Ethical Challenges on Healthcare Big-Data
in Republic of Korea

Sumin Kim
(Department of Medical Law and Ethics, Division of Medical Humanities, College of Medicine, Yonsei University, ROK)
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- Precision Medicine and AI Policies in Korea
- Ethical Challenges
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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
Precision Medicine Policy in Korea (1)

- Ministry of Health and Welfare (MOHW)
  - Signed a cooperative agreement in Precision Medicine Research Collaboration with U.S. NIH in Washington in October 2015
### Precision Medicine Policy in Korea (2)

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

Three dimensions to consider when moving toward universal coverage.

WHO's UHC “cube”
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)

<table>
<thead>
<tr>
<th><strong>Public Sector</strong></th>
<th><strong>Governing Body</strong></th>
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<tbody>
<tr>
<td><strong>Public Data</strong></td>
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<tr>
<td>Genomics Data</td>
<td>Biospecimen from KBN</td>
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<td>Whole genome sequencing data (Clinical Omics Data Archive, CODA)</td>
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<td>Korea Central Cancer Registry (KCCR)</td>
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<tr>
<td><strong>Claim/ Administrative Data</strong></td>
<td>Medical claim data, medical fee data</td>
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<tr>
<td></td>
<td>National health examination data, long-term care insurance data</td>
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<td>Financial aid data for cancer patients, national cancer examination data</td>
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<tr>
<td><strong>Survey Data</strong></td>
<td>National health and nutrition examination survey data, disease surveillance data</td>
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<td>Data from Cancer Registry Program</td>
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<td>Data from Korea Medical Panels</td>
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<tr>
<td><strong>Other Public Data</strong></td>
<td>Data from birth/death registry</td>
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<td>Population census data, household income and expenditure survey data, etc.</td>
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<td>Satellite and ground based data, environmental data</td>
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<tr>
<th><strong>Private Sector</strong></th>
<th><strong>Managing Body</strong></th>
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<tr>
<td><strong>Private Data</strong></td>
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<tr>
<td>Clinical Data</td>
<td>Electric Medical Records (EMR), Imaging data (PACS)</td>
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<tr>
<td>Streaming data</td>
<td>Home monitoring</td>
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<td>Remote medical data</td>
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<td>Data from mobile device</td>
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<td>Web/ Social Networking data</td>
<td>Data from search engine/web data</td>
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<td>Mobile communication data</td>
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<td>SNS data</td>
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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!