

HDC Access Policy

Version 1.0 (April 21, 2023)

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Version History

Version	Description	Approval	Date (yyyy-mm-dd)
1.0	Initial version of the Access Policy		2023-04-21

1 Introduction

The Health Data Cloud (HDC) is a data management platform that is being developed to enable researchers and their collaborators to store, standardize, analyze, and share data generated from their research studies. It provides a platform for researchers to find and use data, to perform modelling, simulation, and virtual experiments, and to access the required computing resources. This access policy is aimed at facilitating the responsible, transparent, extensive, and appropriate sharing, access and use of the services and resources provided through the HDC. It ensures that the processes of applying for access to these services are simple and clear while facilitating ethically and legally responsible use of research data.

2 Principles of Access

The HDC operates with the following principles in accordance with the [European Charter for Access to Research Infrastructures](#).

- HDC services and resources are available for legitimate purposes (e.g., research undertaken by universities, non-governmental organisations, government agencies, research institutions, commercial organizations, independent researchers) which are not excluded by the HDC General Terms of Use.
- Access to some resources is controlled and limited to specific conditions.
- Human datasets transferred to the HDC are in compliance with the General Data Protection Regulation (GDPR) provisions. Owing to the changing landscape of technology and the increasing possibility of a positive re-identification of human datasets, use of the HDC requires that applicants intending to use human datasets enter into an agreement not to make any attempt to re-identify data subjects.

3 Definitions

Data User: Refers to the legal person (individual or organization) that accesses and/or uses datasets on the HDC.

HDC Use and Access Committee: Refers to the committee coordinated by the HDC service provider which reviews applications for access to HDC services (including data submission, use of data and other resources/services).

GDPR: General Data Protection Regulation

http://ec.europa.eu/justice/data-protection/reform/files/regulation_oj_en.pdf

Human Dataset: Collection of related sets of information from human subjects

Human Data Subject: Refers to the identifiable natural person (study participant) whose data are used in research and are accessed on the HDC (as defined in Chapter 1, Article 4 of the GDPR).

Service Provider: Refers to the institution providing HDC services, i.e., Charité - Universitätsmedizin Berlin.

Service User: Refers to legal person (individual or organization) that accesses and/or uses HDC services (such as software or computing services) that are not datasets.

4 Permission for Access and User Registration

A HDC project represents a research project that has received the necessary approvals from applicable institutional bodies, from the HDC Use and Access Committee, and from applicable Service Provider approval bodies (such as the Data Protection Officer) to use the HDC to store, process and share project data. All datasets stored in the HDC are associated with a project.

Each HDC project is assigned a Project Administrator. The Project Administrator is an HDC user that has been granted the authority to use the HDC and is typically the Principal Investigator (PI) of the research project, or a person delegated by the PI to serve the role of Project Administrator. Project Administrators can use the HDC Portal to invite other members of their project to the HDC. Invited users receive an email with a link to activate their HDC account, if they do not already have one, and can then access the project on the HDC Portal. During the activation process, each user is required to accept the HDC General Terms of Use.

Users require an account at the EBRAINS Research Infrastructure (<https://ebrains.eu/register/>). HDC users are additionally required to apply for HDC access by providing a form of personal identification for approval and HDC onboarding. This process is supported by the HDC platform administrators and the HDC Use and Access Committee.

4.1 Levels of Access

Access to HDC project data and services is controlled. There is no open or public level of access, therefore users must be authenticated on the HDC to access HDC services and/or project data. Users can only access data and services associated with the projects for which they have been authorized by Project Administrators.

The HDC uses role-based access control. Roles include Platform Administrator, Project Administrator, Project Collaborator, and Project Contributor, in decreasing order of user privilege. Each user account is assigned one of these roles, and other roles may be added in the future. Each user role is associated with a set of rights that determine the actions that a user can perform, and the data and functionality that the user can access on the HDC.

5 User Access Requirements

Users are required to accept the HDC General Terms of Use to confirm that they will comply with all applicable laws, regulations, rules, and approvals in the use and sharing of the data stored in the HDC, including the General Data Protection Regulation (GDPR). Additionally, users need to provide a means of personal identification, such as a passport number.

Beyond complying with the provisions of the General Terms of Use, the user must adhere to basic ethical principles of respect for autonomy, human rights, dignity, non-discrimination, social benefits and the principles of Responsible Research and Innovation that help the anticipation and assessment of potential implications of research and innovation to align research and technology with values, needs and expectations of society.

Non-EU users must agree to comply with the provisions of the GDPR especially with regard to data subject rights to: access, rectification, restriction of processing, erasure, data portability, object and automated individual decision-making (see GDPR chapter 3 article 12-23).

The HDC General Terms of Use also require users to agree to use the HDC services and project data only for the purposes for which access was granted, and to confirm that they understand that no guarantees are offered regarding service reliability and availability.

6 Access Charges

The HDC generally seeks to provide services to the research community without access charges. Some projects requiring specialized functionality, computing resources or support may be required to contribute funds to offset associated costs.

7 HDC Privacy Policy

The HDC privacy policy can be found at [XXX](#).

8 Terms and Conditions

Access to the HDC implies the user's approval of the HDC General Terms of Use which can be found at [XXX](#).

9 Termination of Access

The HDC and its service providers reserve the right to monitor the use of a user account and to suspend or terminate access with or without notice in case of breach of HDC General Terms of Use or other HDC policies.

10 HDC Liabilities

The HDC does not provide explicit or implied warranties for the data stored in the HDC or for the services provided by the HDC. Data may contain advice, opinions, statements or other information by various authors or entities. Reliance upon any such advice, opinion, statement, or other information is at the user's own risk.

11 Implementation and Compliance

It is the responsibility of users to demonstrate compliance to this policy upon request. Data concerning major breaches of the conditions set out in this policy will be gathered by the HDC administration team and submitted to the HDC Use and Access Committee.