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## RIKEN IMS Basic Policy Regarding the Sharing of Human Genome Data

### RIKEN IMS Human Genome Data Committee

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Since the time of its predecessors—the RIKEN Center for Genomic Medicine (2008-2013) and the RIKEN SNP Research Center (2000-2008) —the RIKEN Center for Integrated Medical Sciences (RIKEN IMS) has been contributing to genome analysis in cooperation with what is now the AMED B-Cure (Biobank–Construction and Utilization biobank for genomic medicine Realization) Program (formerly BioBank Japan’s MEXT Tailor-made Medical Treatment Program). Today, we have come to a point where we must consider the direction and transparency with which we should make the accumulated data available to society. To this end, a committee including outside experts was established to discuss the directions for genomic data generated by RIKEN IMS. The following is an outline of the Center’s basic policy based on the committee’s discussions.

#### 1. Policy regarding making data publically available

RIKEN IMS policy on genomic data sharing will be in line with the data-sharing framework being developed by the Institute of Medical Science of the University of Tokyo for the BBJ genomic data, as well as the data-sharing guidelines\* of AMED.

While there are various opinions regarding the handling of human genomic data that differ from that of the BBJ, it is internationally considered desirable for large-scale genome research projects to make their data available\* at the time of

publication or within two years of data generation. RIKEN IMS will need to deliberate and implement its own policy in this regard.

It should be noted, however, that even within the BBJ framework, the decision on what and how much data to make publically available is made by the organization generating the data. There is some data generated by RIKEN IMS that is currently not publically available. This includes, in particular, raw data (such as idat files) and imputation files. The committee recommends that this kind of data should be made publically available\* after a number of years have passed since publication of the relevant papers and when specifically requested, as long as the user requesting the data follows the security guidelines set by BBJ.

\* The term "publically available" as used in this document refers to any one of the three categories of data set forth in the AMED data-sharing policy for realizing genomic medicine. The three categories are: Unrestricted, openly shared data, restricted openly shared data, and restricted, closed shared data (See <https://www.amed.go.jp/content/000073342.pdf>).

## 2. Cloud computing

Cloud computing is becoming essential in the handling of large volumes of data and in sharing the latest data and analysis technology. Outside of Japan, resources like Genomics England and UK Biobank provide users with cloud-based platforms for human data and its analyses. Within Japan, BBJ is currently considering the use of external servers while it deliberates moving to a cloud-based platform in its fifth term. AMED is in the process of constructing an academic cloud data center it has dubbed CANNs (Controlled shARING of geNOME and cliNical Datasets) that brings together the datasets of several cloud-based genome centers. Also, the National Institute of Informatics offers a GakuNin Cloud Support Service "to encourage the spread of cloud use at universities and research institutions in Japan."\*\* While some progress is being made, there is still a need in Japan to deliberate on how security and stable management of such cloud-based resources can be guaranteed. There are also issues with international data-sharing outside of Japan that need to be addressed.

In the future, it is likely that cloud platforms will be constructed that provide constantly updated data and the kind of computational environment that is needed to analyze it. Hopefully, such platforms will serve to accelerate the research of a variety of users and thereby contribute to society and medicine. Recognizing that both the confidentiality of personal information and the

openness of science are equally important, RIKEN IMS will continue to work in cooperation with BBJ and other organizations in considering how best to release data that will contribute to human health and the conquest of disease.

\*\*<https://www.nii.ac.jp/en/news/release/2016/0920.html>

### 3. Miscellaneous

RIKEN IMS will establish an internal committee and undertake related measures to deliberate the above points and formulate specific measures of implementation.