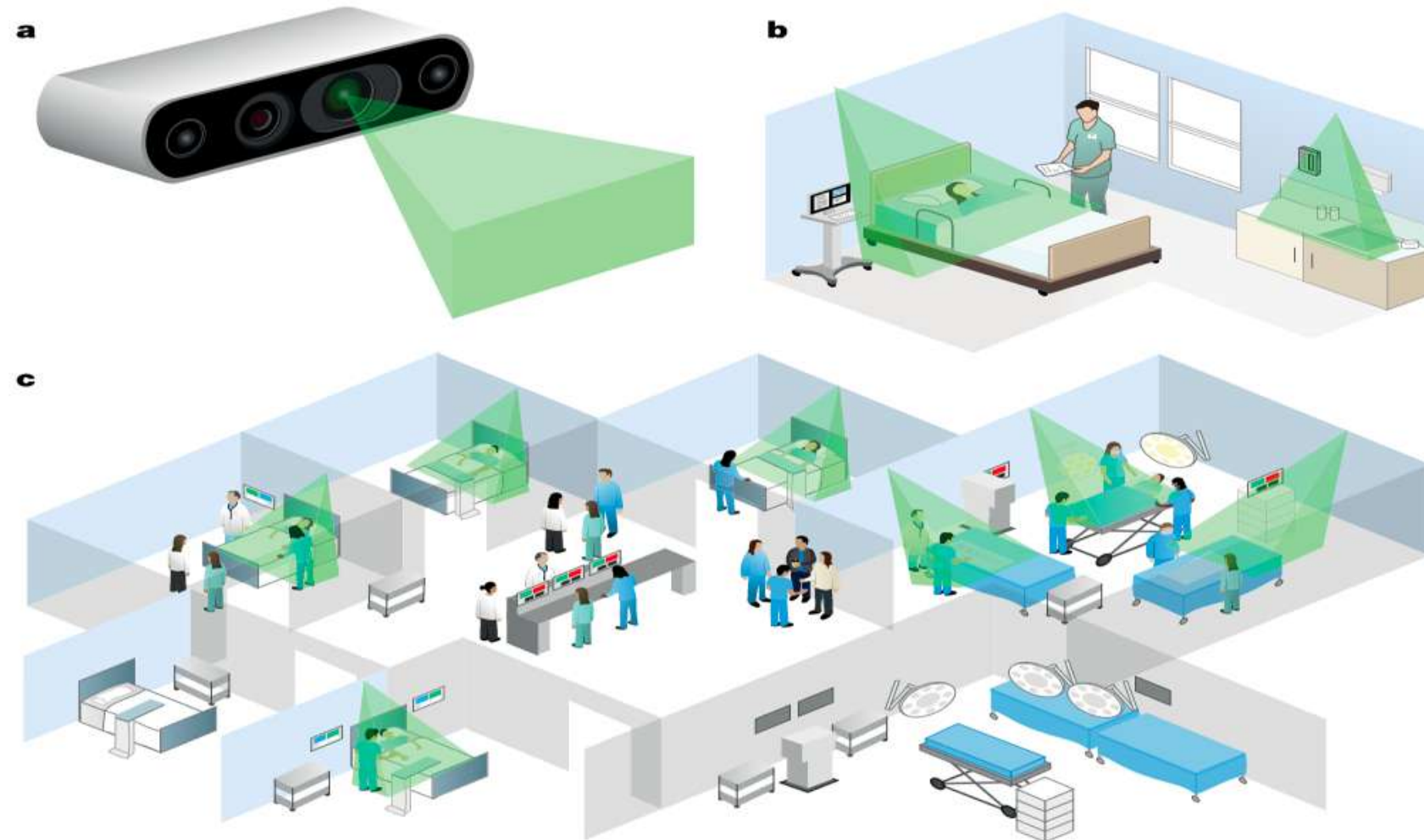
ZHICHENG HE

The Swedish Law and Informatics Research Institute
Stockholm University

visuAAL – GoodBrother Conference
18 June 2024
Alicante, Spain



→ Health Data for Science



Illuminating the dark spaces of healthcare with ambient intelligence

Albert Haque, Arnold Milstein & Li Fei-Fei

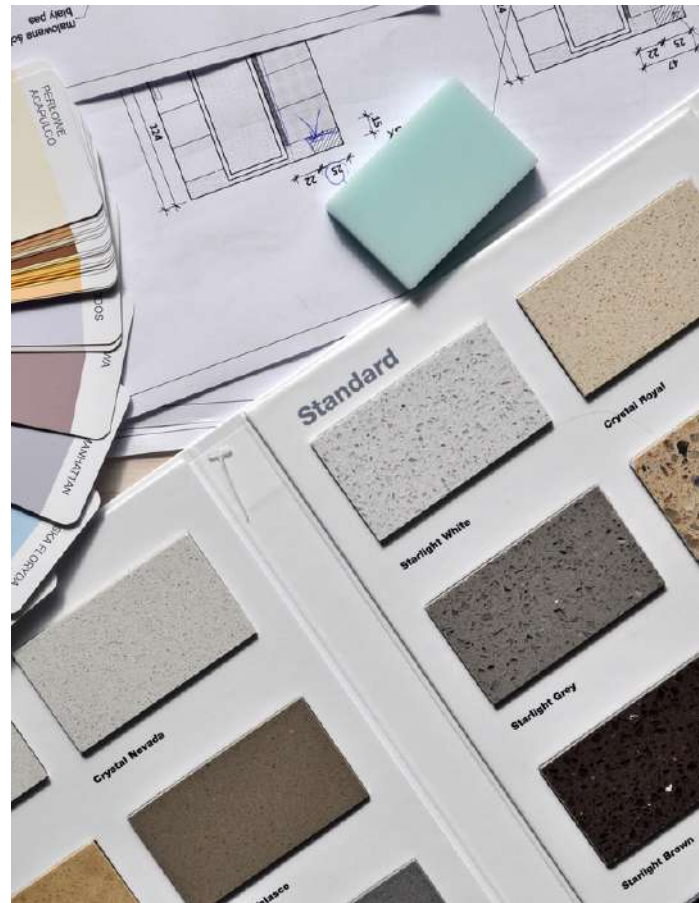
Nature 585, 193–202 (2020) | Cite this article



Hypothesis

If a society wishes to reap the benefits of digital health care, it must respond to these two needs at the legal level.

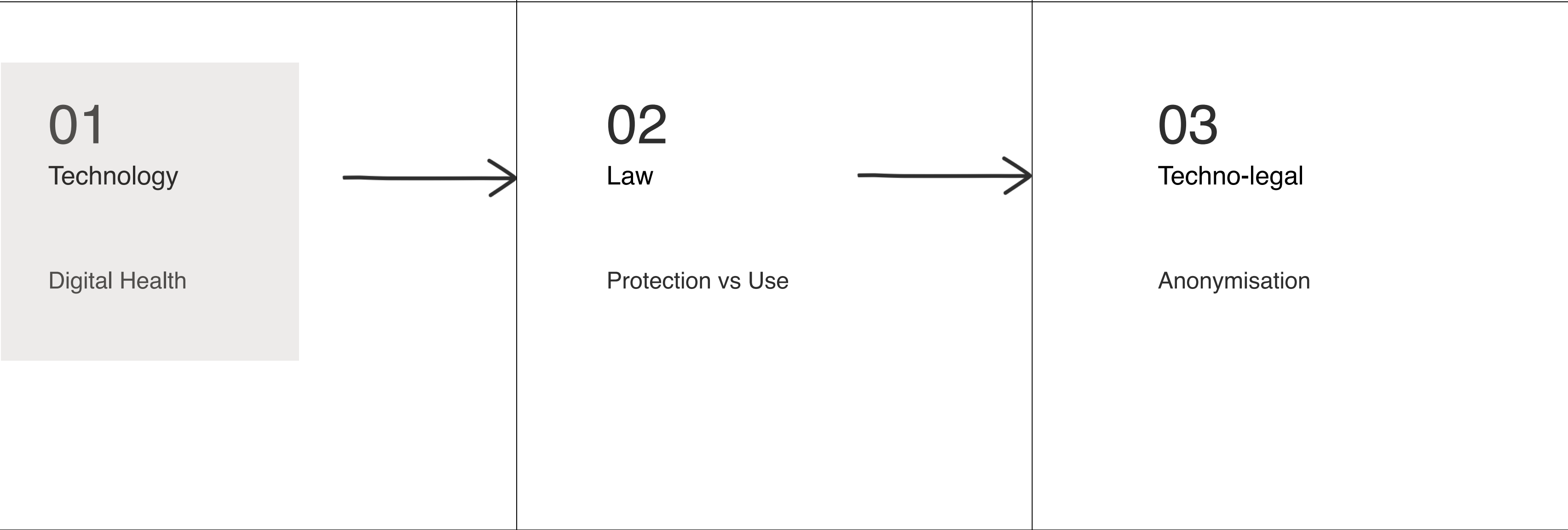
Descriptive	To figure out the legal approaches of health data governance in the EU and China
Normative	To investigate possible updates and make recommendations.
Comparative	To conduct a comparative study between the legal models of health data governance in the EU and China and investigate the similarities, differences, pros and cons of the models.



Objectives

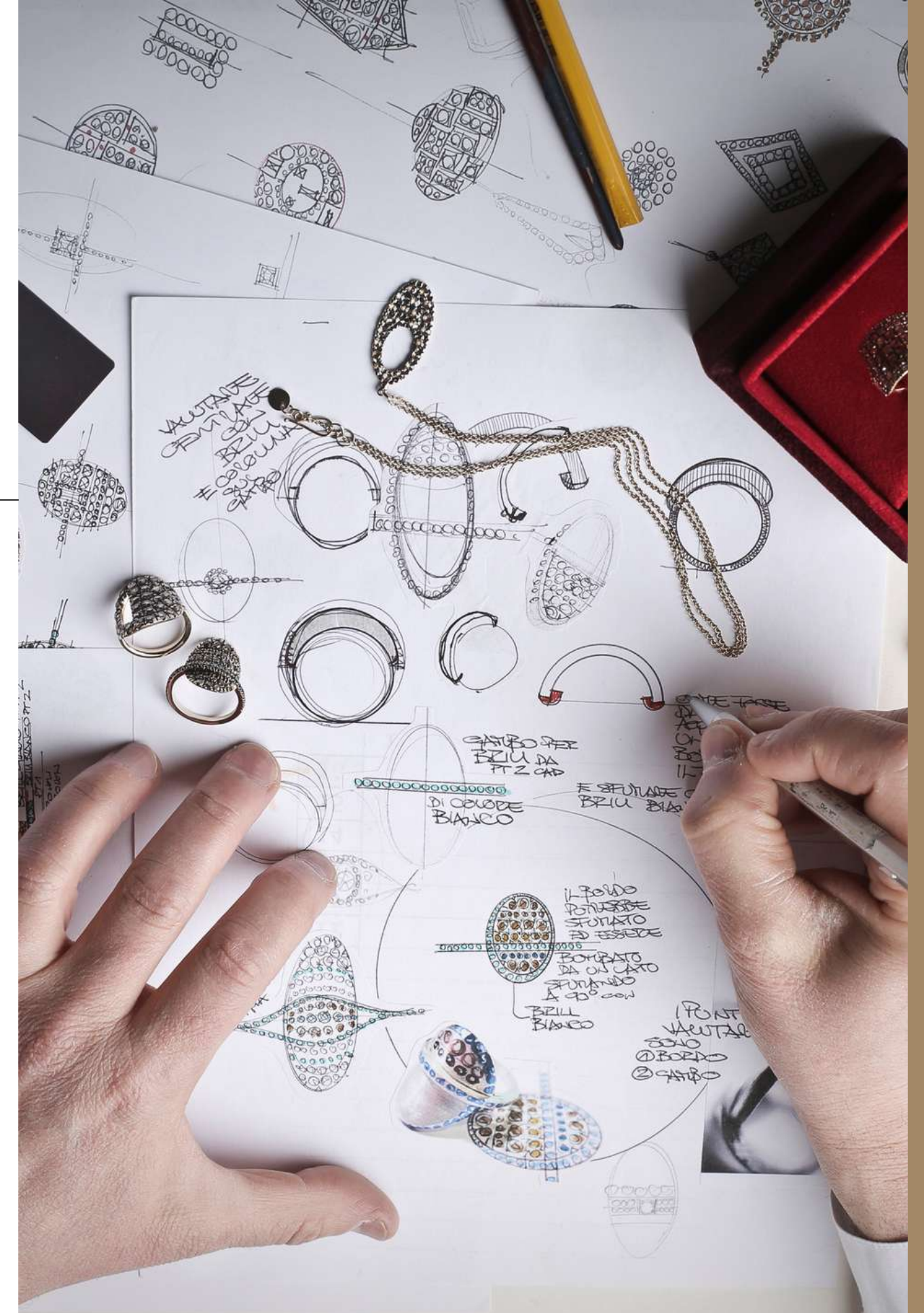


Research Design



Digital Health

- 01 For healthcare providers
- 02 For patients, caregivers, and the public
- 03 For health researchers
- 04 For health system managers



Health Data Privacy



Source: <https://www.healthcareatdistance.com/media/1120/digital-supervision.pdf>

- Googlization of health and care
- The intrusion of IoT and big data
- A “death of privacy” in the extension of healthcare

Research Design



01
Technology

Digital Health



02
Law

Protection vs Use
Privacy vs Science

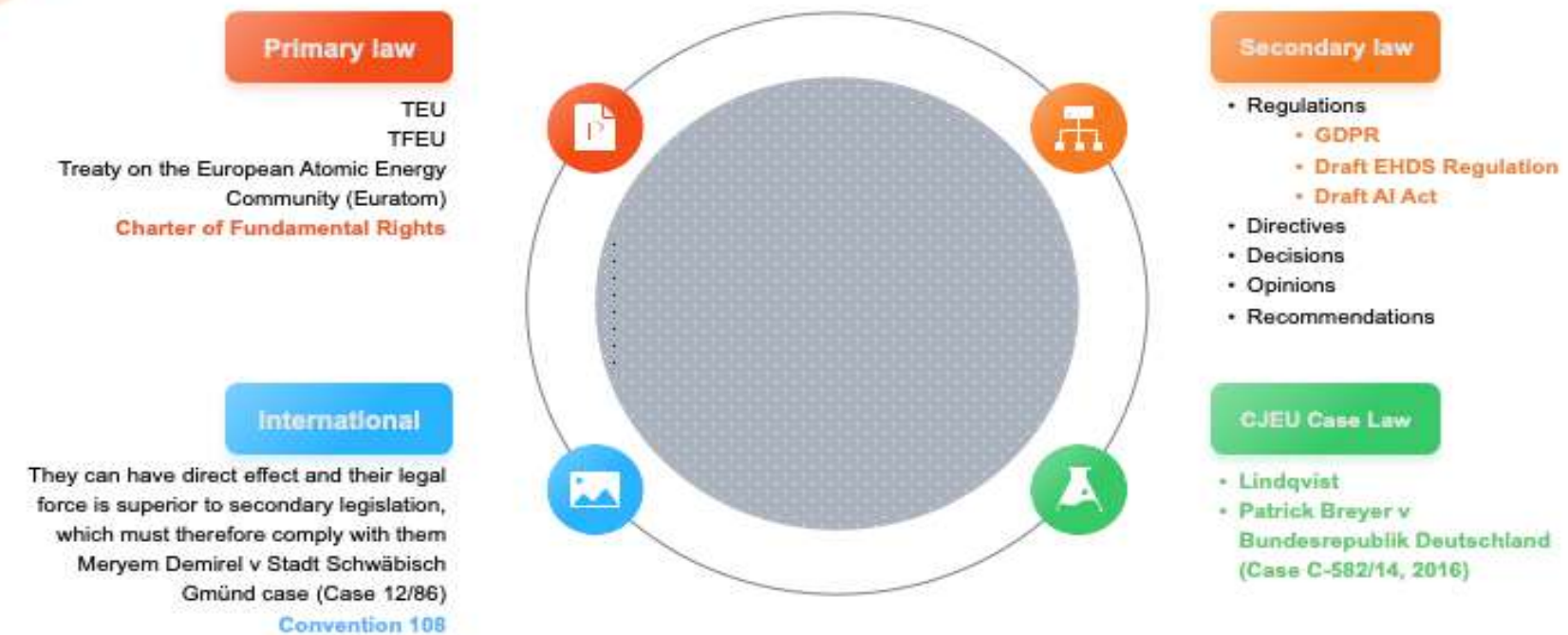


03
Techno-legal

Anonymisation



Legislative Paths



Legislative Paths

China’s data protection legal landscape before 2021

1

PhD Project Recap

2

Progress Report

3


Dissemination

4


Next Steps

China’s data protection legal landscape before 2021

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

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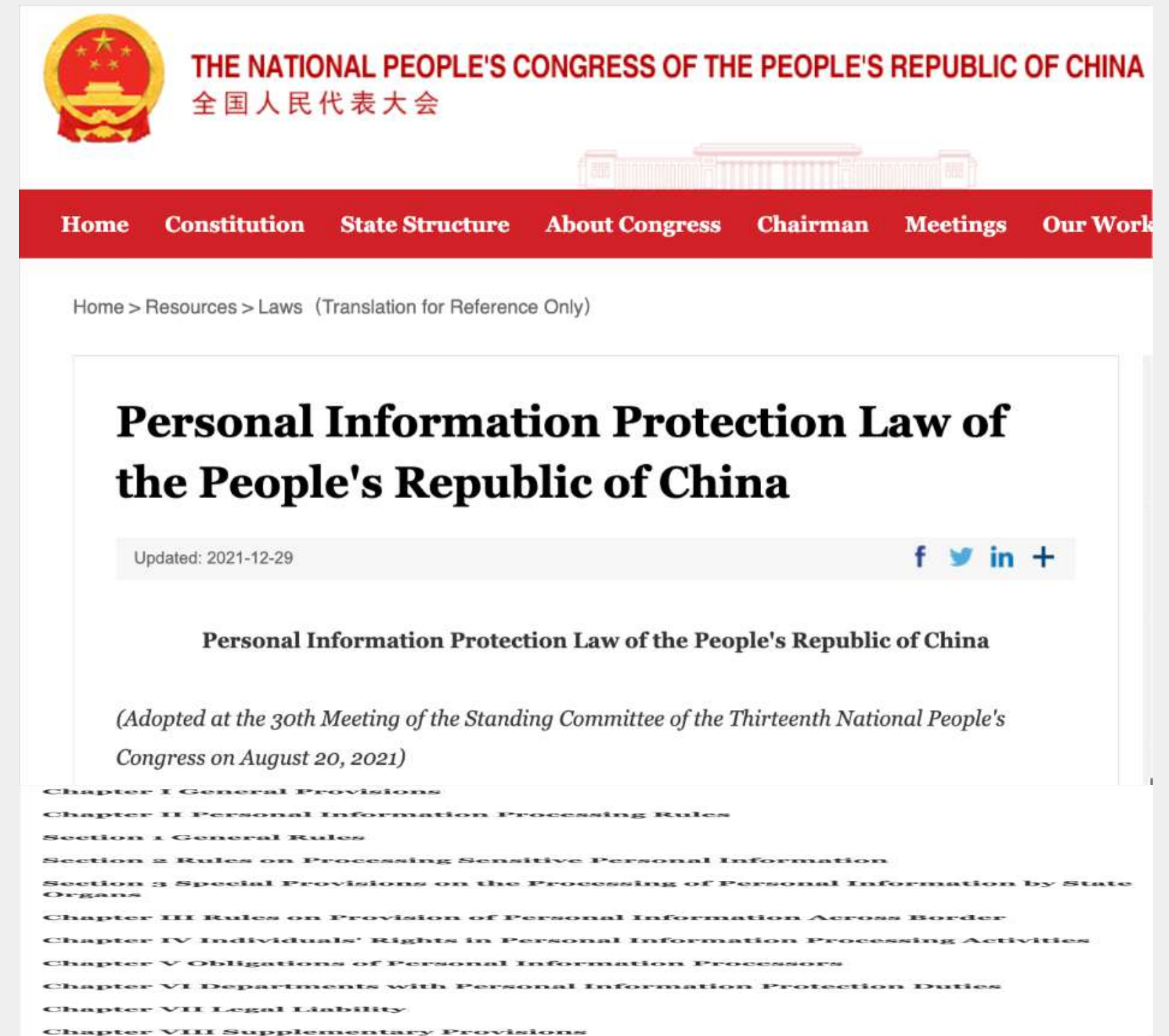
Zhicheng He, Stockholm University, 30 November 2023





Legislative Paths

- 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.



The screenshot shows the official website of the National People's Congress of the People's Republic of China. The header features the national emblem and the text "THE NATIONAL PEOPLE'S CONGRESS OF THE PEOPLE'S REPUBLIC OF CHINA" and "全国人民代表大会". A red navigation bar contains links: Home, Constitution, State Structure, About Congress, Chairman, Meetings, and Our Work. Below the navigation bar, a breadcrumb trail reads "Home > Resources > Laws (Translation for Reference Only)". The main content area displays the title "Personal Information Protection Law of the People's Republic of China" in bold black text. Below the title, it says "Updated: 2021-12-29" and includes social media icons for Facebook, Twitter, LinkedIn, and a plus sign. The law's title is repeated in a smaller font, followed by its adoption details: "(Adopted at the 30th Meeting of the Standing Committee of the Thirteenth National People's Congress on August 20, 2021)". At the bottom, a table of contents lists chapters from I to VIII, including General Provisions, Processing Rules, Cross-Border Provision, Individual Rights, Processors' Obligations, Protection Duties, Legal Liability, and Supplementary Provisions.



Utilization Mechanism

- 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).

The Use Mechanism of Health Data under GDPR

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.

Utilization Mechanism

- ‘This data, accessed under strong safeguards for security and privacy, will also be a treasure trove for scientists, researchers, innovators and policy-makers working on the next life-saving treatment.’

— Commissioner for Health and Food Safety
Stella Kyriakides

The new Use Mechanism for Health Data under EU law



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.

Utilization Mechanism

Health Data Protection Model

Health data as sensitive data.

Health data as a category of sensitive information.

Strict requirements.

Separate consent and limited legal basis.



- Sensitive personal information refers to personal information that, if leaked or used illegally, may easily **cause harm to the dignity** of natural persons, or serious damage to the safety of individuals and properties, including information relating to biometric identification, religious beliefs, specific identities, **healthcare**, financial



- Processors of personal information shall only process sensitive personal information if there is a specific purpose and a sufficient necessity, and when stringent protective measures are in place.
- Separate consent shall be obtained from individuals when processing sensitive personal information, unless otherwise specified by other laws and regulations.

Research Design



01
Technology

Digital Health



02
Law

Protection vs Use
Privacy vs Science

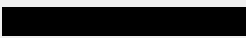


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Anonymisation



Privacy- enhancing Technologies

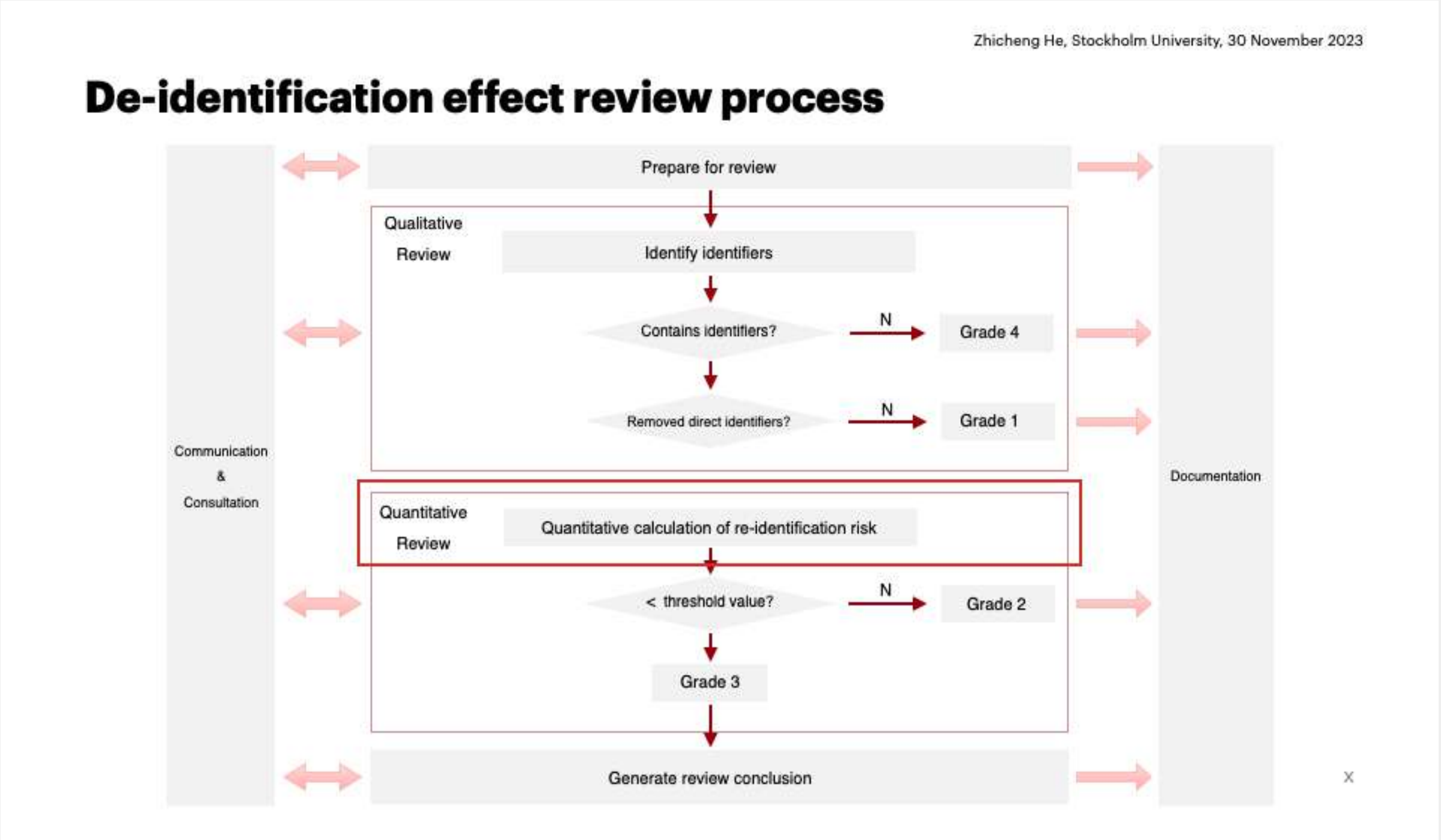


Overview of PETs in Chinese law



Privacy- enhancing Technologies

De-identification effect review process



Thought Experiment

01 Intervention methods

02 Blind vision methods

03 Secure processing Methods

04 Data hiding methods

05 Obfuscation methods

(Siddharth Ravi, Pau Climent-Pérez, and
Francisco Florez-Revuelta. 2021)

Anonymisation

Pseudonymisation

Data Protection by Design



Research Design



01

Technology

Digital Health



02

Law

Protection vs Use



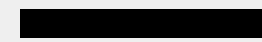
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Anonymisation



Thank You



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