Data as Shared Goods: 
How can we contribute to sustainable shared values

Professor of Health Policy and Management, Keio University
Professor of Healthcare Quality Assessment, The University of Tokyo

Hiroaki MIYATA
**COvid-19: Operation for Personalized Empowerment to Render smart prevention And care seeking [COOPERA]**

**Project summary**
identical with WhatsApp
83 million users in Japan

This project uses the social networking service "LINE" to efficiently screen and follow up high-risk groups of new coronaviruses (COVID-19) and patients with potential coronaviruses, as well as to support patients with mild symptoms.

The system specifically implements the following three points:

- Support for personalized self-care and prevention of secondary infections
- Real-time follow-up
- Population-level feedback and rapid identification of actions

(For more details, see the supplementary material)
COvid-19: Operation for Personalized Empowerment to Render smart prevention And care seeking [COOPERATION]

Project design

Data provision

Individual information provision, consultation support

Outsourcing

Prefectures of Japan

Provision of expertise and operational support

Report on the results to the citizens of the country, the prefecture, and related organizations

Data storage

Provision of data storage space

Report on the results of the data analysis

Data storage and management oversight, and data access

Keio University

Amazon Web Services (AWS)
COVID-19: Operation for Personalized Empowerment to Render smart prevention and care seeking [COOPERERA]

Questionnaire summary

There are two main questions on LINE:

- Basic questions: whether the user have a current fever (>37.5°C) or a strong feeling of weariness (fatigue) or shortness of breath (difficulty breathing), and their durations, those in the past month, gender, age, medical history, and recent overseas travel history, etc.

- Detailed questions: body temperature, symptoms, medications, risk-avoid behavior, history of medical consultations, diagnostic results, stress assessment with K6, information on contact with infected persons in the vicinity, etc.

  - According to the results of the responses, we recommend that the user should consult with the local government's counselors, based on the guidelines set by the Ministry of Health, Labour and Welfare (MHLW), and provide information such as Q&A on COVID-19 from the MHLW.

  - Follow up with detailed questions sent daily to those with symptoms and periodically to those without
Île-de-France

Retail & recreation
-91% compared to baseline

Grocery & pharmacy
-69% compared to baseline

Parks
-89% compared to baseline

Transit stations
-87% compared to baseline

Workplace
-63% compared to baseline

Residential
+20% compared to baseline
Google COVID-19 Community Mobility Reports

Tokyo

Retail & recreation
-63% compared to baseline

Grocery & pharmacy
-32% compared to baseline

Parks
-66% compared to baseline

Transit stations
-80% compared to baseline

Workplace
-27% compared to baseline

Residential
+14% compared to baseline

School Closure
Retail & recreation

-55% compared to baseline

Baseline

+80%
+40%
-40%
-80%

Sun Feb 16  Sun Mar 8  Sun Mar 29

School Closure
Cherry Blossom
Results of emergent survey for 25,000,000 people

- Group 1: Sales worker and Food business
- Group 2: Office worker and Retail business
- Group 3: Doctor, nurse and care worker
- Group 4: Teachers and students Under school closure
- Group 5: Stay at home jobs

Region Risk (Rate of Fever in general publics)
Rt compare with google mobility report
Real-time tracking of self-reported symptoms to predict potential COVID-19

Fig. 1: Association between symptoms and SARS-CoV-2 infection, and ROCs for prediction of the risk of a positive test.

Prediction model = -1.32 - (0.01 × age) + (0.44 × sex) + (1.75 × loss of smell and taste) + (0.31 × severe or significant persistent cough) + (0.49 × severe fatigue) + (0.39 × skipped meals)
画面に表示されているのは、ダミーデータに基づいた分析です。実際のデータではありません。

本機能はIQVIAジャパンの無償協力により作成されました。
General Data Protection Regulation (2018.5-)

The EU General Data Protection Regulation (GDPR) is the most important change in data privacy regulation in 20 years - we're here to make sure you're prepared.

After four years of preparation and debate the GDPR was finally approved by the EU Parliament on 14 April 2016. Enforcement date: 25 May 2018 - at which time those organizations in non-compliance may face heavy fines.

Data Portability

GDPR introduces data portability - the right for a data subject to receive the personal data concerning them, which they have previously provided in a 'commonly use and machine readable format' and have the right to transmit that data to another controller.

privacy. The key articles of the GDPR, as well as information on its business impact, can be found
The principles of Japanese VALUE CO-CREATION SOCIETY

Maneuvering the strengths of American, EU, and Chinese models, CO-CREATION SOCIETY underlies the basis on which diversity and plurality of values can be accomplished with everyone.

1. **Economy-driven innovation**
   - ![Hand holding yen symbol and hand]

2. **Data as an extension of property goods (GDPR and Data Portability)**
   - ![Person with star]

3. **Top-down and uniform management of Social Credit System**
   - ![Downward triangle]

4. **Value-driven innovation**
   - ![Hand holding heart and hand]

5. **Data as common goods through active choice (Going beyond GDPR)**
   - ![Person with stars and three people]

6. **Bottom-up decision, diversity, and pluralism in value sharing and social credit system**
   - ![Upside-down triangle with arrows]
The regime we must build is one for D.F.F.T., Data Free Flow with Trust -- non-personal data, needless to say. It is not the big, capital intensive industries, but rather we individuals who will benefit from both the fourth industrial revolution and what we call “Society 5.0,” which this fourth industrial revolution will bring about.

In Society 5.0, it is no longer capital but data that connects and drives everything, helping to fill the gap between the rich and the less privileged. Services of medicine and education, from elementary to tertiary, will reach small villages in the Sub Saharan region. Girls who have grown up going to school will see, beyond their own village, a wider horizon where the sky is the limit.
C4IR Japan: Healthcare Data Policy Project

Healthcare Data Governance framework

<Data sources>

- Individuals
- Organizations
- Spaces

<Informed consent>
- Opt-in
- Opt-out
- Without Consent

<Authorised Public Purpose Access (APPA)>
- Privacy Protection Law
- Basic Law on Medical Information

<Data platform>
- Data Exchange
- Identification
- Distributed Database
- Standardized Open API

<Data users>
- Companies
- Local governments
- Hospitals
- Universities and research institutions
- AI

<Services and Rewards>

<Anonymised Data>
- Next-Generation Medical Information Law
- Pseudonymised Data/Calculation results

<Trust>
Secure trust by eliminating fake data, obtaining effective consent, satisfying APPA requirements, traceability etc. Includes ethics review committee function.

Keio University
Department of Health Policy and Management
Pursue an active way of living and which lead to healthy life. Inequity or illness does not always mean a burden on life. Possible to receive appropriate support based on scientific basis under a familiar environment. To rapidly cooperate with the best organization when a difficult judgment and advanced response is required. To provide the world's best treatment/diagnosis and care by having good cooperation among organizations. To provide customized treatment and care to individuals by combining global evidence and local real world data.

NCD=Non-Communicable Diseases

Course of Disease

Healthy Living
- Decrease in cell function
- Decrease in blood vessel function (atherosclerosis)
- Decrease in renal function
- Decrease in brain function
- e.g. Geriatric disorders

Diseases Preliminary Group (Diabetes, Hypertension, Dyslipidemia, Hyperuricemia)
- e.g. Early detection, Behavioral change (smoking cessation)
- e.g. Prevention

NCD (Other than cancer)
- e.g. Prevention of complications

Cancer
- e.g. Companion diagnostics

Cardiovascular Disease

Renal Failure (Dialysis)

Cerebrovascular Disease

Dementia

Frailty

Mild Cognitive Impairment (MCI)

Death

Senility

Others

prevention
Management / Treatment
End of life care
Re-invent our Lives

Not only disease management, but also wellbeing empowerment

**Wellbeing Platform**

Empower everyone

Pursue an active way of living and which lead to healthy life.

Inequity or illness does not always mean a burden on life

Community support

Possible to receive appropriate support based on scientific basis under a familiar environment

Rapidly cooperate to the best organization when a difficult judgment and advanced response is required

Value-based care

To provide the world’s best treatment/diagnosis and care by having good cooperation among organizations

To provide customized treatment and care to individuals by combining global evidence and local real world data
The era of human co-being: *Upgrade Our Society*

**The principles of Japanese VALUE CO-CREATION SOCIETY**

- Economy-driven innovation
- Data as an extension of property goods (GDPR and Data Portability)
- Top-down and uniform management of Social Credit System
- Value-driven innovation
- Data as common goods through active choice (Going beyond GDPR)
- Bottom-up decision, diversity, and pluralism in value sharing and social credit system

Maneuvering the strengths of American, EU, and Chinese models, CO-CREATION SOCIETY underlies the basis on which diversity and plurality of values can be accomplished with everyone.
- **CommonHealth** is the Android platform that lets people collect and store their personal health data and share it securely with the health partners they **trust**.

- Data is only shared with clear, informed **consent**.

The CommonHealth model was recently featured in the [New England Journal of Medicine](https://www.nejm.org).
CommonHealth

A Privacy Preserving Model to Enable Societal Re-Engagement

COVIDcheck

De-identified Data

De-identified Data

National State/Local Health Departments

National State/Local Health Departments

LABS

EHRs

WEARABLES

APPS & SERVICES

IOT

Test Results, Immunizations...

Personal health data is stored securely under person's control

COVID Status

Query & Response

COVID Status

Based on government or enterprise-specific criteria

Do you want to share your COVID status with?

None of your personal health data will be shared.

Check if you might have COVID-19 and what to do next

Risk Assessment

Guidance

Check In

Find Services

Subscribe

You have symptoms consistent with COVID. Do you want to share your results and contact info with your local health department so they can contact you?