Ethical Challenges on Healthcare Big-Data

in Republic of Korea

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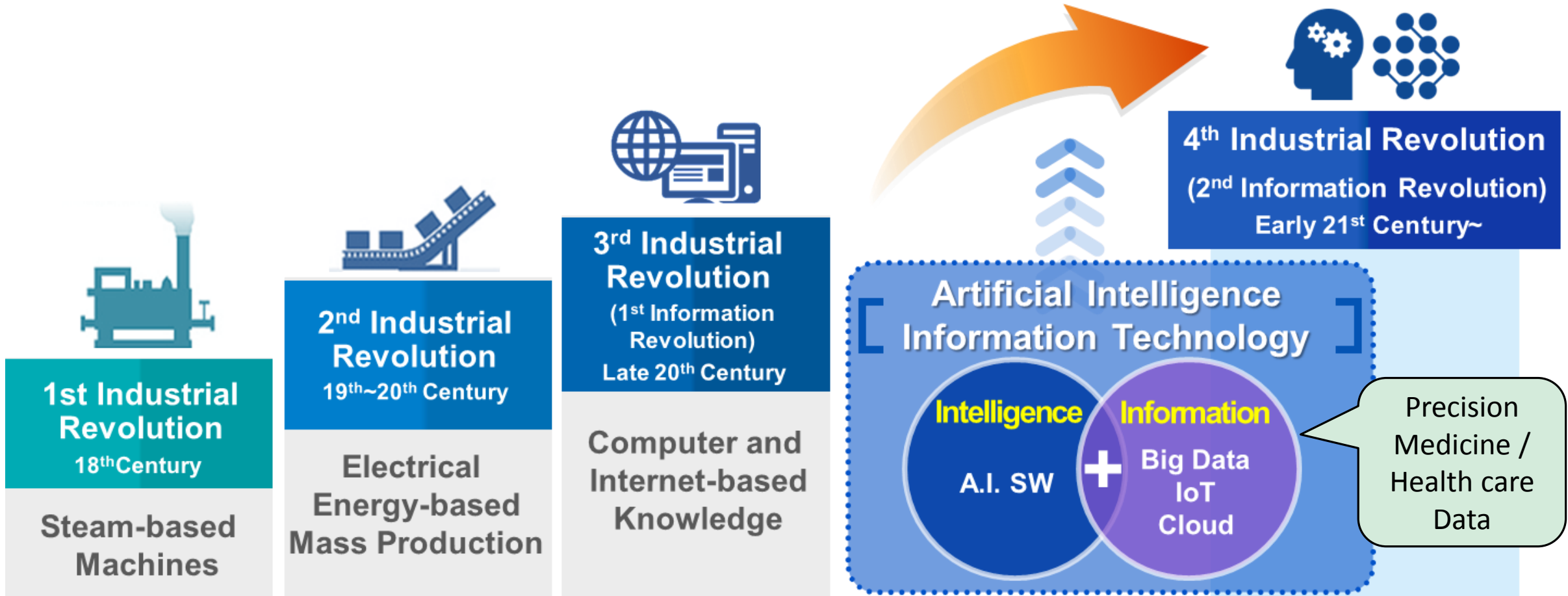
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Introduction

❖ Characteristics of South Korea

- Low birth rate

- High life expectancy

- Decline productive population

- Low employment rate

- Gap between rich and poor

- National health insurance program under the National Health Insurance Act

- Increase healthy-life years and life expectancy

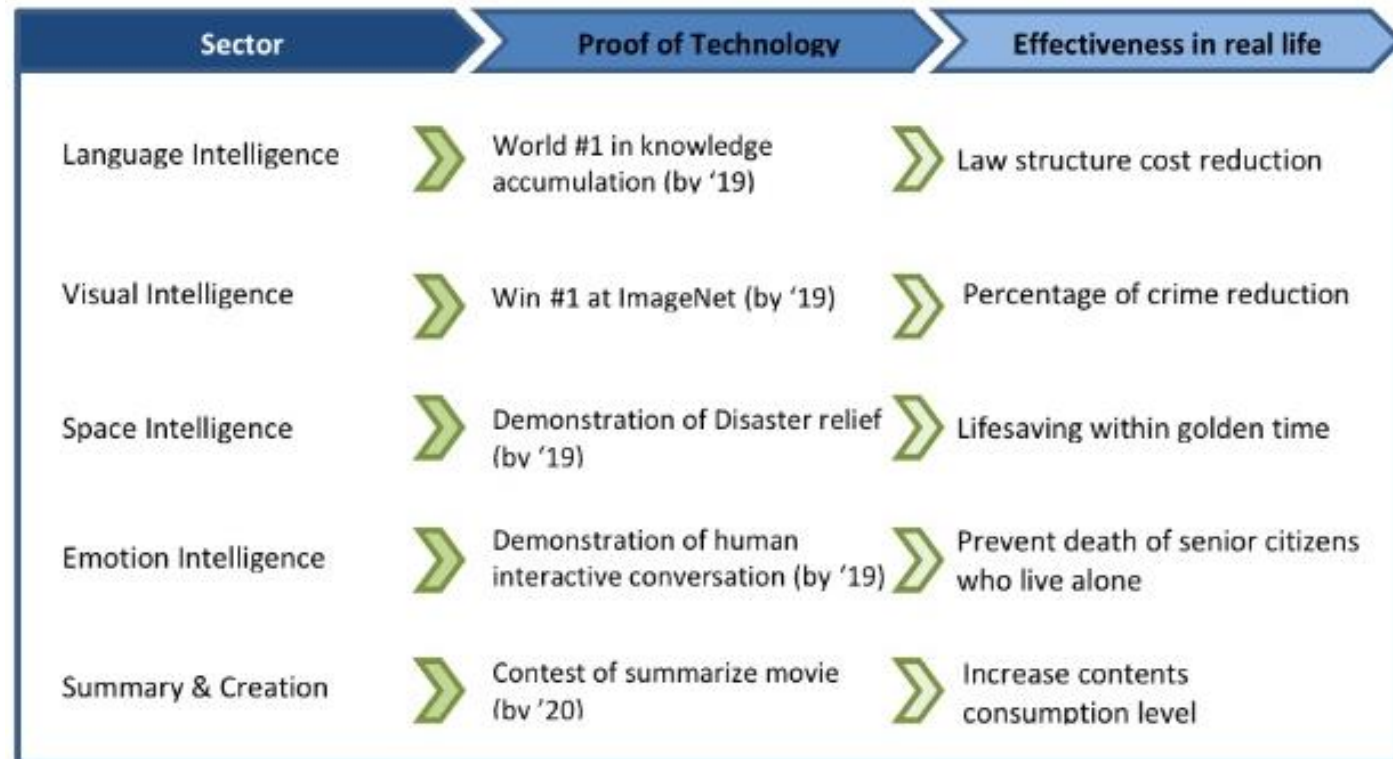# **Precision Medicine and AI Policies in Korea**

Precision Medicine and AI Policies in Korea

1st Industrial Revolution
18th Century
Steam-based Machines

2nd Industrial Revolution
19th~20th Century
Electrical Energy-based Mass Production

3rd Industrial Revolution
(1st Information Revolution)
Late 20th Century
Computer and Internet-based Knowledge

4th Industrial Revolution
(2nd Information Revolution)
Early 21st Century~

Artificial Intelligence Information Technology

Intelligence
A.I. SW

+

Information
Big Data
IoT
Cloud

Precision Medicine / Health care Data

Artificial Intelligence (AI) Policy in Korea (1)

❖ Ministry of Science, ICT and Future Planning (MSIP): Control tower to foster the AI projects and funding plans

▪ Initiated a national project '**Artificial Intelligence Information Industry Development Strategy**' in May 2017

Sector	Proof of Technology	Effectiveness in real life
Language Intelligence	World #1 in knowledge accumulation (by '19)	Law structure cost reduction
Visual Intelligence	Win #1 at ImageNet (by '19)	Percentage of crime reduction
Space Intelligence	Demonstration of Disaster relief (by '19)	Lifesaving within golden time
Emotion Intelligence	Demonstration of human interactive conversation (by '19)	Prevent death of senior citizens who live alone
Summary & Creation	Contest of summarize movie (by '20)	Increase contents consumption level

Precision Medicine Policy in Korea (1)

❖ Ministry of Health and Welfare (MOHW)

- Singed a cooperative agreement in Precision Medicine Research Collaboration with U.S. NIH in Washington in October 2015

Precision Medicine Policy in Korea (2)

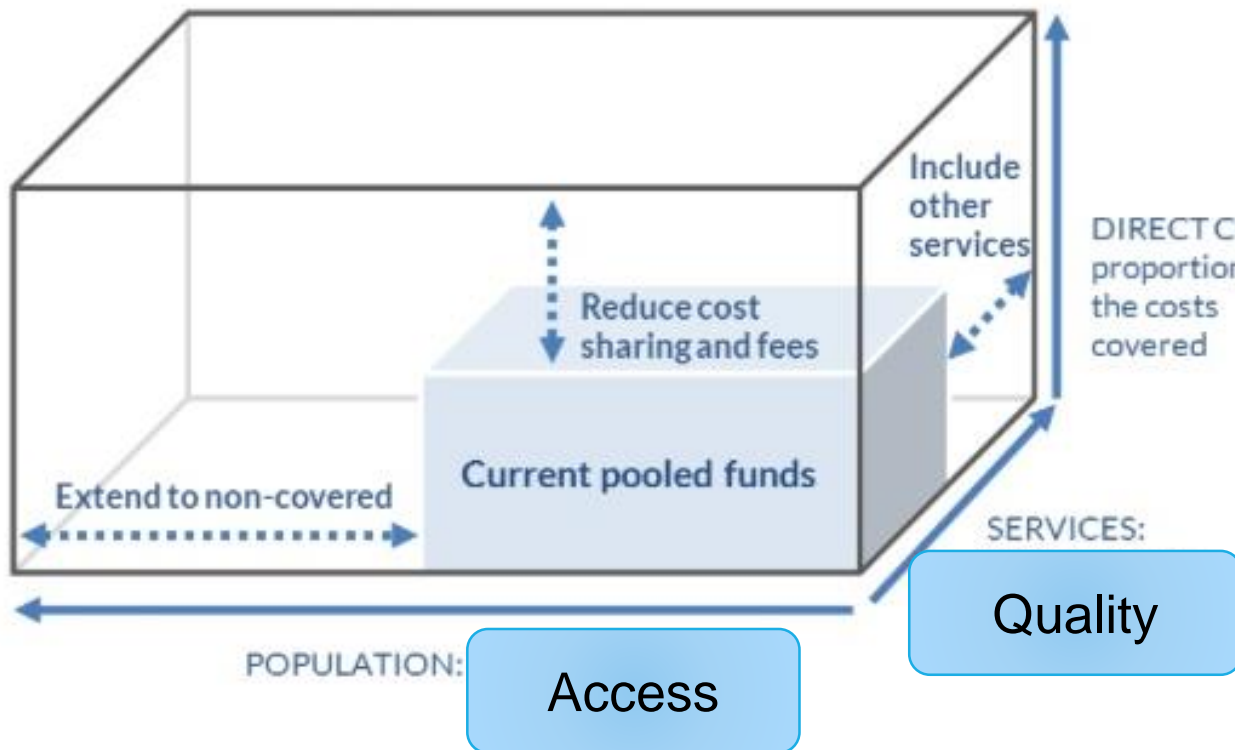|	ROK	U.S.
Project	Genome ・ Health ICT Integration base Development of Precision medicine technology	Precision Medicine Initiative(PMI) The *All of Us* Research Program
Aim	Customized medical care for individual citizens for upgrading of public health services	Development of Individualized Care
Scale	100,000 or more	1 million or more
Related Law	Special Act on Precision Medicine (draft/2017) Act on Promoting Personalized Medicine(pending in NA/2013)	21st Century Cures Act
Budget	<tentative> 5,063.4 billion won (around $ 440,000)	$ 1.455 billion
Duration	5 years (2017~2021)	10 years (2017~2026)
Research Content	1) Establishment of Korean Precision Medicine Cohort 2) Development of Cancer Diagnosis and Treatment method 3) Development of Precision Medicine Service Infra 4) Development of Precision Medicine Service	<u>Not a study on any one disease, but a data resource</u> to inform many research studies on a wide variety of health conditions

Ethical Challenges

1. Considerations from the Perspective of Universal Health Coverage
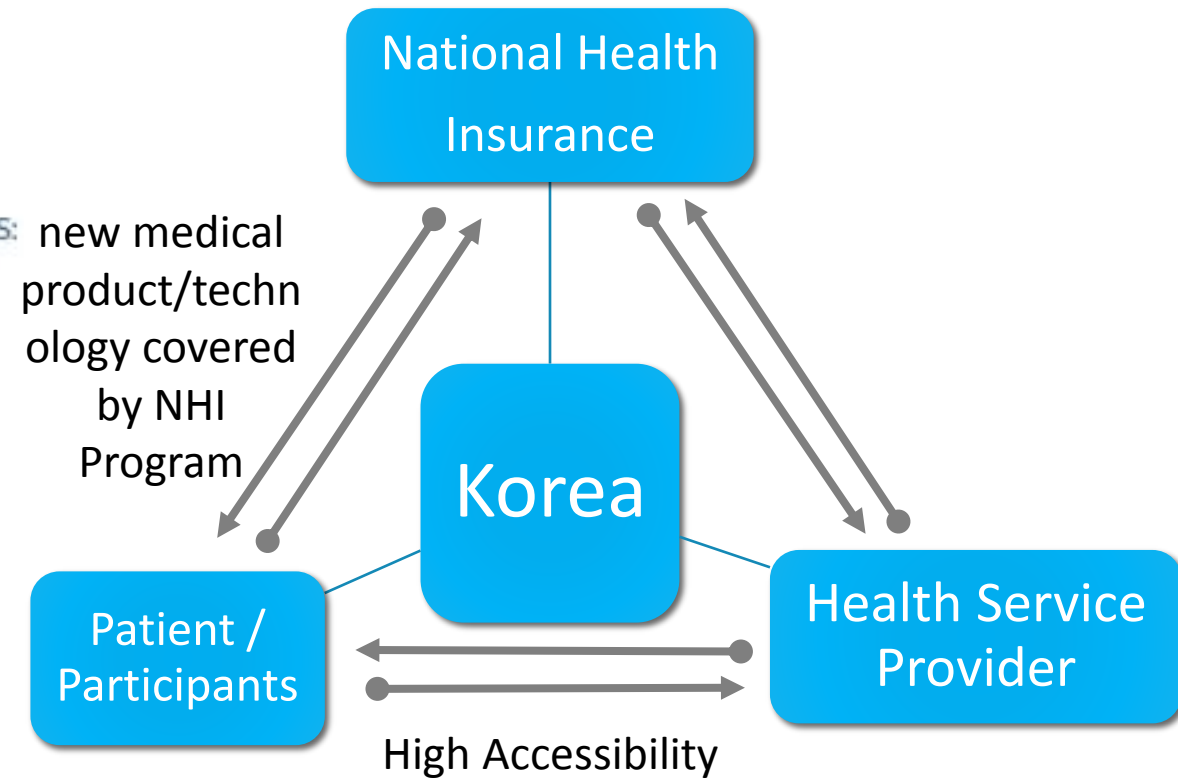

- The National Health Insurance(NHI) program under the National Health Insurance Act

  - If the benefit of individual who provides his/her health related information to the precision medicine cohort research is the return of health data, it would not to be considered the balanced rewarding from risk and benefit assessment.

- A different approach is needed to realize precision medicine based on co-payment system in Korea

  - i.e. the new health technology developed by integration of AI and PM succeeded in non-payment sector, it could be transferred to the payment item, which means it is covered by NHI program.

  - This mechanism could be corresponded to the principle of social welfare which prefer to mix the governmental intervention and market-driven economy in our society.

1. Considerations from the Perspective of Universal Health Coverage

Include other services

Reduce cost sharing and fees

Current pooled funds

DIRECT COSTS: proportion of the costs covered

Extend to non-covered

SERVICES:

Quality

POPULATION:

Access

Three dimensions to consider when moving toward universal coverage.

WHO's UHC "cube"

National Health Insurance

new medical product/techn ology covered by NHI Program

Korea

Patient / Participants

Health Service Provider

High Accessibility

2. Applicability of an algorithm-applied services

- Can the new medical technology/product relating to AI and PM be included to payment items covered by NHI from the non-payment items?

- How can we compensate for the personal damage that was incurred from the errors or the misinterpretation of the data? (i.e. error in risk prediction for type 2 diabetes)

- Exaggerating perspective? (i.e. Dr. Watson)

3. Issues related to Privacy (1)

\<Public Sector\>

	Public Data		Governing Body
Public Health Data	Genomics Data	Biospecimen from KBN	Korea National Biobank
		Whole genome sequencing data(Clinical Omics Data Archive, CODA)	National Institute of Health
		Korea Central Cancer Registry(KCCR)	National Cancer Center
	Claim/ Administrative Data	Medical claim data, medical fee data	Health Insurance Review & Assessment Service
		National health examination data, long-term care insurance data	National Health Insurance Service
		Financial aid data for cancer patients, national cancer examination data	National Cancer Center
	Survey Data	National health and nutrition examination survey data, disease surveillance data	Korea Centers for Disease Control & Prevention
		Data from Cancer Registry Program	National Cancer Center
		Data from Korea Medical Panels	Korea Institute for Health and Social Affairs
Other Public Data	Data from birth/death registry		Ministry of the Interior and Safety
	Population census data, household income and expenditure survey data, etc.		Statistics Korea
	Satellite and ground based data, environmental data		Korea Meteorological Administration/ Ministry of Environment
	Geospatial information		Ministry of Land, Infrastructure & Transportation, Statistics Korea

\<Private Sector\>

	Private Data	Managing Body
Clinical Data	Electric Medical Records(EMR), imaging data(PACS)	Hospitals, National Cancer Center
Streaming data	Home monitoring	Consumers, private company
	Remote medical data	Patients, hospitals
	Data from mobile device	Consumers, private company
Web/ Social Networking data	Data from search engine/web data	Consumers, private company
	Mobile communication data	Private company
	SNS data	Private company

3. Issues related to Privacy (2)

- ❖ Re-identifiability

  - ▪ Current concept of privacy right should be abandoned, because it has been proved that even the anonymized personal data can be identifiable when being combined with other data

  - ▪ Do we need to collect all those data necessary for achieving the efficient PM? (i.e. personal medical examination information of NHI and health care facility billing data of the Health Insurance Review and Assessment Service, HIRA)

  - ▪ There isn't enough social consensus/awareness on whether to proceed combining/collecting the big data of government agencies

3. Issues related to Privacy (3)

❖ Changing perceptions of the public about privacy

▪ Low social awareness to provide their own information to receive cyber incentive from some corporates

through Social Network Service(SNS)

▪ Emerging issues to disclose and share other personal information through the group SNS talk (i.e.

Kakao Talk)

❖ Insufficient original data security technology

4. Issues related to Industrialization

❖ Big data producing companies in Korea

▪ Mobile Carriers: SK, LG, KT

▪ Mobile Phones and wearable devices: Samsung, LG, etc.

▪ Portal website: Naver, Daum, etc.

❖ Data monetization from private sectors

▪ What kind of data do those companies have now?

▪ It would be difficult to exchange and distribute their own collected data to other companies for Korean conglomerates (Chaebol).

5. Issues related to Democracy

❖ Policy making process

▪ Legacy of former government as being characterized into science and technology as one of the most important driving forces to develop the nation's economy

❖ Possible danger to the public

▪ Possibility to use those technologies to the population surveillance for political purpose

Implications

❖ Through the AI and PM strategies, it will reveal that the importance of data is varied from disease to disease.

  ▪ Such data can affect individuals and society in many ways, including health, disease, employment, insurance, personal credit rating, education, and even career path, etc.

❖ It would be needed to discuss on a further framework for the healthcare data non-discrimination to prevent social discrimination and protect individual autonomy while we are utilizing the data as a good reason.

Thank you for your attention!