



Unlocking Data for Healthy Living

Takanori Fujita
Centre for the Fourth Industrial Revolution Japan
Healthcare Data Policy Project

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Centre for the Fourth Industrial Revolution (C4IR)

In March 2017, The World Economic Forum established a public-private platform in San Francisco to co-design and pilot innovative new approaches to policy and governance. The aim is to harness technology for the benefit of society.

With the aim of promoting global rule-making, the Centre Network involves **a wide range of stakeholders** from government, industry, academia, civil society, local government and international organizations



The C4IR network has now expanded to 13 centers with 37 partner countries and institutions.



World Economic Forum Centre for the Fourth Industrial Revolution Japan

Our Organization



Founders :



Objectives : Maximizing the benefits of the Fourth Industrial Revolution by promoting open innovation in policymaking, filling governance gaps and ensuring policy interoperability

C4IRJapan Partners :

- AISIN SEIKI
- NEC Corporation
- Suntory Holdings
- Salesforce.com
- SOMPO Holdings
- Takeda Pharmaceutical Company
- DENSO CORPORATION
- Toyota Motor Corporation
- Hitachi
- McKinsey & Company Incorporated Japan
- Mitsubishi Chemical Holdings
- MORI Building
- HORIBA
- Eisai
- Nippon Telegraph and Telephone Corporation (NTT)

Forum Partners engaged in C4IRJapan Projects :

- Mitsubishi UFJ Research and Consulting
- Deloitte Tohmatsu Consulting
- Baker & McKenzie
- Visa Worldwide Japan

World Economic Forum Centre for the Fourth Industrial Revolution Japan

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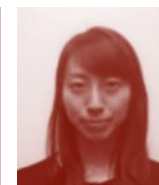
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Goal

- Develop a data governance framework to improve prevention and quality of life for people with dementia and other aging-related diseases, from the view point of individual and social value

Impact

- Help expand the health frontier for the world
- Gather and leverage a large, comprehensive data set for the population to improve wellbeing, including in the pre-diagnosis phase
- Leverage the unique public-private set-up of the Japan Centre to achieve real regulatory impact in a difficult health data area

Partners

Eisai, Mitsubishi Chemical Holdings, SOMPO Holdings, Takeda Pharmaceutical

Timeline

Spring-Summer 2019: Research and compare international and domestic legal regimes for health data. Compile examples of existing best practices and potential framework upgrades.

July 2019: Institutional Session at AMNC19

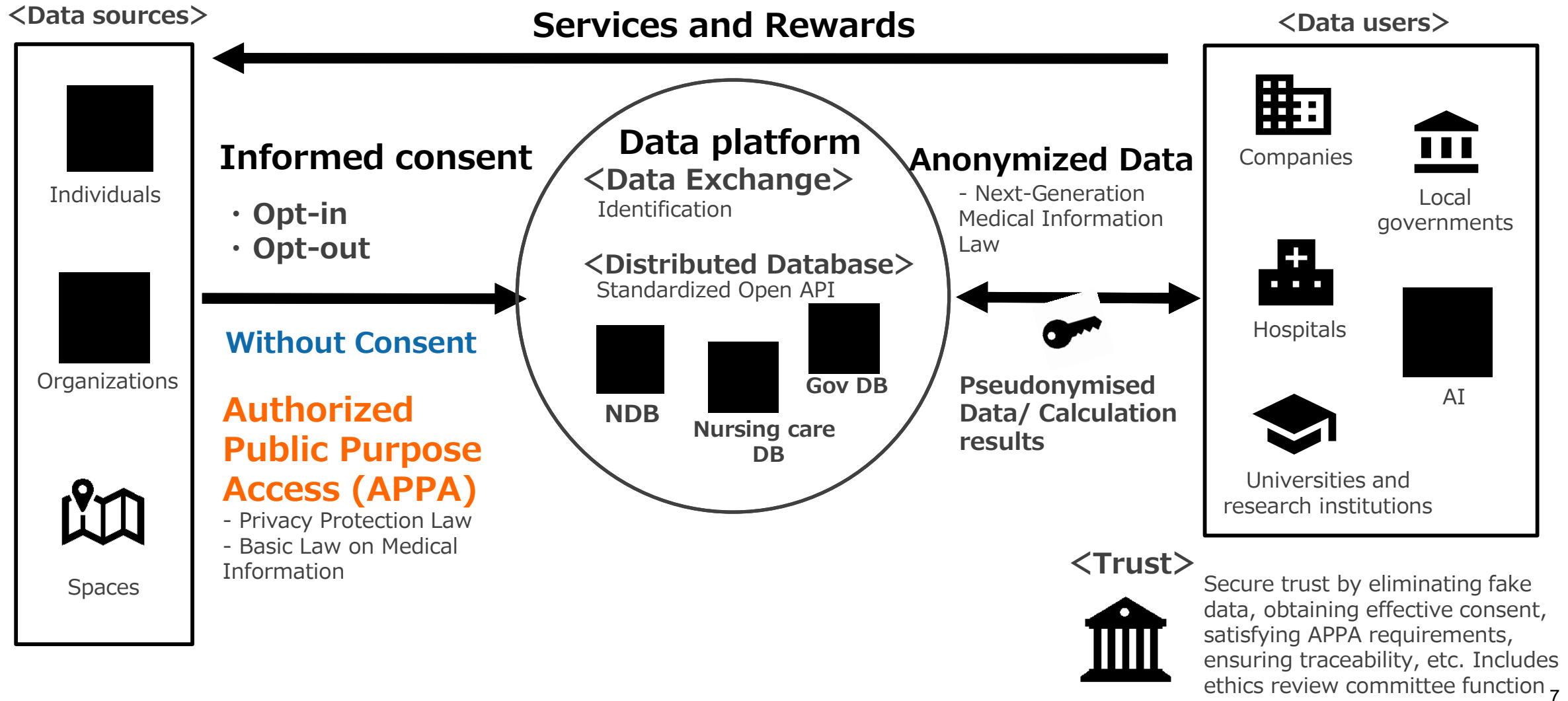
January 2020: APPA white paper published

February 2020: Implementation project of APPA started

Late 2020: 2nd white paper published for GTGS

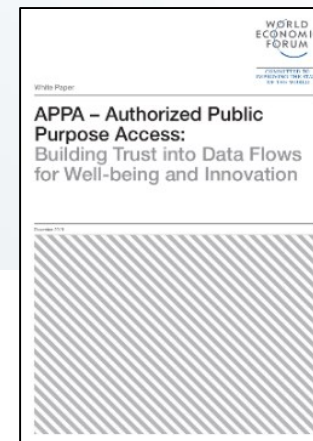


Healthcare Data Governance Framework



Authorized Public Purpose Access (APPA) Social implementation

Present 'APPA Principles' and evaluation criteria, along with examples of social implementation, to promote data utilization for the public interest



Goal

We have proposed a data governance model, APPA, that supports the use of data for public-interest purposes while protecting the rights of individuals through mechanisms including, but not limited to, explicit individual consent, while securing cooperation from data holders. This project seeks to promote the social implementation of APPA-based models by providing examples of evaluation criteria and establishing core "APPA Principles" through a close examination international laws and regulations.

Impact

Impacts of the project

- Promotion of data utilization for the public interest through "APPA principles"
- Support for social implementation of APPA concept through presentation of evaluation criteria
- Proposal for ideal governance approach that supports practical implementation of APPA

Milestones

~ **Aug. 2020**

Determination of APPA principles and evaluation criteria based on close examination of international laws and guidelines regarding data utilization

Sep.- Oct. 2020

Discussion with experts in C4IR network

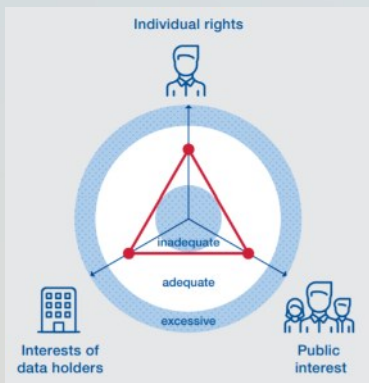
Nov. 2020

White Paper

Apr. 2021

Presenting "APPA Principles" in GTGS to raise public awareness of the need to promote data utilization for "public interest" purposes

APPA movie: <https://www.weforum.org/videos/wef-authorized-public-purpose-access>

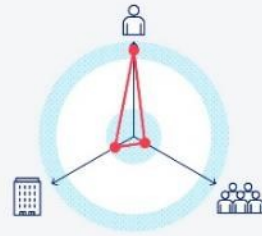


Governance Gap Analysis Based on Three Factors

- We have been struggling with the balance among three factors even before this pandemic
- With our new approach, trying to offer a systematic framework that can apply to these problems

Biased toward individual

Ex: GDPR



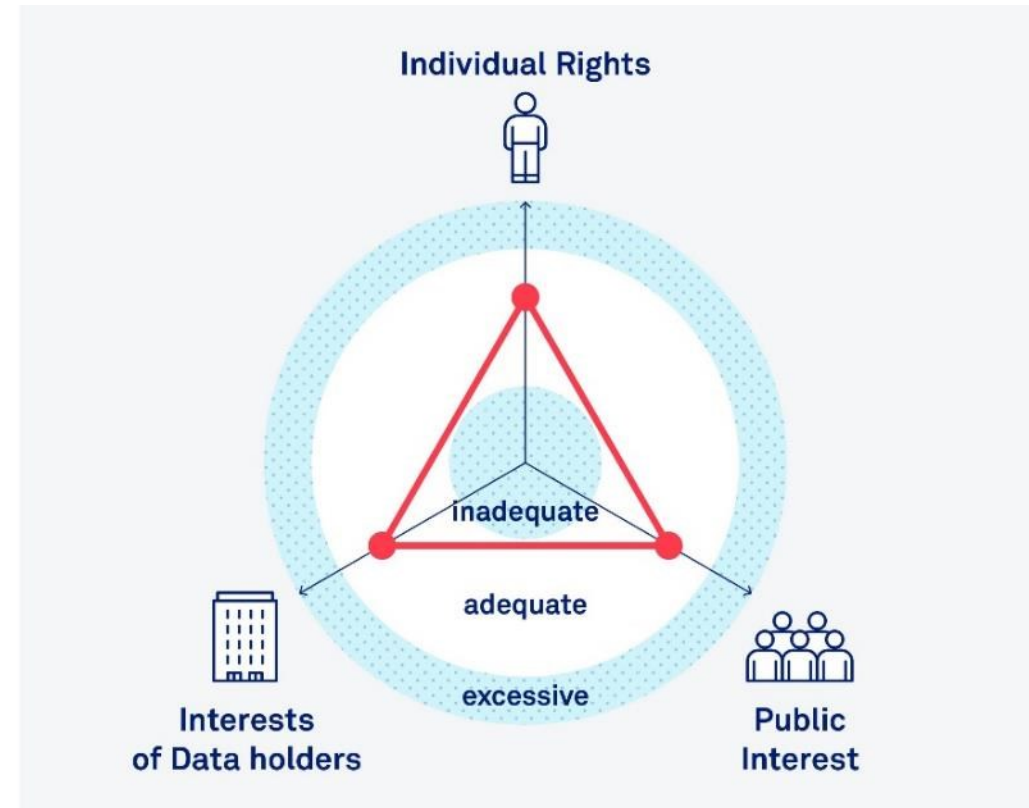
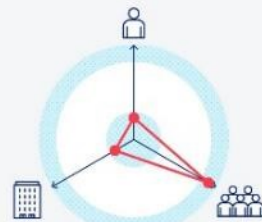
Biased toward data holders

Ex: GAFA data hegemony



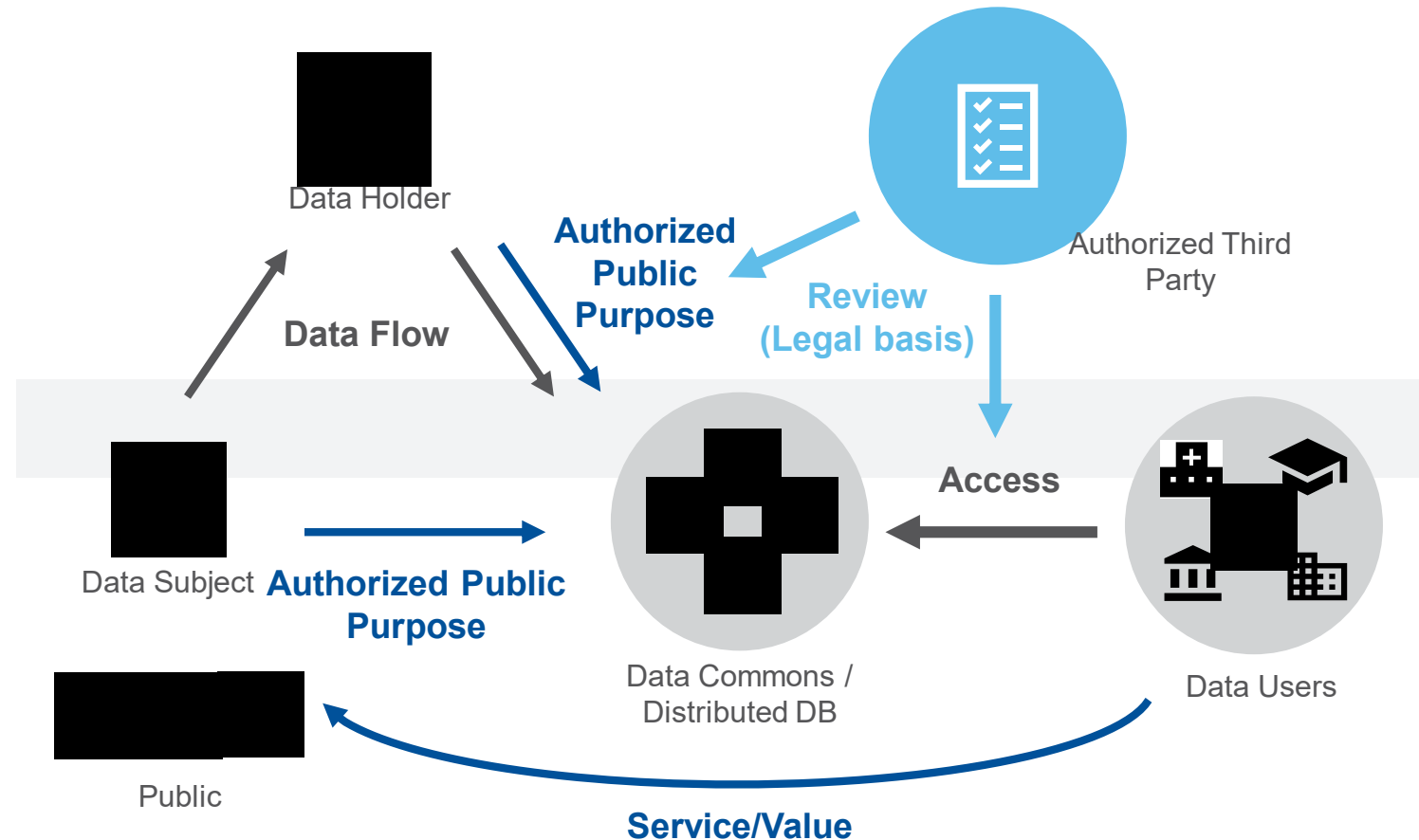
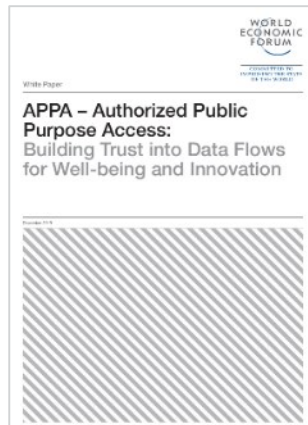
Biased toward public purpose

Ex: Authoritarian social credit systems



APPA: Authorized Public Purpose Access

- APPA is a new concept for **managing access authorization to healthcare data without relying on explicit consent**
- Japan Centre has pitched it through the Institutional Session at AMNC19 and the White Paper issued in January 2020



Value of APPA

Existing Examples

Natural disaster

Use of personal medical data to care for victims of a natural disaster



Disease pandemic

Data on infectious disease patients used to prevent outbreaks



Cancer registry

Registration of all cancer patients for policy planning and monitoring of morbidity trends



Value Created by APPA

Expanding disease registry other than cancer

- Government: To monitor morbidity and mortality trends and plan countermeasures
- Pharma: To provide list of clinical trial candidates
- Patients: To facilitate access to public services

Efficient Post Marketing Surveillance (PMS)

- Pharma: To track side effects and therapeutic outcomes of drugs

Prevention of child abuse

- Children: To share information about suspected child abuse learned through professional position (doctors, teachers, etc.) with local government and others

Development of healthcare service by medical records connected with life log data (on meals, steps, purchase records, etc.)

- People: To access to innovative healthcare services

Trust & Willingness in the use of personal data

- How can private companies secure Trust & Willingness from individuals and society when they seek to use personal data? This project looks for answers by sharing best practices of building and implementing a corporate code of conduct framework.
- As a Use Case, the project looks at nursing care data, which can include data on vulnerable people such as the elderly

Goal

- Specify practical and useful applications of data governance for private companies that wish to secure Trust & Willingness from individuals and society when they seek to use personal data. Examples include "governance organization and workflow patterns in private companies," "Know-how for communication with individuals and society," and "Hints for navigating gray zones in laws and guidelines."

Impact

- Create innovative value by making it easier to harness data
- Protect individual rights and social value
- Reduce costs for companies seeking to study or establish data governance systems

Milestones





June 2020 and beyond

- Gathering best practices, Community building
- Scoping key components of Trust and Willingness
- Scoping pilot projects

January-February, 2021

- White paper
- Consideration of social implement

Possible Issues in the Use of Nursing Care Data (hypothesis)

 Planning	The pros and cons of using data related to people with dementia	 Data processing analysis/learning	Risks in the care data analysis and evaluation phase
	The pros and cons of using employee data		Consideration of dataset bias
	Sympathy for the purpose of use by parties and society		Ensuring transparency (data use, processing purposes, etc.)
	An internal system to achieve Ethics by design		Other social values (e.g., consideration for vulnerable groups)
	Risks and benefits of using nursing care data		Appropriate anonymous processing methods for care data
 Data Acquisition	Appropriate method for obtaining consent from people with dementia	 Implement /Operation	Human involvement principle
	UI and communication methods for people with dementia and the elderly		Explanation on how to make decisions using data
	Consideration of potential bias in the data set being collected		Handling of profile scored information
			Literacy and safety management of data handlers

CommonPass : Initiative for safe border crossings



This project aims to develop a framework to ensure the interoperability of rules at a global level for free movement of people across borders.

Goal

1. Establish international standards for the free movement of people across borders using a multi-stakeholder approach.
2. Starting with the sharing of test results and vaccination histories in response to COVID -19, ensure a balance between safe economic activities and public health through the use of individually portable data

Impact

- Efficient sharing of certified digital data, reliable test certificates, anti-counterfeiting
- Providing an interoperable tool that is not subject to complex multi-country rules
- Support for immigration authorities when organizing international events

Partners in Japan

The Commons Project, Japan Business Federation, Japan Association of Corporate Executives, Japan Association of New Economy, Information Technology Federation of Japan, Japan Association for Medical Informatics, Japanese Society of Laboratory Medicine, Suntory, NEC, etc.

Milestones

Jul, 2020

International kick-off (350 participants from 52 countries)

Aug, 2020 -

Pilots in six East African Community countries

Sep, 2020-

Pilot on international flights

Apr, 2021

Use at GTGS

Jul, 2021

Use at Olympic/Paralympic

Border reopening: a global challenge

How can we trust a lab test or vaccination from another country?



Is the lab or vaccination facility accredited/certified?



What kind of lab test/vaccination? When was it? What was the result?

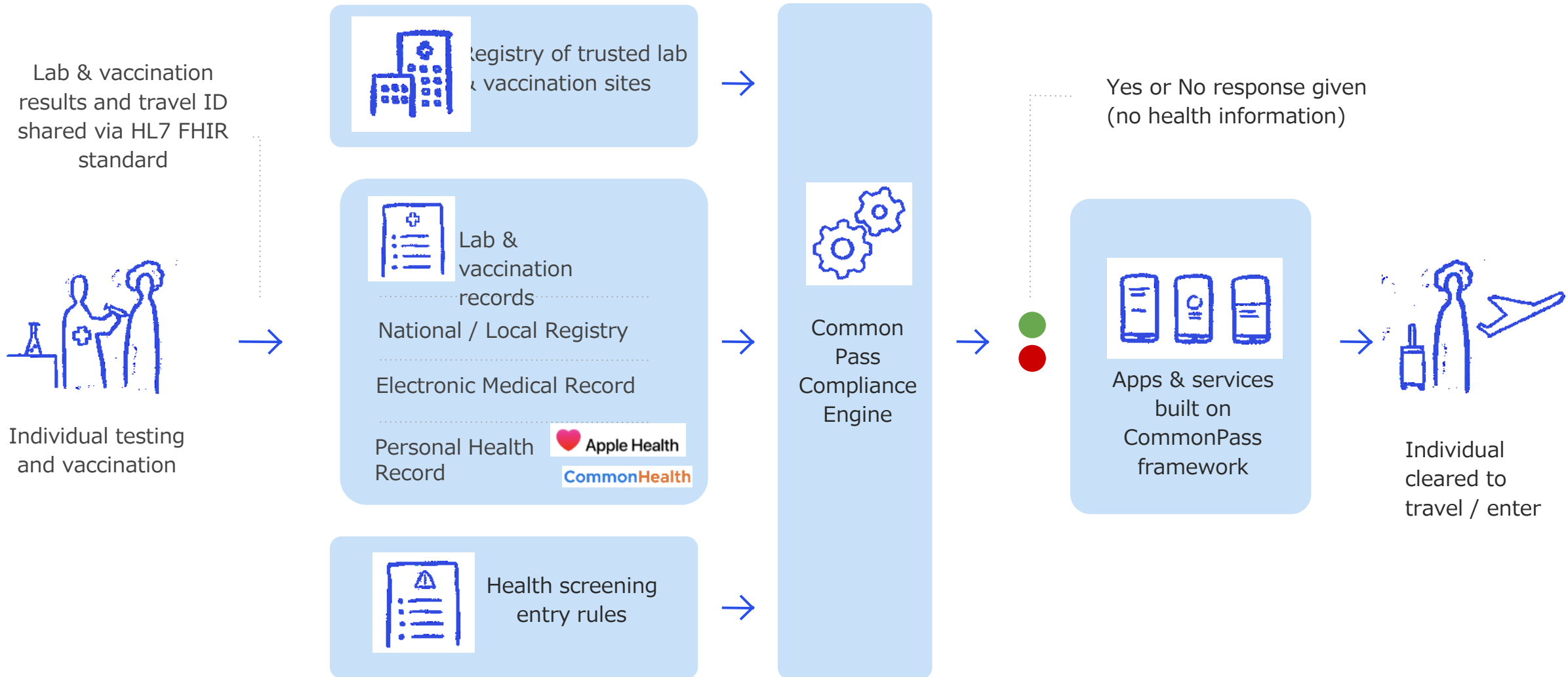


Is it the same person?



Does the traveler meet border entry requirements?

CommonPass Framework



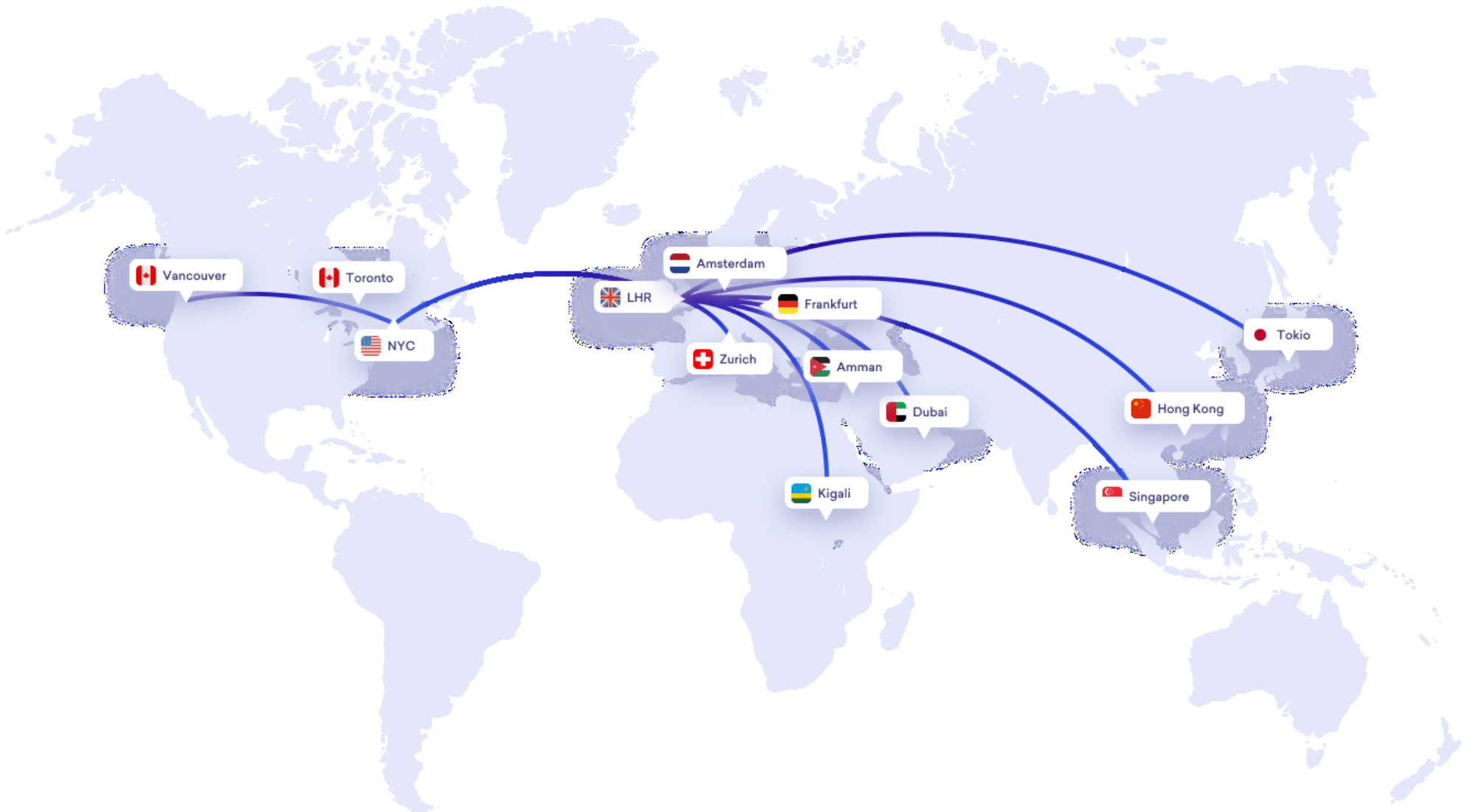
On July 9th, The Commons Project, The Rockefeller Foundation and The World Economic Forum...



https://www.youtube.com/watch?v=57IYp_cQEsE

Pilot Phases:

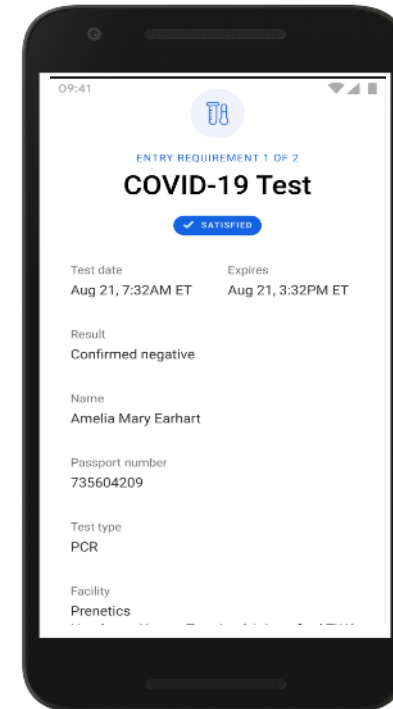
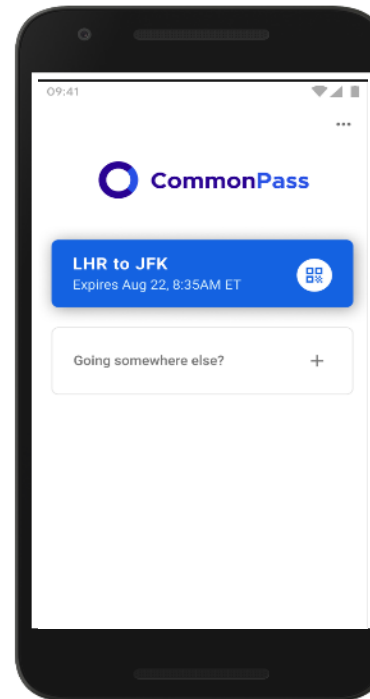
1. Demonstration flight & evaluation
2. Commercial flight & evaluation
3. Expansion to multiple flights on route
4. Expansion to additional routes, using hubs and airline alliances to scale



Key Principles and App Prototype

CommonPass adheres to the following key principles:

- **Agency:** Data is stored or shared only with explicit, informed consent
- **Data Minimization:** Only the minimum amount of personal data is used for any transaction
- **Federation:** Personally identifiable health information is stored only at the source or on the user's phone
- **Use:** Data are only stored to the extent necessary and never used for any other purpose



Project members in Japan



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Japan Business Federation (Keidanren), Japan Association of Corporate Executives, Japan Association for Medical Informatics, Japanese Society of Laboratory Medicine

Discussion Points

1. How do we face **diversity** and ensure **inclusiveness** in digital health?

How can we support for data collection and utilization of elderly and disabled people regarding PHRs?

2. How and by whom can digital health build **TRUST** under covid-19 pandemic?

How can social consensus on the data utilization be formed?

How can we ensure the interoperability of systems or apps with other countries?

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