


## **Notice to patients who participated in the COVID-19 Registry: Call for participation in REpository of Data and Biospecimen of INfectious Disease (REBIND) and development of treatments for the novel coronavirus**



The COVID-19 Registry (NCGM-G-003494) is utilizing medical records documented and stored at various hospitals for clinical researches. In addition, it has been decided that these medical records will be transferred to the emerging/re-emerging infectious disease databank project described below. However, if you do not wish to participate in this project, please let us know. For details, please see the section below entitled “For those who do not wish to participate in the project.”

### 1. REpository of Data and Biospecimen of INfectious Disease (REBIND) Project

The Repository of data and biospecimen of infectious disease Project (hereafter, “REBIND project”), which was launched jointly by the National Center for Global Health and Medicine (NCGM) and the National Institute of Infectious Diseases (NIID) commissioned from the Ministry of Health, Labour and Welfare (MHLW). REBIND project has the following objectives: to conduct research to determine the pathology of the novel coronavirus (hereafter, “COVID-19”) and other emerging/re-emerging infectious diseases as well as infectious and non-infectious diseases in general, and to establish a platform to accelerate the development of prevention, diagnosis, and treatment of infectious diseases. The Project is led by the National Center for Global Health and Medicine.

REBIND project collects biospecimens (e.g., blood samples) and medical records related to COVID-19 and other emerging/re-emerging infectious diseases as well as infectious and non-infectious diseases in general throughout Japan. Samples and information will be collected with prior consent from participants. These samples and information will be stored and managed centrally along with gene analysis results with the aim to construct a national database (hereafter, “REBIND”) that will serve as the platform for the uses described above. The word “repository” generally refers to a facility where things such as data are stored; in the REBIND project, this repository will store and manage the samples and information described above. Furthermore, these samples and information will be widely utilized for various medical research and development, which will promote the progress of medicine in general as well as infectious

diseases.

## 2. Samples and information provided to REBIND

- Medical records

## 3. Uses of samples and information provided to REBIND

Samples and information stored by REBIND project may be used for various purposes of high social importance in addition to the following researches.

- ① Research on emerging/re-emerging infectious diseases
- ② Medical research in general
- ③ Provision to other research institutions in Japan (e.g., universities, laboratories) for research and development activities at those institutions

Specifically, samples and information are expected to be used for the following medical research and development.



- Elucidating various pathological conditions associated with disease onset and progression
- Study on therapeutic effects and side effects such as types and frequencies
- Elucidating the causes of diseases
- Research and development of new diagnostic, therapeutic, and preventive methods
- Research and development of new diagnostic, therapeutic, and prophylactic agents
- Research in hospital management, medical economics

In the future, samples and information stored by REBIND may be transferred to other public databases. In such an event, it will be conducted in accordance with legal, ministerial, and ethical guidelines regarding the protection of personal information.

## 4. Handling of personal information

Samples and information being transferred from COVID-19 registry to REBIND have already been anonymized; names, addresses, and any other information that would directly identify an individual have been deleted and a new code or number has been assigned. The table showing the correspondence of codes

and numbers to participants will be strictly controlled and will not be provided to REBIND project. Thus, personal information is managed in accordance with all legal, ministerial, and ethical guidelines regarding the protection of personal information. In addition, personal information – your name, address, and other information – will not be provided even if the samples and information were utilized as indicated in 3.

5. For those who do not wish to participate in REBIND project

If you do not wish to participate, please contact the below. Rest assured that you will suffer no disadvantages whatsoever in terms of treatment should you wish to not participate. Please note, however, that we may not be able to completely dispose of your data if it has already been used for research and part of it has been made public, or if it has been provided to other research institutions.

6. Principal investigator of REBIND project

Wataru Sugiura, Director, Center for Clinical Sciences, National Center for Global Medicine

Principal Investigator at Nagasaki University Hospital: Koich Izumikawa, Director, Infection Control and Education Center

7. Contact information

Participating Facility Partnership Office, Repository of Data and Biospecimen of Infectious Disease

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