

## **BBMRI.nl & Health-RI expert meeting 2021: The next step in making health data available for research.**

### **#3 – Searching and accessing data**

Following the previous session on [linking health data](#), the next and final expert meeting in our series on making health data available for research focussed on making data accessible and what procedures are needed to accomplish this. The session was the scene for 2 presentations on how to make data accessible to requesters and included some provocative propositions sparking lively discussions. This session was attended by 57 experts.

The session was moderated by Prof. dr. Folkert van Kemenade (ErasmusMC). In his introduction he highlighted the journey on making data findable and accessible during the BBMRI.nl 1.0 and 2.0 respectively. BBMRI-NL 1.0 focussed on making data, samples and images findable through the development of the BBMRI.nl Catalogue ([link](#)) and the PALGA Portal ([link](#)). BBMRI-NL 2.0 further explored data findability through the integration of registry and cohort data in the BBMRI.nl Catalogue and improved data accessibility through developing the request portal: Podium.

After the introduction, Sandra van den Broek from the Hartwig Medical Foundation (HMF) shared the experiences and challenges she faced while setting up and running a data request and access platform. HMF envisions to stimulate scientific research for improving prevention and treatment of cancer by enabling large-scale DNA analyses and systematic clinical data collection. In order to do so, the HMF hosts the largest whole genome sequencing database of metastatic cancer. At the moment, HMF hosts data of ~5500 patients (of which ~2500 have RNA sequencing data as well) and is growing continuously. The data access request procedure ([link](#)) starts with the submission of a request through the automated digital software application. Special attention is focussed on the motivation why the data is needed for the specific research questions. Received requests are reviewed by an (independent) Scientific Board and Data Access Board. When positively reviewed, a [Licence Agreement](#) between HMF and the requesting party is signed. After signing, Hartwig only makes a specific set of data (not the whole database) available, that may only be used for the approved, relevant and specific research purpose.

Data is made available by bringing the researcher to the data. In order to do so, data is accessed by the researcher in the Google Cloud Platform for several reasons, including the large amount of data per request and compliance with the GDPR-requirements. HMF believes that using the Cloud is needed for the (growing) amounts of data as the (research) community processes. Therefore, collaborations are required to find the balance between meeting all ethical, legal, societal, and technical requirements and maintaining optimal feasibility for researchers.

The second speaker Dr. Aletta Debernardi (director of PALGA) presented the request and access procedures implemented in the PALGA foundation - a nationwide registry

for pathology data. At the moment, the PALGA hosts >75 million records of >13 million patients. PALGA has been archiving since 1971 and reached country wide coverage since 1991. PALGA has two roles: 1) provide excellent support to make the best possible diagnosis and 2) excel at the collection, management and provision of structured pathology data in order to promote data quality, patient safety and to enable scientific research.

PALGA includes different databanks, being the Patiënten Zoekvraag Databank, the PALGA Informatie Databank, and the [PALGA Openbare Databank](#). The PALGA Openbare Databank allows researchers to explore PALGA's wealthy source of data and materials on an aggregated level to gain a preliminary insight. In collaboration with BBMRI.nl the [PALGA Portal](#) has been developed as a one stop shop to request pathology data and tissues federated stored at the various pathology laboratories across the Netherlands.

Importantly, requesters are supported by Data Request Consultants ('Adviseur Gegevensaanvragen') throughout the access procedure. These Data Request Consultants ensure that the requested data fits the research question, explain differences in data sources when linking data, and take their experiences and knowledge to ensure valid interpretation of the data and improve the performed research. For the future, PALGA aims to develop a digital research environment to keep data at the source to maintain data integrity, to optimise linkage with other data sources, and to ensure GDPR-compliance. In line with HMF, PALGA aims to optimise the balance between meeting all ethical, legal, societal, and technical requirements and maintaining a workable access procedure.

This series of expert meetings continued the discussions initiated in our [expert meeting series of 2020](#), focussing on the next steps in making health data available for research. Over the past few weeks, we informed you regarding [data generation according to the FAIR principles](#), [available \(meta\) data standards and solutions to find and link data sources](#), and currently implemented data access procedures and tools. Please contact Robin Verjans (robin.verjans@lygature.org) to inform us about topics you prefer to discuss during future events or regarding any additional questions or remarks.