Key Agendas for Healthcare Data Use in 2040: The Future of Health Data in the Fourth Industrial Revolution

WORLD ECONOMIC FORUM

Introduction: How can we achieve successful healthcare data use in a super-ageing society by 2040?

With more than four in 10 people over the age of 60, Japan is a "super ageing society". Ageing creates many challenges, including putting the nation's social security system in crisis. To tackle the issue, both in Japan and globally, and to realize a sustainable society suitable for older people will require more healthcare initiatives that use Fourth Industrial Revolution technologies[1] such as artificial intelligence (AI), robotics, and internet of things.

The COVID-19 pandemic has served as a reminder of the importance of data in healthcare. Controlling acute diseases requires leveraging data and developing "contactless" services on a global level. Furthermore, concepts such as Web3[2] and the metaverse[3] can also be important elements in healthcare.

Despite the fact that diverse cultures and values sometimes clash, countries should be able to build consensus in healthcare because the objective is fundamental – to protect life. However, successful healthcare data use examples are rare. In Finland, for example, promoting e-health and secondary data use are regarded as best practice, but the sensitive nature of health data makes it difficult to replicate such initiatives. The pandemic has demonstrated both the importance and the difficulties of utilizing data.

In this paper, we summarize the challenges for healthcare data use by the public and private sectors, based on a multistakeholder approach. Japanese government agencies, companies and experts also discussed the future of healthcare between 2030-2050.[4] Our study summarizes the key visions and makes proposals on what should be addressed to achieve them.

Values and social vision

The value of health is important to everyone and in Japan, where the population is ageing, the goal is to extend healthy life expectancy by three years to over 75 by 2040.[5] The focus is not only on health but also on the well-being of those who are ill – an area that is receiving growing attention.

Individual behaviour does not always exclusively prioritize health and it is important to identify citizens' values and insecurities and to incentivize people to act in ways that are beneficial both for the individual and society.

The same applies to data utilization in terms of decision making. The major challenge is how to coordinate diverse values.[6] Hiroaki Miyata, Professor and Chair, Department of Health Policy Management, Faculty of Medicine, Keio University, who researches data-based well-being, states that the aim should be to move from "maximum happiness for the greatest number" to "maximum happiness for the greatest diversity".[7] In other words, the aim should be to maximize diverse well-being in line with each individual's values, while also aiming to maximize the well-being of society as a whole. In doing so, various freedoms of action in line with diverse well-being should be guaranteed, and there is room for a certain degree of recognition of the right to "health-related folly".

Personal health records (PHRs) can be used not only to evaluate and represent the health of each individual but also as a tool for self-care that individuals can use to become more healthy.[8] The city of Kobe[9], which is publicly implementing a PHR project, explains to its citizens that "health is important to being the way you want to be and doing what you want to do". The idea is that happiness and well-being are personal and not uniform, but it is desirable to guarantee the freedom of each individual to express their values.

Such a view does not necessarily elevate health as the sole personal value but targets well-being in a broader and more diverse sense. In order to maximize individual well-being, the ideal system is based on the principle that each individual has sovereignty over their own data. But it also clarifies exceptional circumstances in which data can be used publicly (for social values) so that the individual can actively seek to improve their own well-being.

The World Economic Forum Centre for the Fourth Industrial Revolution Japan has proposed the concept of authorized public purpose access (APPA) regarding rules for using data for public purposes.[10]

FIGURE 1 The APPA Framework and Implementation Process

1st White Paper: Authorized Public Purpose Access (APPA) Conceptual Framework

2nd White Paper: Principles and Application Criteria for APPA Implementation

APPA Deployment Principles

APPA evaluation criteria

Realization of the ideal APPA

Individual rights

Inadequate

Adequate

Excessive

Interests of data holders

Public interest
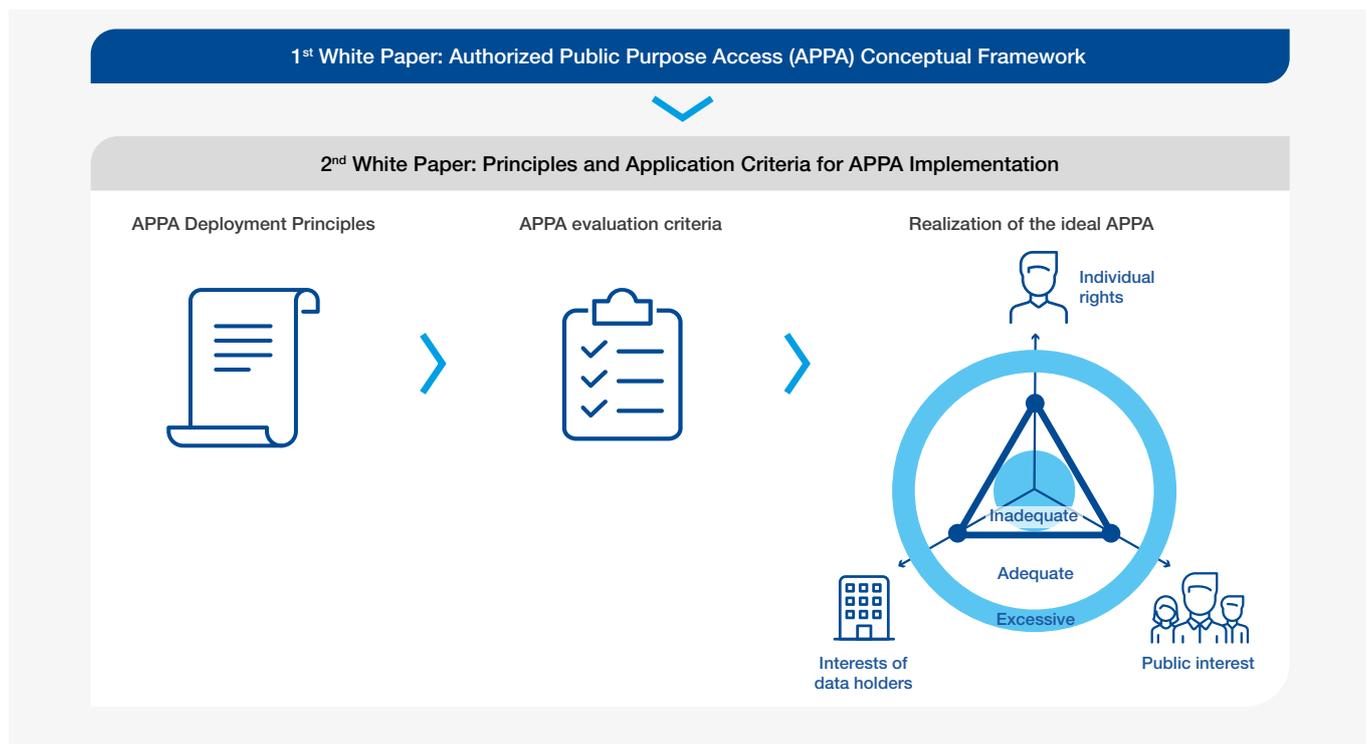
The key idea in implementing APPA is that the realization of shared social values (e.g., improved public health) should be achieved while minimizing the risk of constraints on individual rights (diverse well-being). The range of communities of shared value in APPA can be large or small. Indicators of diverse well-being could be created and used not only globally, as is the case in the OECD[11], but also include locally specific values, or values specific to particular communities within cyberspace.In other words, depending on the size and characteristics of each community, rules will be formed not only by law but also by architecture. This will also be a determining factor in the form of social design.

In terms of the future of healthcare, there are two directions. One is to promote universal health coverage (UHC)[12], which uses technology to make healthcare available to all people, and the other is to promote individual optimization (precision healthcare). At the same time, there is a need to reduce costs as much as possible and make the social security system sustainable.

In Japan, the Health and Medical Care 2035 document[13] compiled by the Ministry of Health, Labour and Welfare in 2016, states that towards 2035 the direction should shift from the conventional top-down enhancement of UHC to autonomous and proactive rule-making by the people involved in healthcare, and the creation of a system centred on value for the patient.

In the same year, the Ministry of Health, Labour and Welfare's Round-table Conference on the Promotion of ICT Application in the Health and Medical Care Sector[14] continued to discuss the direction of realizing personalized well-being through the use of data centred on the individual.

The social vision presented at various meetings such as the Health and Medical Care 2035[15], Future Innovation WG[16] and Moonshot Goals[17] is generally as follows:

– People can make decisions with conviction, based on predictions of the future health of each individual

– Mechanisms that lead to good health are embedded in every conduit of daily life

– Regardless of the diversity in care-giving skills, everyone can provide quality care without anxiety

– Everyone, regardless of where they live, can access and play a role in providing adequate and necessary care, even in the event of a disaster or emergency

– Even when faced with declining mental and physical functions or changes in life stages, people are empowered by technology and social infrastructure and are able to bring out their individual "can do" without becoming infirm

The use of data is key to achieving these goals. The amount of available healthcare data is increasing in many countries. In the European Union, for example, primary and secondary use of data is being promoted through the European Health Data Space[18]. In Japan, there is an increasing amount of public data available through the My Number infrastructure[19], as well as high expectations regarding the use of data held by the private sector.

With regard to data utilization, there is a need to construct highly reliable data, minimize risks to privacy and other areas and address cybersecurity. Standardization has always been an issue in the construction of highly reliable data. In healthcare, standards for electronic medical records, etc., have been set out in ISO, HL7[20] and elsewhere. but when dealing with vaccination information as a countermeasure against COVID-19, for example, standards differed from country to country and coordination was extremely difficult. The application of Web3-related technologies is also expected to help ensure the reliability of such data. For example, the SMART Health Card[21], which was also used to present vaccination history, could serve as a model for sharing decentralized healthcare data.
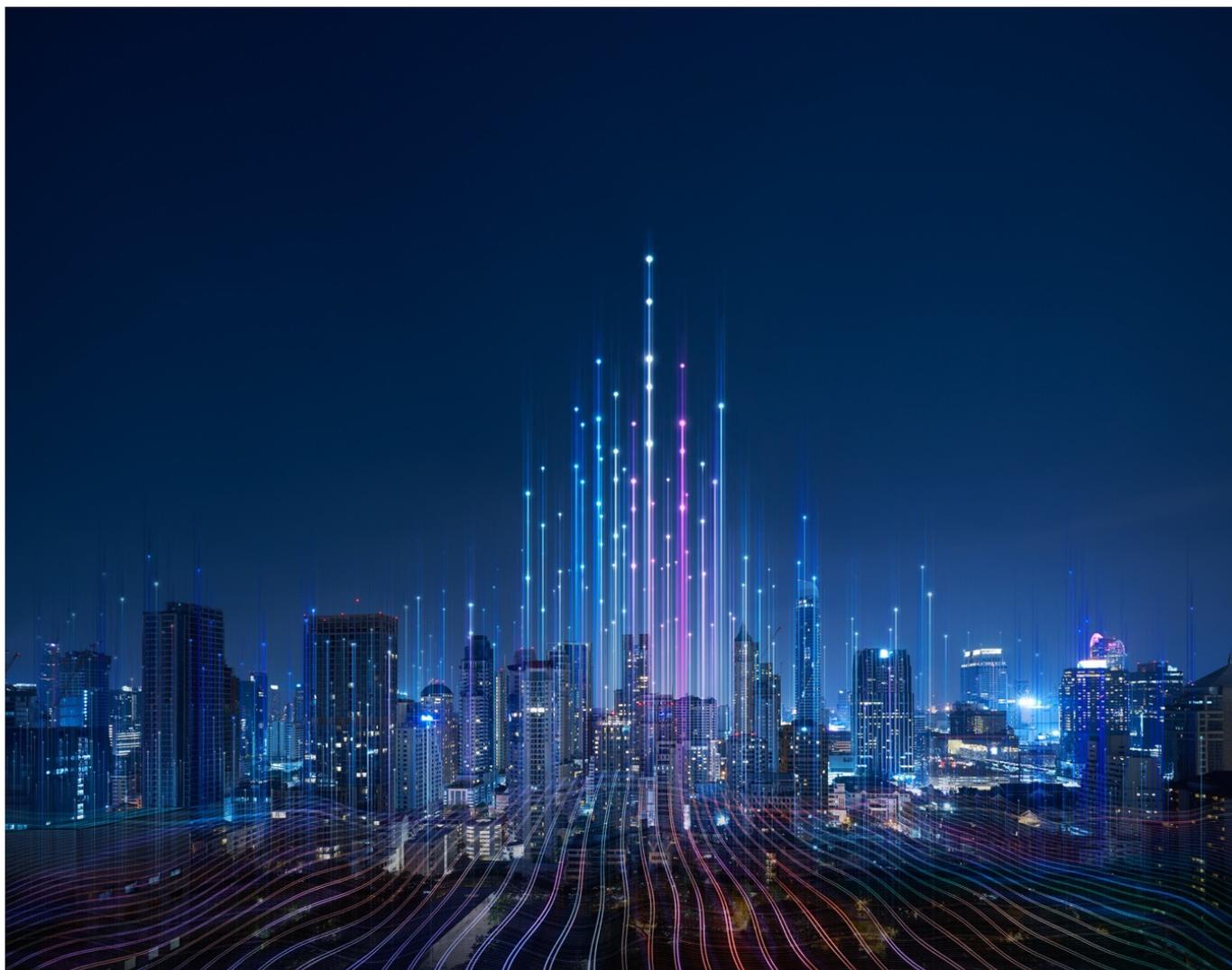
Proposed goals and action plans

In response to the future predictions above, we facilitated a Japanese multistakeholder group to map the challenges and create a comprehensive roadmap for future healthcare data use.

Based on this, the following four goals and action plans are proposed:

1. Provision of optimal services tailored to individual needs (primary use)
2. Improved efficiency and quality of work through data/information sharing among professionals and stakeholders (semi-primary use; use that falls somewhere between primary and secondary)
3. Formation of sustainable public-private models (especially secondary use)
4. Human resource development, social consensus and rule formation to support the above

FIGURE 2 **Four key agendas to promote healthcare data use**

1		Provision of optimal services tailored to individual needs (primary use)
2		Improved efficiency and quality of work through data/information sharing among professionals and stakeholders (semi-primary use)
3		Formation of sustainable public-private models (especially secondary use)
4		Human resource development, social consensus and rule formation to support the above

1. Provision of optimal services tailored to individual needs (primary use)

The first fundamental step is to enhance the use of data for its original purpose; i.e., primary use for the provision of medical and nursing care services.

First, efforts need to be made to increase the amount of usable data. It is necessary to standardize in line with the particular kind of value realization that is the goal of a given initiative. In addition, as services expand to include cyber (metaverse) space, it is necessary to ensure that services are available to everyone, including elderly people experiencing cognitive decline. With regard to these issues, examples have already emerged in the public and private sectors and efforts need to be made to organize such examples for interoperability and expansion.

– Appropriate identification of the needs and well-being of diverse individuals (data collection and evaluation for this purpose)

– AI/robot utilization for optimal service provision

– Online/metaverse utilization (including 5G and 6G) for access to services anywhere

– Universal design to enable anyone to receive services (universal design)

2. Improved efficiency and quality of work through data/information sharing among professionals and stakeholders (semi-primary use)

Healthcare data can be used not only for the benefit of the individual but also to improve the quality and efficiency of medical and nursing care generally, with indirect benefits to the individual. For example, sharing information on rare diseases is highly necessary medically and efforts are being made in this area but it is expected that various types of data will be further used by professionals and other related parties. Efforts have already begun to implement blockchain or Web3-related technologies and it is necessary to build a system that enables the sharing of such use cases as well as the smooth sharing of information across countries.

– Creating interoperable data and applications

– Use of Web3-related technologies to ensure data reliability

– AI to support data interpretation

3. Formation of sustainable public-private models (especially for secondary use)

Several PHR projects have been pursued in the public and private sectors, but sustainability is often a major challenge. In many cases, such as in Nordic countries like Finland[22] and Estonia[23], the state has taken the lead in providing PHRs as part of e-health as a public service, and such models are feasible if public funds such as taxes are used. The design of models in the public and private sectors will also define the nature of public services themselves and especially how secondary use of data will be made, including the possibility of a cedentralized society as expected by Web3.

– Utilization model formation for the benefit of society (APPA)

– Sustainable business modelling (including secondary use of anonymized information)

4. Human resource development, social consensus and rule formation to support the above

Although there is likely to be little opposition to the primary use of healthcare data, social consensus may not always be reached as the data becomes semi-primary or secondary use. In addition, there may be a lack of human resources for data utilization even if utilization is agreed on. Furthermore, we need a long-term perspective to foster social consensus. In particular, it is necessary to keep in mind conflicts of values and work with the media to develop laws in individual countries and create global rules.

– Education and cooperation with the media for each stakeholder

– Creating space for social consensus building (including town meetings, etc.)

– International framework to ensure trust in international data distribution

– Incorporation into national and regional legal systems

Conclusion

Discussions about healthcare systems can be depressing, particularly when the topic concerns the problems related to the ageing of society. It is easy for healthy people to feel they are not affected. However, as nobody can escape ageing, the issue is a serious one for all individuals and all societies worldwide.

The authors hope that this paper can serve as a reference for stakeholders not only in Japan but also in other countries. Regarding social implementation, we expect more discussions with stakeholders around the world in the future.

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