

Toolkit for Personal Health Records and Data Use by Municipalities: Proposal for Healthcare Data Management through Public-Private Partnerships

BRIEFING PAPER

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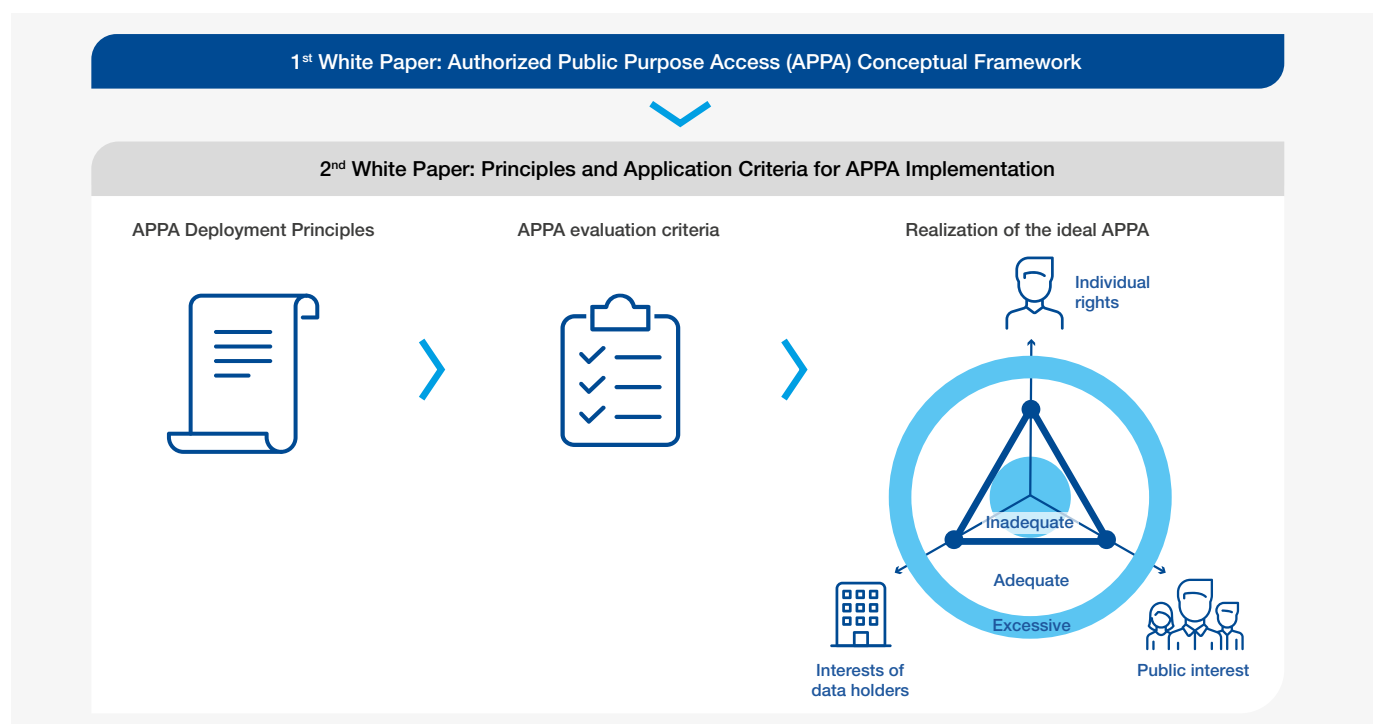
PHRs and healthcare data use in a super-ageing society

Japan is a famously ageing country. With nearly four people in 10 over the age of 60 – the highest proportion in the world – it has been called a “super-ageing society”. Ageing has put the system under pressure and created demand for innovative solutions. Among the ideas receiving growing interest is one to promote more widespread and effective use of healthcare data, including the introduction of digital Personal Health Records (PHRs). Better data use, and PHRs in particular, could help address the consequences of ageing while also contributing to countermeasures against infectious diseases and natural disasters.

Using healthcare data in new and creative ways can be challenging due to the sensitive nature of such information. Successful examples exist, such as the promotion of e-health and the secondary use of data in Finland, but they are rare.

The World Economic Forum Japan Centre for the Fourth Industrial Revolution has been examining these issues and has proposed a model for health data use that strikes a balance between individual rights, the interests of data holders and the public interest¹.

FIGURE 1 The APPA Framework and Implementation Process



1. World Economic Forum White Paper, Resetting Data Governance: Authorized Public Purpose Access and Society Criteria for Implementation of APPA Principles, <https://www.weforum.org/whitepapers/resetting-data-governance-authorized-public-purpose-access-and-society-criteria-for-implementation-of-appa-principles>

One key to success, we have concluded, is the establishment of appropriate public-private partnerships that consider the highly public nature of healthcare service delivery while taking into account individual human rights such as privacy.

To elaborate this point and guide policy-makers and other implementation-focused stakeholders, we have created a toolkit for building appropriate partnerships between local governments and companies that are innovating in the PHR space. The toolkit has been produced with Japan in mind, but its principles and approach could, we hope, guide similar efforts elsewhere.

Configuration of the toolkit for PHR and data use by municipalities

This toolkit is designed to promote communication with citizens through PHRs and help to implement appropriate healthcare-related policies for the usage of public data such as receipts held by local governments.

The toolkit's aims are:

- To provide basic principles and checklists that municipalities can use to analyse their status, identify issues and resolve problems, which will promote the implementation of PHRs and the use of healthcare data by municipalities
- To be a reference for corporate governance, which will facilitate collaboration among municipalities, avoid vendor lock-in, and reduce implementation and maintenance costs
- To achieve well and healthy ageing for citizens and minimize the risk of privacy and other breaches

Much of the content is common to the public and private sectors and overlaps with what is presented in existing guidelines for businesses. However, few concrete tools have been made available to date for the use of healthcare data from a municipal perspective.

The toolkit consists of the following: basic principles; a checklist for benchmarking; tips; a Q&A section; and advanced case studies.

Basic principles

A municipality should follow six principles in PHR implementation and utilization of healthcare data:

1. Individual autonomy and interests of the individual
2. Transparency and privacy
3. Interoperability and openness
4. Fairness and inclusiveness
5. Value realization and social justice
6. Sustainability

These principles will satisfy the five principles of smart cities², the four principles of medical ethics³ and the five digital principles⁴ set forth by the Japanese Digital Agency.

Checklist for benchmarking

To ensure that implementation is based on the above six principles, the following items should be checked. When using this checklist, compliance with rules such as laws, ordinances and related guidelines of the implementation site is required. If there are detailed regulations on security, etc., confirmation of such rules is also required.

This checklist is intended to be used for scoring and evaluation of business proposals as well as for evaluation by third-party organizations such as ethics review committees and personal information review boards. All of the following items are not required to be satisfied.



2. Transparency & Privacy, Safety Security & Resiliency, Interoperability & Openness, Equity Inclusion & Societal impact, Operational & Financial Sustainability https://globalsmartcitiesalliance.org/?page_id=90

3. Respect for autonomy, Non-maleficence, Beneficence, Justice

4. Digital Completion and Automation Principle, Agile Governance Principle (agile and flexible governance), Public-Private Partnership Principle (G to B to C model), Principle for Ensuring Interoperability, Common Infrastructure Use Principle <https://www.digital.go.jp/meeting/posts/91qdfD4B>

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|---|--|---|
| 1 | Individual autonomy and interests of the individual | <ul style="list-style-type: none">- Is the identity verified appropriately?- Are the health and other benefits to the individual clear?- Is there a mechanism for returning benefits (e.g., points) to the individual (in line with provision to a third party)?- Is data management by the individual, or data portability, possible?- Is there a tool that enables the data controller to check the status of your consent?- Is there a contact point for the individual to file an objection, etc.? |
| 2 | Transparency and privacy | <ul style="list-style-type: none">- Are the purposes of data use sufficiently clear?- Is data collection conducted in an appropriate manner?- Is the controller of the data, and how it is managed, clearly indicated?- Is responsibility for the use of the data clear?- Are appropriate security measures in place?- In the case of anonymous processing, is the processing appropriate?- When AI is used, are the criteria for AI clearly indicated?- Is there clear compliance with other privacy-related laws and regulations? |
| 3 | Interoperability and openness | <ul style="list-style-type: none">- Are standards used to ensure smooth data exchange and utilization?- Does it enable interoperability across municipalities, e.g., API linkage, easy data migration, etc.?- In the case of secondary use of data for public interest purposes, will the results of data use be disclosed to the public or otherwise appropriately returned to society?- Will the data be made public after anonymisation? |
| 4 | Fairness and inclusiveness | <ul style="list-style-type: none">- If a service requires a specific device, are citizens who do not have or cannot use that device taken into account?- Is the UI/UX properly designed, including appropriate considerations for universal design?- Is there any unfair treatment by recommendation, etc., to the person in question? |
| 5 | Value realization and social justice | <ul style="list-style-type: none">- Is data quality and authenticity ensured?- If the value is to be realized for persons other than the data subject, is it clearly specified? Is such value a reasonable objective?- Are scientifically grounded interventions planned?- Are appropriate considerations given to cases of disadvantage in line with value realization?- Is third-party verification of value realization or disadvantage possible?- If data is accessed by third parties without consent, is it limited to socially consensual public interest purposes, etc.? |
| 6 | Sustainability | <ul style="list-style-type: none">- Is the system capable of maintaining minimum functionality, including during emergencies such as disasters and pandemics (i.e., is the system resilient)?- Is the model sustainable over the medium to long term (i.e., not dependent on subsidies)?- Is the workload of the municipality appropriate?- Is the design of the programme appropriate in relation to medical equipment, online medical care and other healthcare-related regulations? |

1. Individual autonomy and interests of the individual

This item concerns whether the autonomy of each individual, as a citizen and data subject, is respected; whether there are health or other benefits (including financial benefits) through PHRs, etc.; and whether the individual is appropriately involved in the process.

It is important to clarify the division of roles between the public and private sectors with regard to the point of contact for filing objections, etc. When a municipality plans to include secondary use of data, the relationship with services for the individual should be clearly defined.

- Is the individual's identity verified appropriately?
- Are the health and other benefits to the individual clear?
- Is there a mechanism for returning benefits (e.g., points) to the individual (in line with provision to a third party)?
- Is data management by the individual, or data portability, possible?
- Is there a tool that enables the data controller to check the status of your consent?
- Is there a contact point for the individual to file an objection, etc.?

2. Transparency and privacy

When utilizing data and operating PHRs, a municipality should sufficiently consider privacy and security measures in accordance with personal information protection laws and regulations.

In addition, a municipality should ensure in the decision-making process and operation, and the potential impact and threat of privacy risks should be assessed as much as possible before implementation. To ensure transparency, it is also important to hold briefing sessions and encourage citizen participation from the planning stage.

- Are the purposes of data use sufficiently clear?
- Is data collection conducted in an appropriate manner?
- Is the controller of the data and how it is managed clearly indicated?
- Is responsibility for the use of the data clear?
- Are appropriate security measures in place?
- In the case of anonymous processing, is the processing appropriate?
- When AI is used, are the criteria for AI clearly indicated?
- Is there clear compliance with other privacy-related laws and regulations?

3. Interoperability and openness

The public nature of municipalities requires that openness regarding data use and its results be ensured, especially including measures against vendor lock-in, so that data utilization can be maximized without interorganizational barriers.

In addition, incompatible systems are frequently established within a municipality or across multiple municipalities, resulting in inconvenience to citizens. Therefore, the ecosystem should be created while ensuring interoperability that enables connection to a variety of data among systems.

- Are standards used to ensure smooth data exchange and utilization?
- Does it enable interoperability across municipalities; e.g., API linkage, easy data migration, etc.?
- In the case of secondary use of data for public interest purposes, will the results of data use be disclosed to the public or otherwise appropriately returned to society?
- Will the data be made public after anonymisation?

4. Fairness and inclusiveness

Since health is a common issue for all citizens, it is necessary to strive to ensure that no one will be left behind. This is an essential element of public municipal services.

- If a service requires a specific device, are citizens who do not have or cannot use that device taken into account?
- Is the UI/UX properly designed, including appropriate considerations for universal design?
- Is there any unfair treatment by recommendation, etc., to the person in question?

5. Value realization and social justice

The primary purpose of PHRs is to deliver health benefits to individuals (see items in 1.). On top of that, when data is subject to secondary use, or when it is collected and used for the benefit of a third party from the outset, the value realized through such use must be in accordance with social justice. In a municipality, the realization of public value is required more than in the case of a service provided by a business alone.

- Is data quality and authenticity ensured?
- If the value is to be realized for persons other than the individual, what kind of value is to be realized is clearly indicated and is this a reasonable objective?
- Are scientifically grounded interventions planned?
- Are appropriate considerations given to cases of disadvantage in line with value realization?
- Is third-party verification of value realization or disadvantage possible?
- If data is accessed by third parties without consent, is it limited to socially consensual public interest purposes, etc.?

6. Sustainability

In the event of natural disasters, unforeseen accidents, information security failures, etc., public services must have the resilience to recover as soon as possible while maintaining minimum functions. In addition, it is important to ensure that projects are implemented sustainably, effectively and efficiently, from both operational and financial perspectives. Increased operational efficiency is a good in itself and it benefits citizens by allowing municipalities to devote more resources to other services.

- Is the system capable of maintaining minimum functionality, including during emergencies such as disasters and pandemics (i.e., is the system resilient)?
- Is the model sustainable over the medium to long term (i.e., not dependent on subsidies)?
- Is the workload of the municipality appropriate?
- Is the design of the programme appropriate in relation to medical equipment, online medical care and other healthcare-related regulations?

Tips, Q&A and advanced examples for response

Tips and Q&A through actual cases collected will be presented. This will include especially important elements from each stakeholder's perspective, such as the scope of actions that municipalities may take for administrative purposes and how to encourage companies to participate more in the environment provided by the municipality.

Conclusion

There is an ongoing worldwide search for public-private partnerships for healthcare data management. In this toolkit, we have introduced some key points for the appropriate implementation of PHRs in particular. We hope that the implementation of PHRs based on these points will help to realize important values such as improving public health worldwide.

Further workshops will be held in the future to discuss the framework and issues presented in this document in more depth. For more detailed information on individual items, please participate in these workshops or wait for the white paper to be published soon as a result of these workshops.

Contributors

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