



# **How to tackle against COVID-19 in AMED**

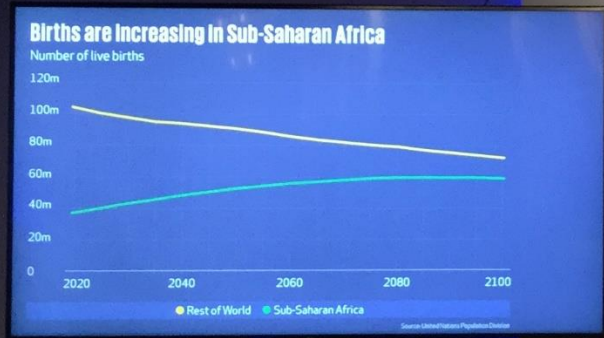
**President, Japan Agency for Medical Research and Development (AMED)**

**Makoto Suematsu, MD, PhD**

No conflict of interests

Clinical data are shown under Patients' IC

# Baby bust and superaging in our planet



In 2120

Birth in Sub-Saharan Africa = Birth in the rest of the world

Davos in January 24, 2019

# Global Future Council (Nov 2018~Oct 2019)

## *4 Elements for Healthy Longevity*

1. Global data sharing and linkage
2. Development of “Silver Market”
3. Equity and Ethics
4. Building human capitals

Dubai November 2018

Davos-Kloster January, 2019

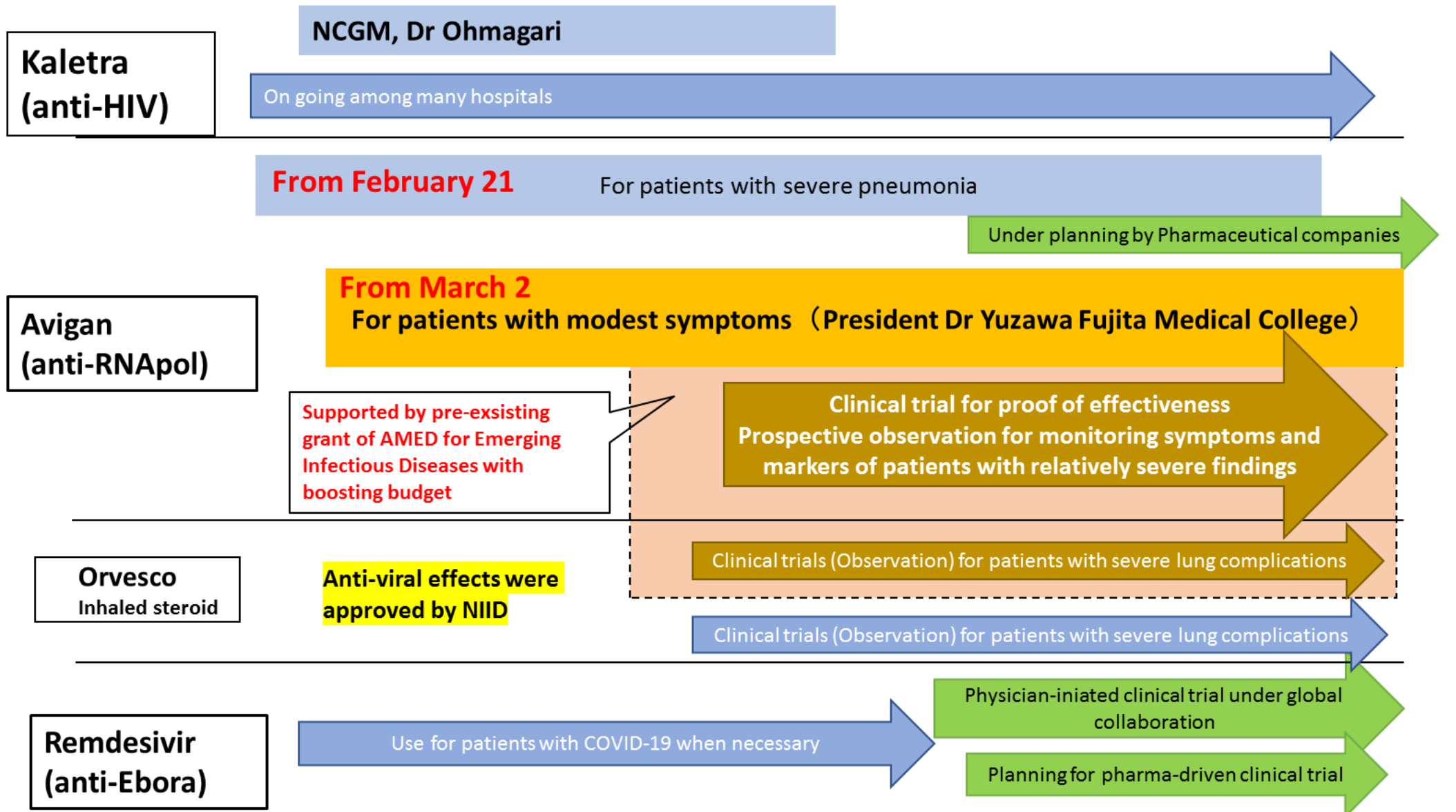




# **Actions of AMED to tackle against COVID-19**

- 1. Providing 30 million USD (FY2019 budget) for anti-SARS-CoV2 platforms**
- 2. In response to the 1<sup>st</sup> report in China, AMED start planning from the middle of January, assuming global outbreak or pandemic conditions**
- 3. HIROs and GLOPID-R took initiatives for global data sharing under the initiative of Dr Jeremy Farrar, Wellcome Trust, signing up on January 29, 2020.  
(Ex. Zika fever in 2016, Ebola fever in 2018)**
- 4. Empowering BSL-3 facilities to develop small molecular compounds, vaccines, neutralizing MoAbs and biologics**
- 5. Dialogue with Director Dr Wakita, National Infectious Disease Institutes**
- 6. Invitation by WHO and GLOPID-R to the 1<sup>st</sup> WHO meeting for medical R&D for COVID-19**
- 7. Providing information of **Yokohama Cruise Ship** to NAM and US government  
→ A swift response by AMED and MHLW to share the manuscripts in review.**
- 8. Visiting JPMA (President Nakayama) to empower collaboration with AMED**
- 9. Suppl. Budgets (**CiCLE: Government Investment 150 mil USD** + Suppl Budget in FY2020)**

## Pre-existing medicine and clinical trial (Information from Dr Ohmagari, NCGM)



※Just started in Tokyo University IMS

Press release in March 18

**Nafamostat**

a protease inhibitor used in pancreatitis and/or DIC

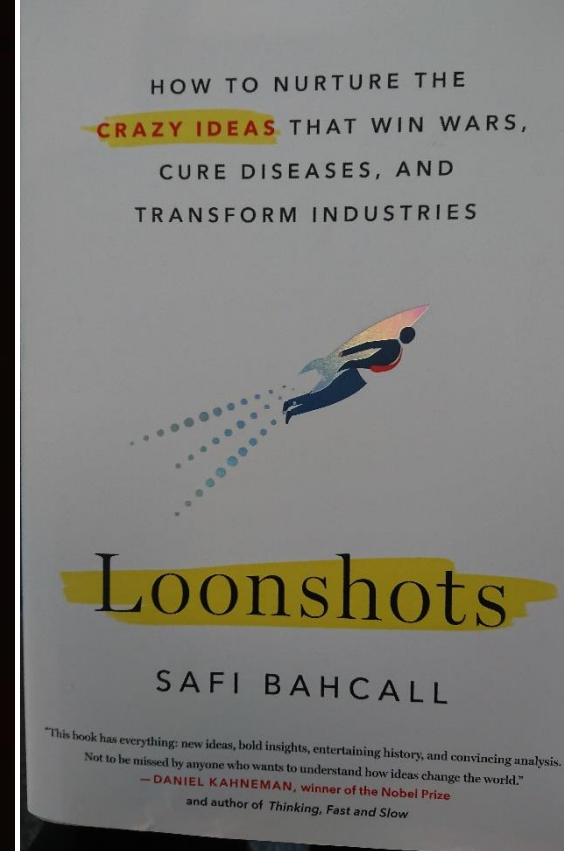
**Supported by AMED J-GRID**

**Collecting data over Japan, and sharing beyond Japan ?**

**1. Japan Excellence for Diagnostic Imaging (JEDI)  
(画像兄弟)**

**2. Initiative on Rare and Undiagnosed Diseases (IRUD)  
(未診断疾患イニシアチブ)**

**3. COVID-19: Challenging but urgent contribution by Japan**



Moonshot

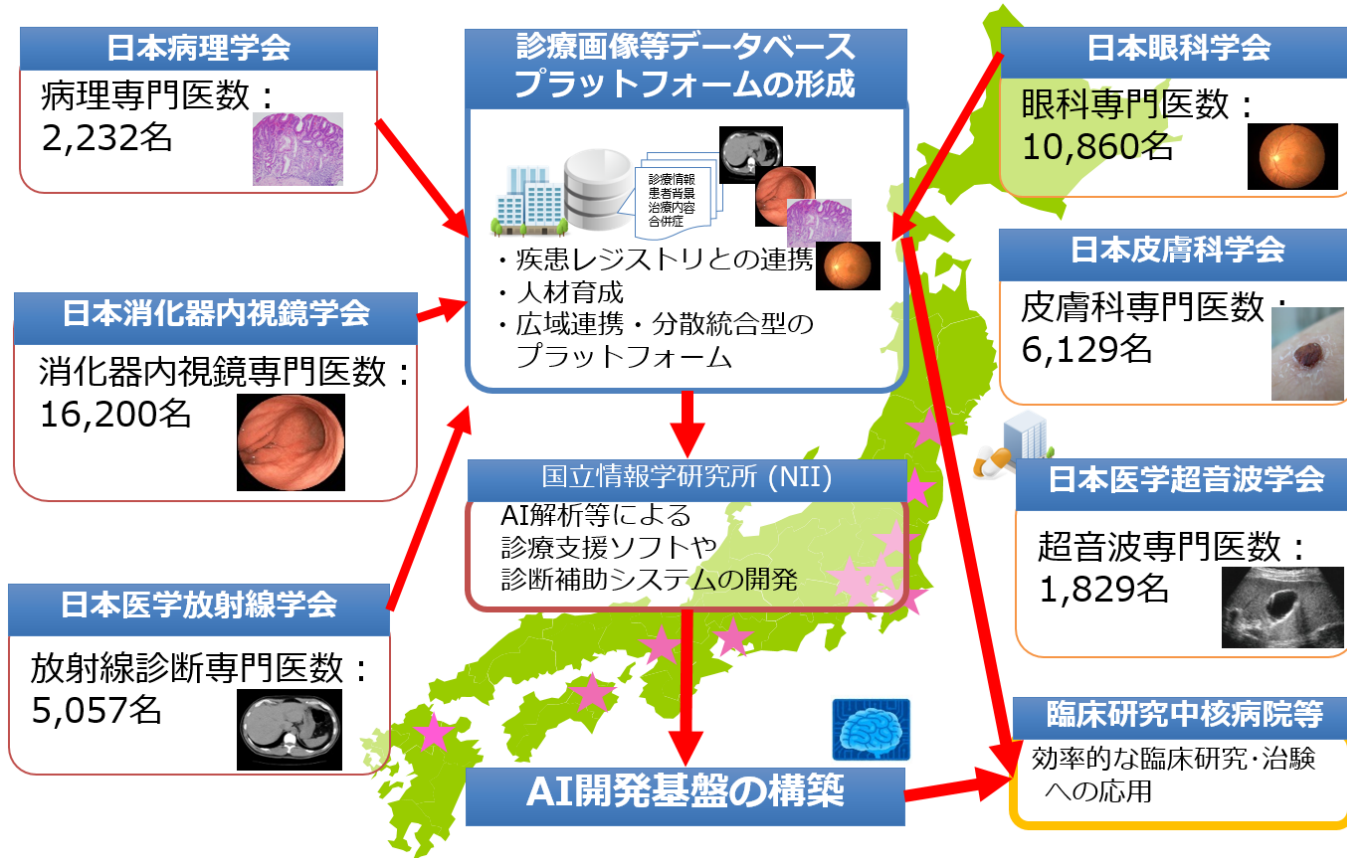


Loonshots



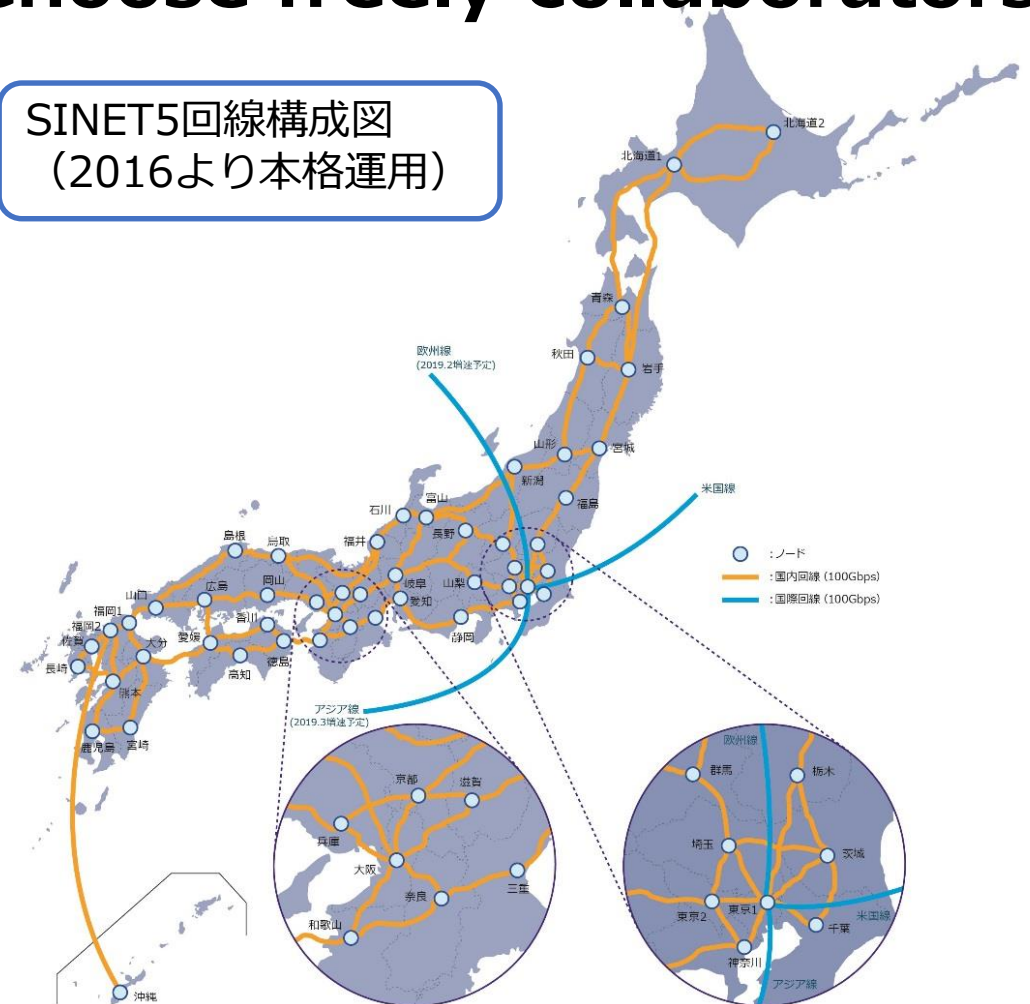
# JEDI: Japan Excellence of Diagnostic Imaging

"Competition and Collaboration in the same cloud computer" in NII



**Access from everywhere  
Choose freely collaborators**

SINET5回線構成図  
(2016より本格運用)

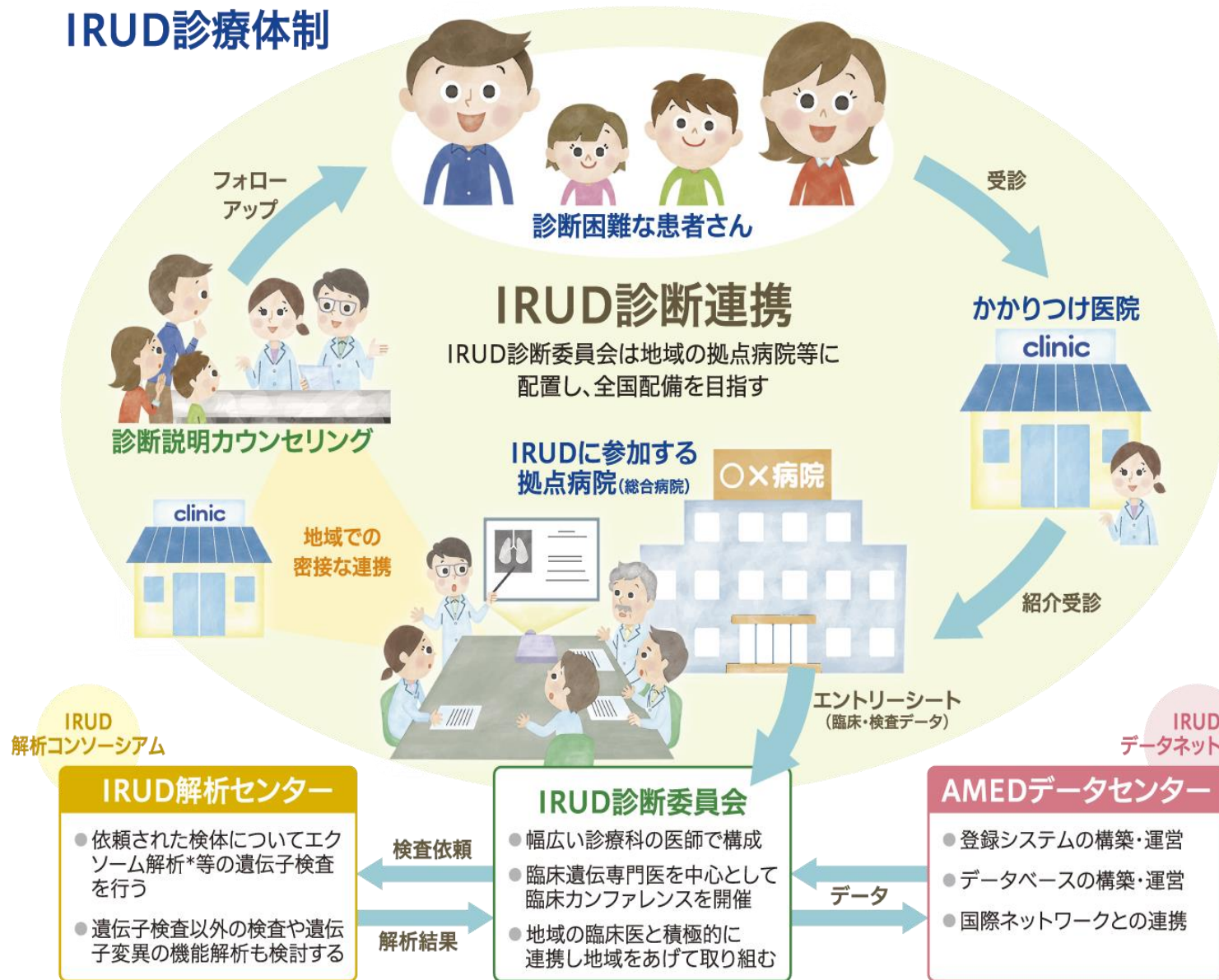


- 学術情報ネットワーク (SINET : Science Information NETwork) は、日本全国の大学、研究機関等の学術情報基盤として、国立情報学研究所 (NII) 構築、運用している情報通信ネットワーク。



# AMED facilitates global DATA Sharing for patient to overcome diagnostic odyssey

## IRUD診療体制

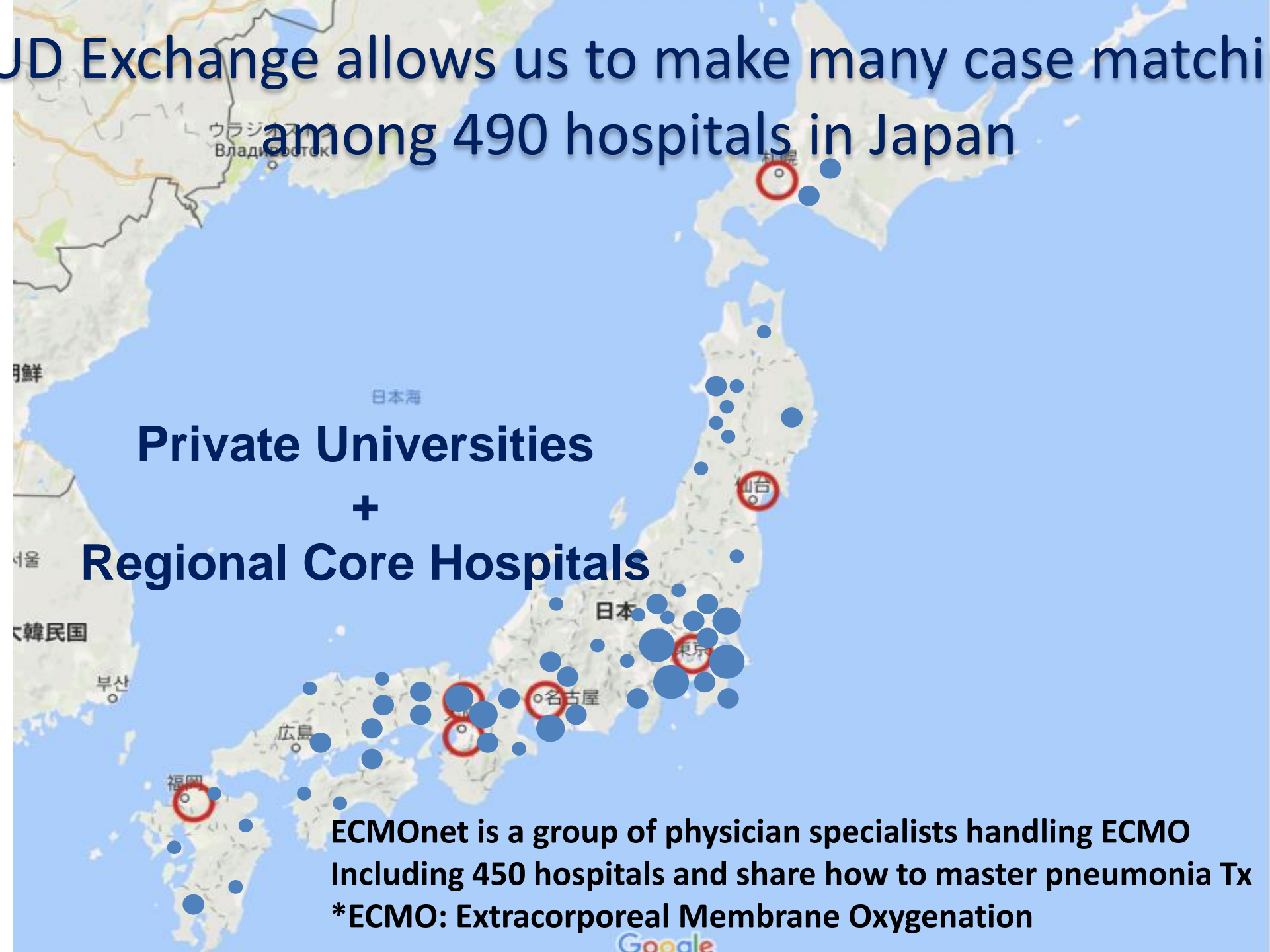


日本は、NCや都市部の大学病院だけでなく「全国」をカバーして情報を集め、活用ができるかどうか？

日本は、集めた情報を海外とも共有して患者さんに「答え」を回付することができ、海外の人々にも自国の人々にも恩恵をもたらすことができるかどうか？

難病・未診断疾患領域でそれができないなら認知症や人生100年の健康情報を収集し全く新しい医療のR&Dを推進し、世界にも展開することはまず不可能である。

IRUD Exchange allows us to make many case matching  
among 490 hospitals in Japan



ECMOnet is a group of physician specialists handling ECMO  
Including 450 hospitals and share how to master pneumonia Tx  
\*ECMO: Extracorporeal Membrane Oxygenation

IRUD



## IRUD Beyond

### Beyond diagnosis

Nation-wide Dx coverage→bridging from TR to Tx

Supporting Pre-orphan drug development and drug repositioning  
Basic sciences of gene editing Utilization of iPS cells for screening drugs

### Beyond genotyping

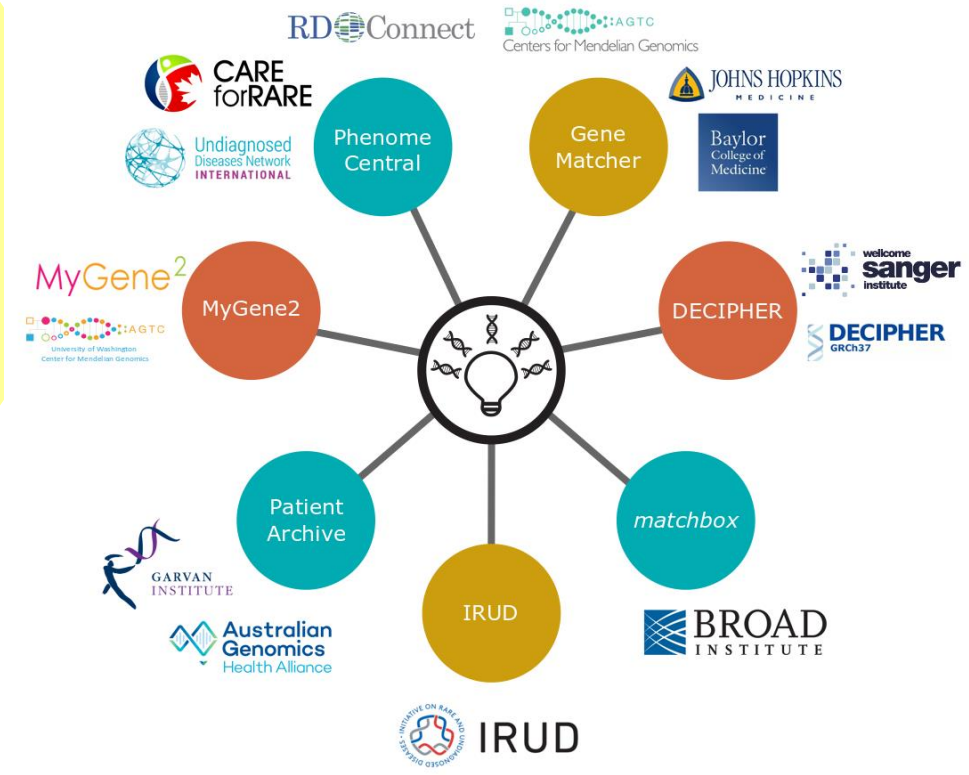
What is missing in genotyping ? How can we improve deep-phenotyping ?

What is missing in WGS ? Enrichment of phenotyping technologies

### Beyond borders

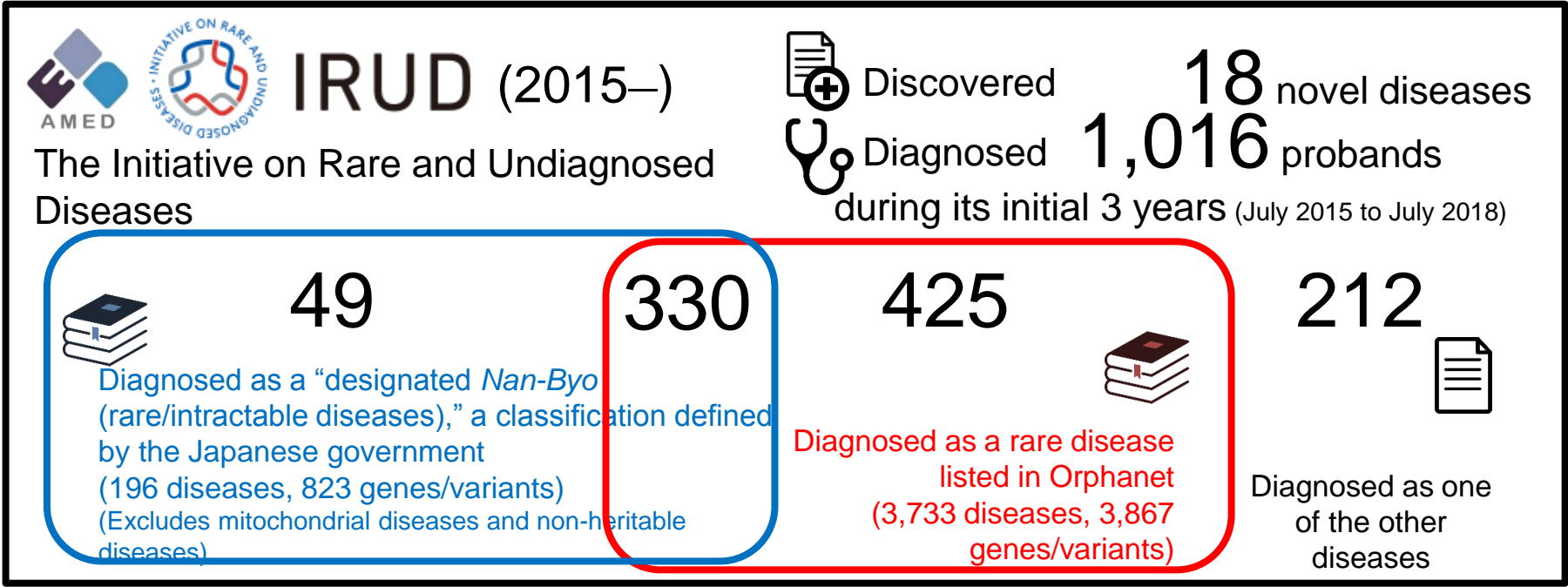
Global data sharing and fostering young investigators through bilateral funding

**AMED joined in MATCH MAKER EXCHANGE**  
**We are the first in Asian countries**

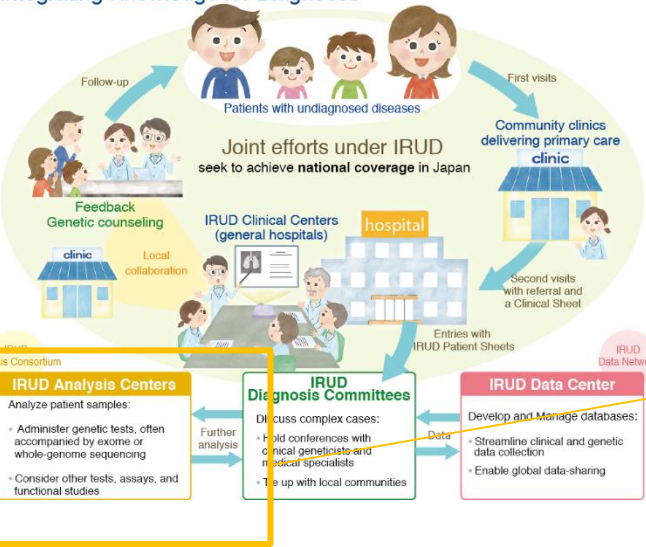




# Data linkage between different DBs empowers physicians and patients' benefit



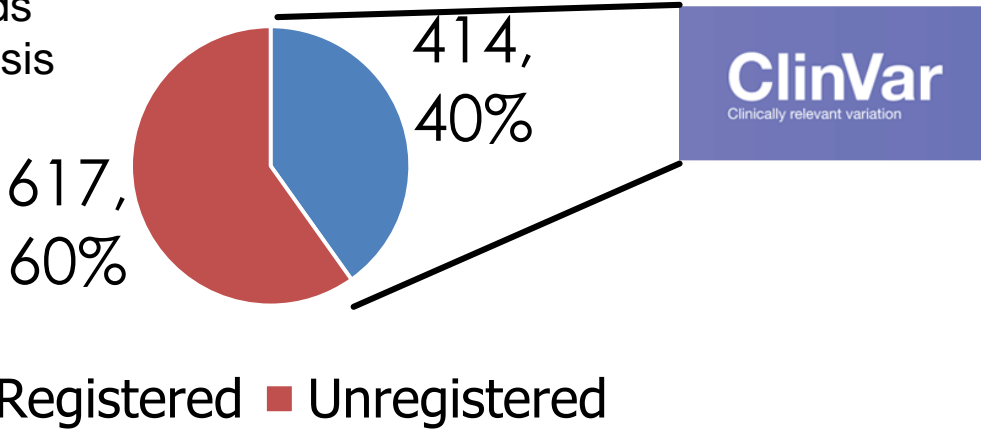
Initiative on Rare and Undiagnosed Diseases (IRUD)  
: Integrating Knowledge for Diagnoses



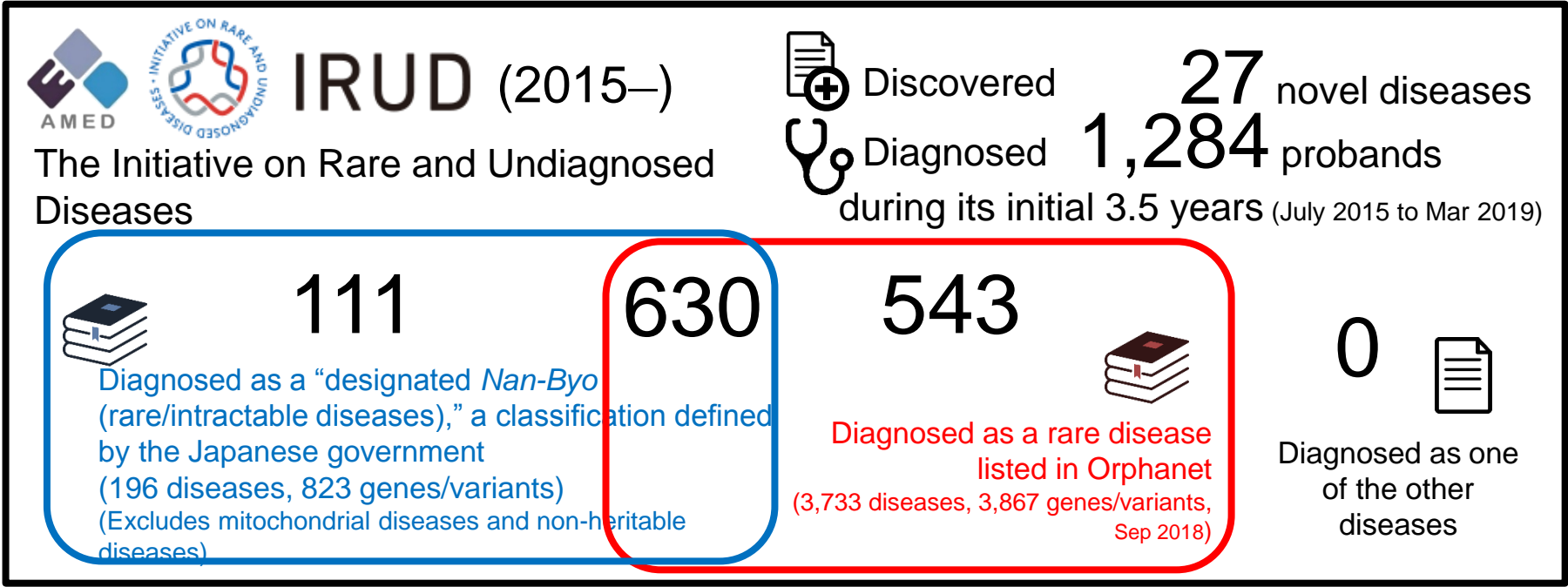
1,016

or **36.9%** of otherwise hard-to-diagnose probands received definitive diagnosis

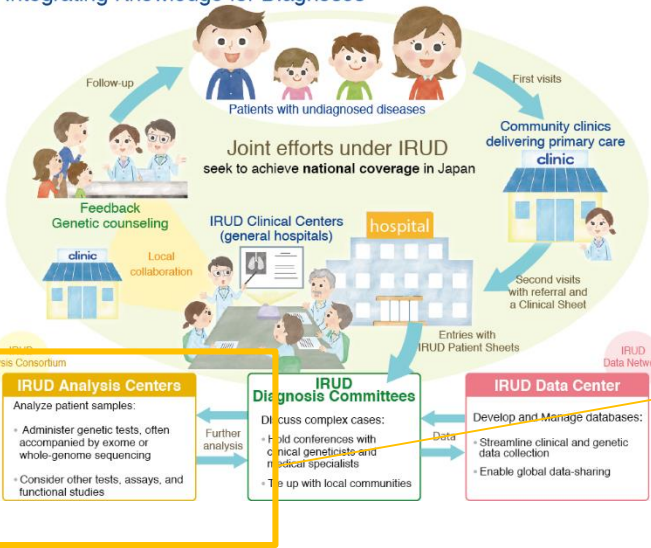
2,756 probands analyzed by the IRUD Analysis Centers



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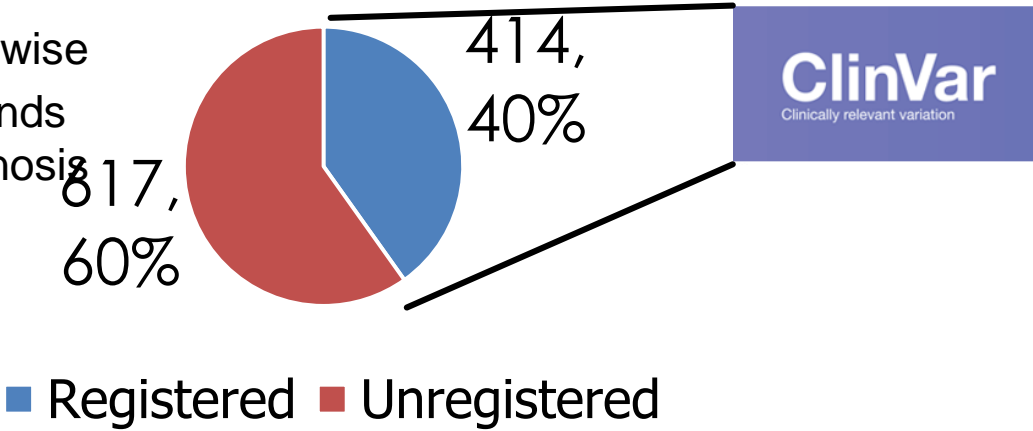


Initiative on Rare and Undiagnosed Diseases (IRUD)  
: Integrating Knowledge for Diagnoses



**1,284** or **39.9%** of otherwise hard-to-diagnose probands received definitive diagnosis

**3,217** probands analyzed by the IRUD Analysis Centers



**IRUD Exchange:** (1) Roles for patients' registry for ultrarare diseases  
(2) Deciphering molecular signaling of neuropsychiatry diseases

IRUD



## IRUD Beyond

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### Beyond genotyping

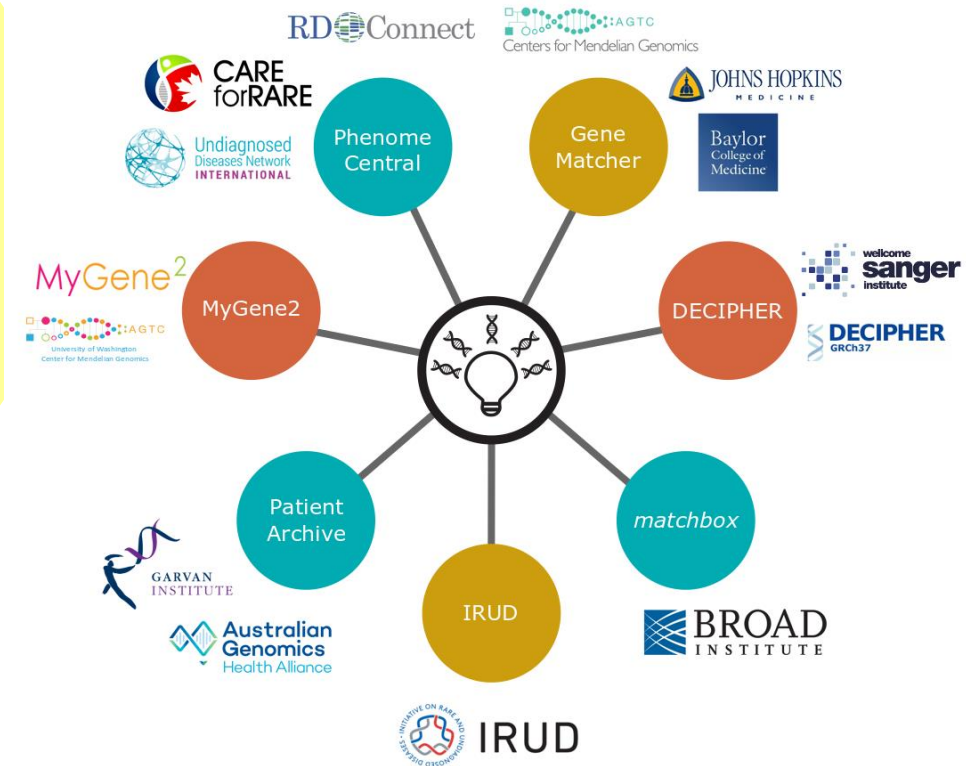
What is missing in genotyping ? How can we improve deep-phenotyping ?

What is missing in WGS ? Enrichment of phenotyping technologies

### Beyond borders

Global data sharing and fostering young investigators through bilateral funding

IRUD Exchange joins  
MATCH MAKER EXCHANGE to share data





# Learning from UK and EU

## Your Data Matters to the NHS

Information about your health and care helps us to improve your individual care, speed up diagnosis, plan your local services and research new treatments.

In May 2018, the strict rules about how this data can and cannot be used were strengthened. The NHS is committed to keeping patient information safe and always being clear about how it is used.

You can choose whether your confidential patient information is used for research and planning.

To find out more visit: [nhs.uk/your-nhs-data-matters](https://nhs.uk/your-nhs-data-matters)

個人の医療情報は、本人の医療に役立つと共に、サービスのプランニングや治療法研究に役立つ

2018年5月からのルールの厳格化に対応し、患者個人情報の安全と利用の透明化

プランニングと研究目的の利用（二次利用）については、意思表示が可能（医療目的については拒否不可能）

You can choose whether your confidential patient information is used for research and planning.

二次利用の目的は、プランニングと研究目的。  
なるべく匿名化するが、患者個人情報を用いる場合がある

to help us research new treatments, decide where to put GP clinics and plan for the number of doctors and nurses in your local hospital. Wherever possible we try to use data that does not identify you, but sometimes it is necessary to use your confidential patient information.

患者個人情報とは、個人が特定でき、かつその人の健康や治療について示す情報

Identifies you and says something about your health, care or treatment. You would expect this information to be kept private. Information that only identifies you, like your name and address, is not considered confidential patient information and may still be used:

二次利用が可能なのは、NHS、自治体、大学や病院の研究者、新たな治療法の研究を行う医学部や企業

It is used by the NHS, local authorities, university and hospital researchers, medical colleges and pharmaceutical companies researching new treatments.

以下は二次利用についての記載

### Making your data opt-out choice

You can choose whether your confidential patient information is used for research and planning. However, even if you opt out, we may still use your information for research and planning in some circumstances, such as during a public health emergency. You can still opt out at any time.

### Will choosing this opt-out affect your care and treatment?

No, your confidential patient information will still be used to help you and says something about your health, care or treatment. You would expect this information to be kept private. Information that only identifies you, like your name and address, is not considered confidential patient information and may still be used: Choosing to opt out will not affect your care and treatment. For example, you can still be screened for bowel cancer.

### What should you do next?

You do not have to opt out. You can choose to opt out securely online or through a telephone service. If you do not opt out, your confidential patient information will be used for research and planning. You can choose to opt out securely online or through a telephone service.

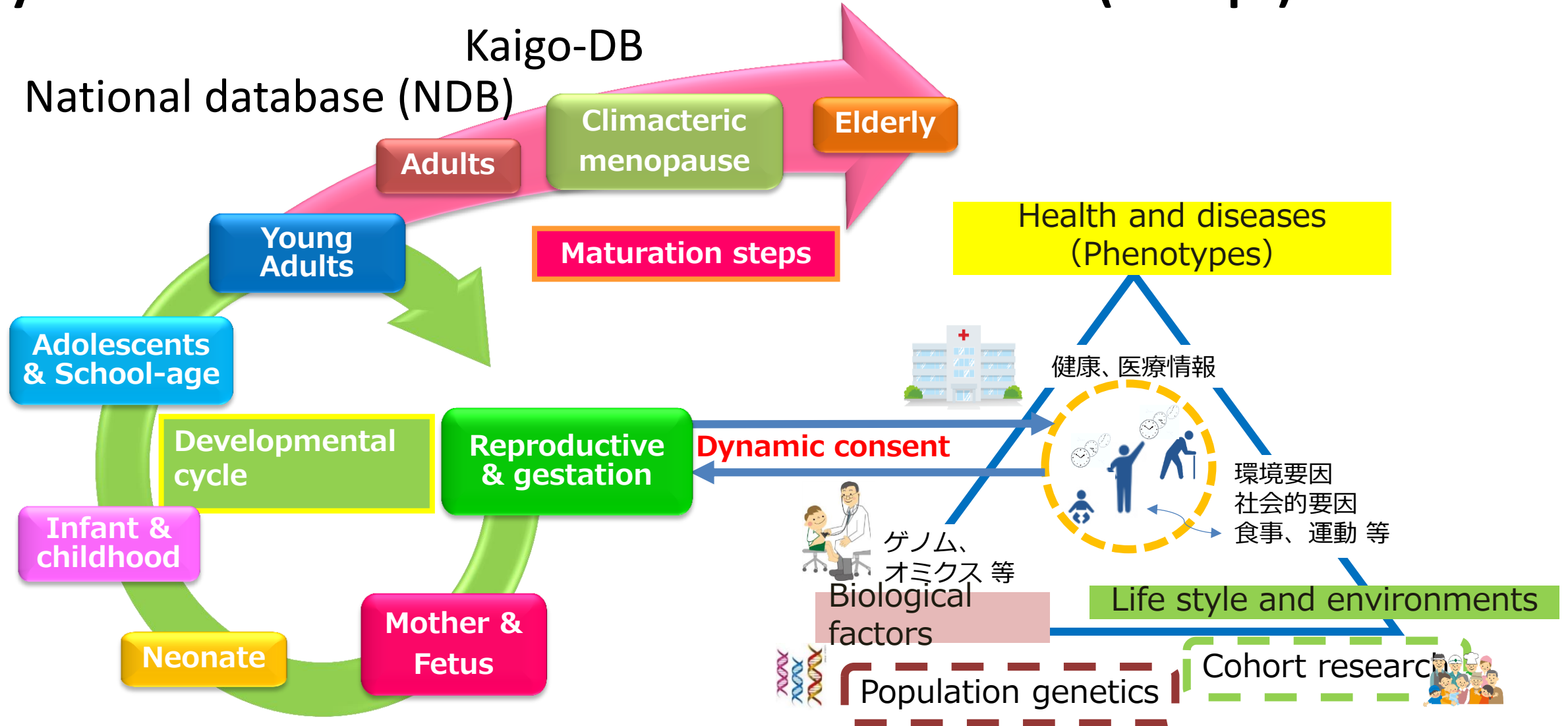
決定はいつでも変更可能

You can change your choice at any time.

# Comparing NDB data between winter times in 2019 and 2020 by NDB which contain de-identified clinical cost (receipt) data

Kaigo-DB

National database (NDB)



Life-course data linkage and sharing

# Japan shared information of YOKOHAMA CRUISE SHIP CRISIS with NAM and US Gov.

Please note: This report has been corrected. An erratum will be published.

Morbidity and Mortality Weekly Report

## Initial Investigation of Transmission of COVID-19 Among Crew Members During Quarantine of a Cruise Ship — Yokohama, Japan, February 2020

Kensaku Kakimoto<sup>1</sup>; Hajime Kamiya<sup>2</sup>; Takuya Yamagishi<sup>2</sup>; Tamano Matsui<sup>2</sup>; Motoi Suzuki<sup>2</sup>; Takaji Wakita<sup>3</sup>

On March 17, 2020, this report was posted as an MMWR Early Release on the MMWR website (<https://www.cdc.gov/mmwr>).

An outbreak of coronavirus disease 2019 (COVID-19) among passengers and crew on a cruise ship led to quarantine of approximately 3,700 passengers and crew that began

on February 4. By February 9, a total of 20 cases\* among crew members had been laboratory-confirmed, including three in those who reported close contact with other crew members with laboratory-confirmed COVID-19 before implementation of quarantine. Seven ill crew members had symptom

## Data from NIID HP

Percent of persons aboard who were confirmed with COVID-19 by age group and symptom status at the time of specimen collection.

Age group	Symptomatic confirmed cases (%)	Asymptomatic confirmed cases (%)	Total confirmed cases (%)	Persons aboard on 5 February
00–09	0(0)	1(6)	1(6)	16
10–19	1(4)	1(4)	2(9)	23
20–29	18(5)	2(1)	20(6)	347
30–39	18(4)	5(1)	23(5)	429
40–49	18(5)	7(2)	25(8)	333
50–59	27(7)	22(6)	49(12)	398
60–69	73(8)	56(6)	129(14)	924
70–79	92(9)	136(13)	228(22)	1015
80–89	27(13)	25(12)	52(24)	215
90–99	2(18)	0(0)	2(18)	11
<b>Total</b>	<b>276(7)</b>	<b>255(7)</b>	<b>531(14)</b>	<b>3711</b>

Lancet Oncology

Cancer patients in SARS-CoV-2 infection: a nation wide analysis in China

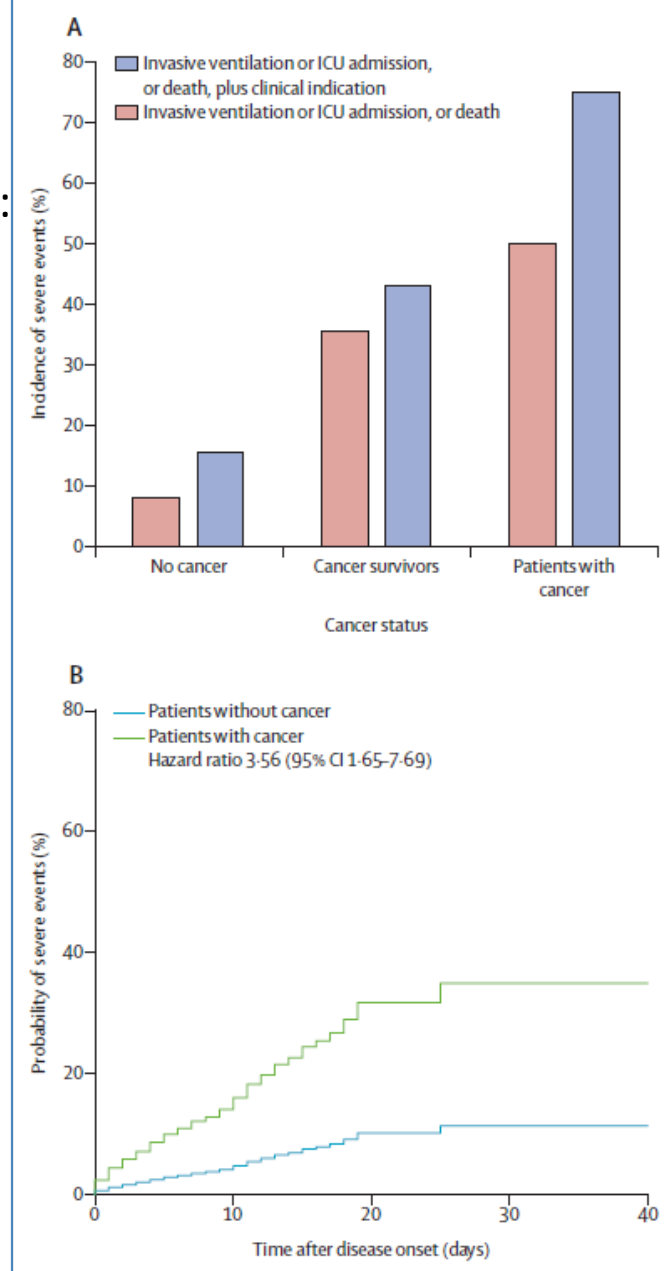
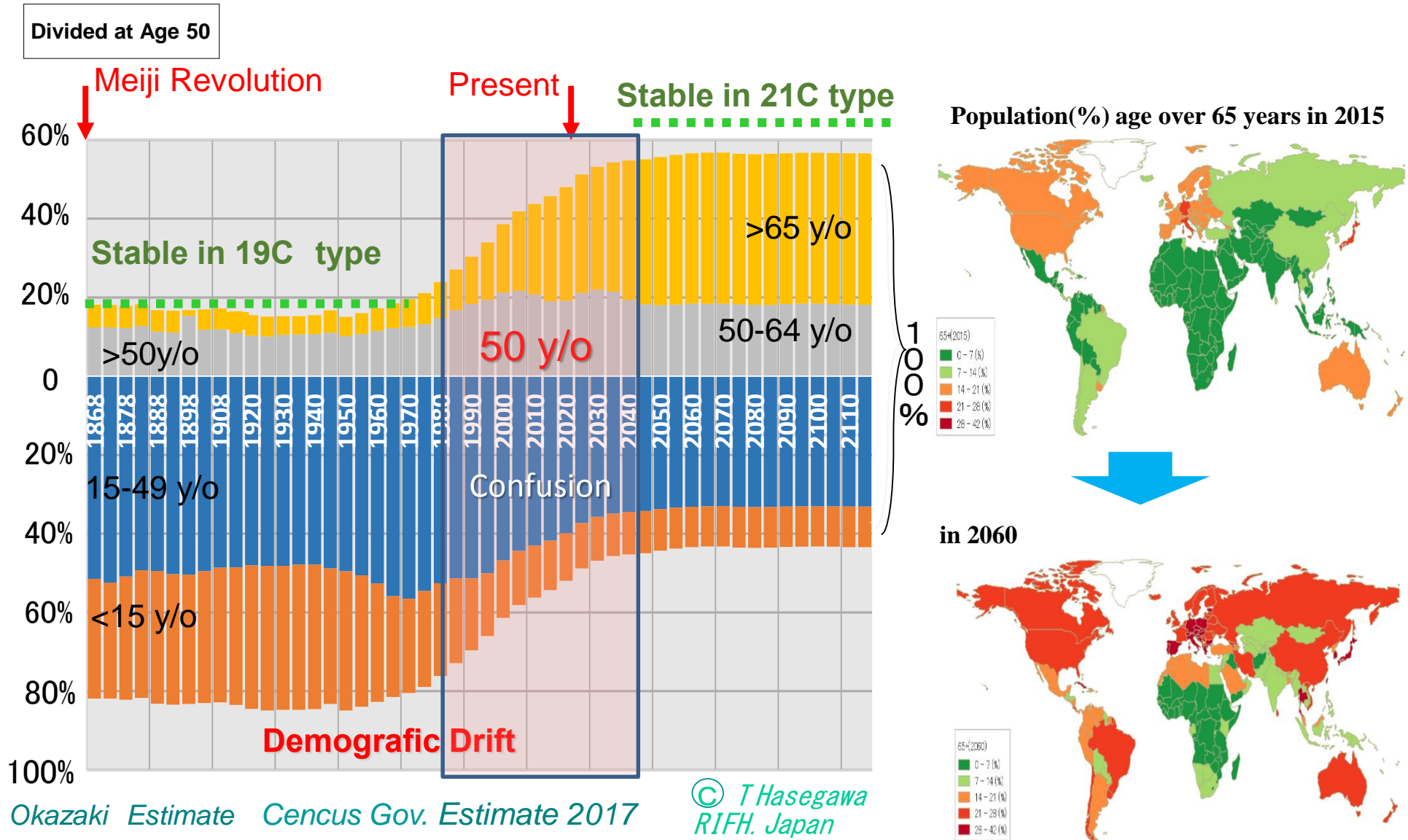


Figure: Severe events in patients without cancer, cancer survivors, and patients with cancer (A) and risks of developing severe events for patients with cancer and patients without cancer (B)  
ICU-intensive care unit.



# Not only Japan but also other countries will suffer from great demographic transition



From GFC council presentation by Suematsu M under permission by Dr Hasegawa T

# Data Free Flow with Trust for tackling against COVID-19

- ✓ Not only cardiovascular patients but also those under cancer Tx or cancer survivors
- ✓ How to relieve fears of orphan patients (neuromuscular diseases)
- ✓ Bidirectional investigation for proof of concept to develop new drugs
- ✓ Not only low molecular medicine and vaccine, but neutralizing MoAbs and biologics
- ✓ Catalyzing gaps between academia and pharmaceutical companies
- ✓ Collecting the present epidemiological data, utilizing for the present crisis
- ✓ Balance between privacy and public benefit:
- ✓ **Respect of autonomy, Do no harm, Beneficence, and Justice**  
**These 4 elements should be comparably important)**
- ✓ Supporting regional hospital staffs who take care of the elderly and those suffering from dementia

*No man is an island, entire of itself.*

*Every man is a piece of continent, a part of the main.*

*Any man's death diminishes me, because I am involved  
in mankind, and therefore, never send to know  
for whom the bell tolls; it tolls for thee.*