Electronic Catalogue-based Database of National Center Biobank Network

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Kato⁽⁶⁾ (1)Kyoto University, (2)Ohta Nishinouchi Hospital, (3) National Cancer Center, (4)National Cerebral and Cardiovascular Center, (5)National Center of Neurology and Psychiatry, (6)National Center for Global Health and Medicine, (7)National Center for Child Health and Development, (8)National Center for Geriatrics and Gerontology Electronic Catalogue-based Database National Center Biobank Network (NCBN) (Catalogue DB) NCBN Project aims to store and manage human biological samples that are collected by The Central Biobank collects each NC's bio-resource-related information that is extracted in a 6 National Centers (NCs) and to make effective use of these samples for academic research, drug discovery, or the development of new diagnostic methods or personalized medicine, through establishing joint research. For the disease that I am interested in. common format for individual Inquiry about joint research, etc data to create catalogue data. Such information includes the are any samples available? catalogue data I would like to know: disease name of a patient, the (1) which NC biobank stores samples. type of samples, and information from the patient's medical questionnaire sheet (including (2) what type of samples, (3) how many samples, the medical history of the patient and his/her family). (4) how they are stored, and (5) which type of medical information joint research or Searching for for Researche Researcher Hardware Configuration of NCBN Catalogue DB Catalogue data Not including identifiable personal information such as the name Date of the hospital visit, age, height, weight, and blood pressure NCBN Catalogue DB The NCBN promotes the construction and maintenance of Catalogue DB in stages in coordination with the maintenance of databases in NC biobanks and the cooperation between Patient's basic information Medical history of the patient and his/her family, history of surgery allergies, and history of drinking and smoking databases in NC biobanks and Catalogue DB and these databases. Information from medical SonicWall E6500 The standard code of disease names and comorbidities (based on the ICD-10 and the Japanese standard disease-code master) Disease information WindowsServer2008 Sample information SQLServer2012 Types of pathological samples : Tissue, FFPE, blood cells (bone marrow), urine, feces, or sputum Catalogue DB Infrastructure System Flow of Individual Data from the Upload until Storage in Catalogue DB This system is responsible for a series of processes to store catalogue data (i.e., extracted individual data in a NC biobank) in the NCBN Catalogue DB. Catalogue DB Central Biobank Uploaded data are stored in File Box with a tag of "data with errors" or "data before being stored in Catalogue DB" 1 Collection of The system registers information related to bio-resources that are collected Data upload catalogue data and stored by each NC biobank (i.e., the disease name, the type of samples. additional medical information) as catalogue data in the Central Biobank. Notification of upload completion Data management The system performs a logical check to examine whether the registered and File Box Data Manage listed data are created in accordance with the formatting rules for E-mail notification of data receipt individual data. 3 Data storage in The system stores verified catalogue data in Catalogue DB. Queries are sent for questions about "Data before being Catalogue DB stored in Catalogue DB" are checked Data re-upload after "Successfully uploaded" correcting data if applicable Completion of data confirmation ar data storage in Catalogue DB disease name is used as the primary retrieval keyword Data storage in Catalogue DB ◆The disease name is coded based on the ICD-10 classification that is also used in overseas biobanks. Alternatively, the disease name control number in the Standard Master for Disease Name by the Japanese standard disease code master can be used. Notice of storage in E-mail notification of storage in Catalogue DB ♦The retrieval window displays the availability of additional clinical information that warrants Catalogue DB the diagnosis of each disease Retrieval window Results and Discussion in Japanese CBN Electronic-Catalogue-based Databa NCBNカタログデータベース We constructed the Catalogue DB infrastructure system to collect catalogue data in the Central Biobank via internet in a common format for individual data among 6 NCs. This system is functioning without any problems. This DB contains data from 25,886 registrants (patients) as of Mar. 25, '16 and has ~ 700 accesses to the retrieval page per (English) Availability of additional clinical information (Japanese) Availability of additional clinical information in a specific NC through the result The ICD-10 code is used as the standard code of disease name, (Japanese) Availability of through the retrieval window

additional clinical information through the retrieval window 年級 MINISTER . Close

- rier icu-1u code is used as the standard code of disease name, resulting in use of the same infrastructure system for the retrieval service in Japanese and English.

 Because the ICD-10 code is also used in overseas biobanks, we anticipate the possibility of cooperation between our Catalogue DB and their databases.

Future Plans

- Implementation of a natural language processing function that allows us to enter a disease name for search.
 Real-time data update by networking of in-house databases in
- each NC and by introducing a distributed database control
- Enhancement of the flexibility for the registration of medical information associated with samples or the additional clinical information about multiple tissues or sites in a patient.