

# Data and Values

## Japanese perspectives on Science, Technology and Innovation (STI) Policy

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# The 6<sup>th</sup> Basic Plan for Science, Technology and Innovation

- 1995: Basic Act on Science and Technology
- 1996-2001: The 1<sup>st</sup> Basic Plan for Science and Technology
- 2016-2021: The 5<sup>st</sup> Basic Plan for Science and Technology: “Society 5.0” proposed
- 2021: Basic Act on Science, Technology and Innovation
- 2021-2026: The 6<sup>st</sup> Basic Plan for Science, Technology and Innovation

# Collection and Analysis of Personal Genomic Data -> Personalized Medicine

- Bio Bank Japan  
<https://biobankjp.org/en/index.html>
- Tohoku Medical Megabank Organization (ToMMo)  
<https://www.megabank.tohoku.ac.jp/english/>
- Issues
  - Incidental findings
  - Informed consent
  - Personal information
  - Anonymization

# Data Sharing

- Contribution
  - Promotion of R&D
  - Creation of knowledge
  - Overcoming data defects
- What impedes it?
  - Scientific Competition
  - Trade secret
  - Mindset of researchers
  - Incomplete dataset

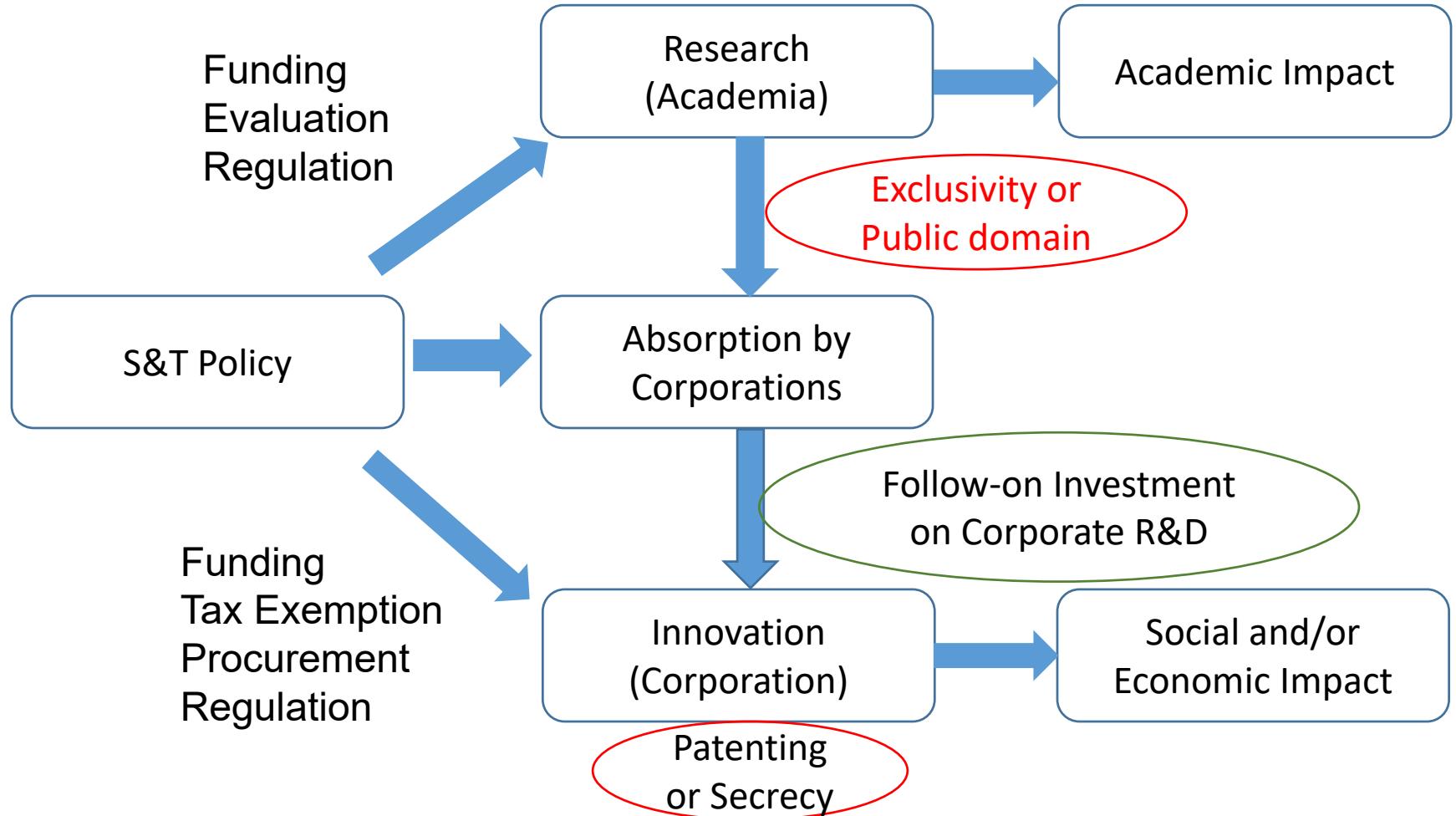


# AMED Data Sharing Policy

- AMED: Japan Agency for Medical Research and Development
- Classification of data
  - Limited-Shared, for scientists contributing to collection and improvement of the data.
  - Limited-Open, for scientists who applied for using the data and are approved.
  - Unlimited-Open, for everybody.
- Timing of sharing: 2 years after raw data generation or publication of research results, whichever sooner.
- Registration, sharing or opening of data depends on Data Management Plan (DMP).

<https://www.amed.go.jp/content/000060867.pdf>

# Toward Data-driven innovation: Exclusive usage or public domain?



# Data from Cooperative Research between EU and Japan: issues on GDPR

- Japanese national laws for protection of personal information were divided into three,
  - the Act on the Protection of Personal Information (targeted at private companies and private universities),
  - the Act on the Protection of Personal Information Held by Administrative Organs (targeted at national administrative organs, including national research institutes),
  - the Act on the Protection of Personal Information Held by Incorporated Administrative Agencies, etc. (targeted at national university corporations and national research and development corporations).
- The adequacy decision regarding Japan under the GDPR was limited to the scope of the Act on the Protection of Personal Information. Therefore, national university corporations and national research and development corporations were excluded from this scope.
- Furthermore, while private universities were subject to the Act on the Protection of Personal Information, they were exempted of the obligations of personal-information-handling business operators specified in Chapter 4 of the Act, pursuant to Article 76 of the Act, when personal data were handled for the purpose of use for academic researches. Therefore, they were also excluded from the scope of adequacy decision under the GDPR.



# Amendment of the Act on the Protection of Personal Information, promulgated in May 19, 2021.

- The three laws have been integrated into the Act on the Protection of Personal Information as one law, and the supervision and execution of personal information protection has been centralized to the Personal Information Protection Commission.
- Therefore, after enforcement of the amended law, the Commission is responsible for protecting personal information at national university corporations and national research and development corporations.
- Refinement of exemption of academic research will make academic research included within the scope of adequacy decision for Japan under Article 45 of the GDPR, thereby facilitating the cross-border transfer of personal data.