

# Health Data Task Force Terms of Reference

## 1 General Part

### 1.1 Statutory Role

Advisory Bodies, such as **task forces**, workgroups, and committees, **advise and support** the General Assembly and the Board in carrying out their mandates. An Advisory Body would not act on behalf of the General Assembly or Board but would **provide guidance** to those who are authorised to act on behalf of the Association.

#### Article 6.3 of the Articles of Association stipulates:

- Chair(s) of operational and advisory bodies must come from members of the Association.
- Members of advisory bodies may be internal or external to the Association.
- Members of the Board shall not be part of an advisory body. However, they may act as a liaison between the chair(s) of the body or subgroup and the Board as a whole.
- The appointment, term of service, and revocation of the role of Chairs is the responsibility of the Board.
- Members of advisory bodies may be nominated by the Board, with approval of membership determined by the Board.

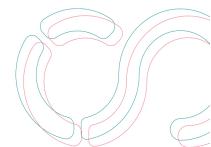
Any other criteria or restrictions for membership desirable for an Advisory Operational Body to be able to fulfil its purpose should be specified in the Terms of Reference for that Operational Body.

# 1.2 Reporting

All Bodies must keep minutes of the transactions of its meetings. The minutes shall be made available to the General Assembly and Board. All Bodies will report to the General Assembly upon request by any Member or Observer of the General Assembly.

The Task Force will report to the EOSC-A Board about its proceedings within 14 calendar days after the end of a quarter, to its Board liaison person, who will ensure the EOSC-A Board will receive the report including his/her comments.







The Board Liaison is responsible for reporting back to the Task Force on the conclusions of the discussions of the Task Force's quarterly report in the Board (if any).

The reporting framework is further described in the "EOSC-A Task Force Operational Handbook".1

## 1.3 Budget & Resources

Running costs for the meetings of these Bodies would be managed by the Secretariat subject to its usual budget approval and oversight processes (as defined in <u>Bylaws Article 7</u>).

The Budget & Resource framework is further described in the "EOSC-A Task Force Operational Handbook".

# 2 TF Background & Scope

The Health Data Task Force focuses on alignment and establishing synergies between EOSC and the European Health Data Space (EHDS). This includes, inter alia, reducing redundancies between the two initiatives and working on the common aspects such as interoperability and sharing of health data and services among the EHDS and other related activities with EOSC, or using EOSC as a capacity provider (storage, compute resources among other relevant infrastructure solutions) for EHDS. The EHDS and EOSC share challenges in making the data compliant with FAIR and FAIR-Health principles, with special emphasis in this case on interoperability (semantic interoperability in an international environment), data quality, and privacy protection mechanisms that provide good balance between the utility of data and privacy of data subjects.

The Strategic Research and Innovation Agenda (SRIA) of EOSC has among its Strategic Objectives the fostering of an increased number of services and resources across disciplines (SO6) and the coordination with the Data Spaces (SO8). Moreover, the Operational Objectives OO4 (co-develop discipline-specific standards) also relate to the health data and their correlations to environmental and socio-economic data, among others. The TF is also well aligned with some priorities of the Multi-Annual Roadmap, such as the liaison with HE projects and the domain-specific environments (in objective 1), Interoperability with Data Spaces (in objective 2).

# 2.1 Main Objective

The main principles and delivery objectives of the specific TF are listed next:





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- Develop the EOSC Strategic view towards the extensive use of Health Data in research projects through the identification of special requirements, regulations and the ethical and legal grounds to make the access and processing of health data in the context of EOSC fair (e.g., impartial and just) and safe.
- Foster the interoperability with European Health Data Space including legal, organisational, semantic and technical interoperability requirements, to minimise redundancies and maximise synergies between EOSC and EHDS.
- Build networks and partnerships mobilising EOSC and EHDS communities.

## 2.2 Key Focus Areas

The TF defines a set of measurable Key Focus Areas (KFAs) contributing to the main objective defined in the initial scope of the TF:

- KFA1: Identify business process models (i.e., needs and requirements) of health data research projects, understanding their limitations and capabilities in the context of EOSC.
- KFA2: Map and align the health research projects business process models to EOSC specific services and tools (Findability, AAI, Technical and Semantic interoperability, etc.), expecting collaboration with the TFs in the Technical Challenges Advisory Group.
- KFA3: Propose solutions to enable the alignment with EOSC actors relevant to the Health Data domain (the research health data community, research infrastructures (ERICs) and the e-Infrastructures).
- KFA4: Foster the development of partnerships among EOSC and EHDS communities.
- KFA5: Map and align EOSC solutions and nodes with the European Health Data Space needs for secondary use infrastructure (HealthDAta@EU).

## 2.3 Expected Membership

The TF is expected to raise the interest of experts from research-performing institutions related to health data, research infrastructures (ERICs) and e-infrastructure providers, who jointly will gather the necessary skills required for the objectives of the TF. We expect that the TF will comprise researchers in the health domain, experts on Research Infrastructures, research data providers and e-infrastructure experts and experts from the EHDS landscape, including from the Health Data Access Bodies (HDABs).

#### 2.4 Core Activities

Rue du Luxembourg 3, BE-1000 Brussels, Belgium +32 2 537 73 18 | info@eosc.eu | www.eosc.eu

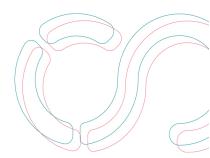
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The core activities planned for the Task Force are the following:

3

#### **EOSC Association AISBL**







Activity 1: Map involvement of different stakeholders with EOSC and EHDS on the national level in all relevant countries. Engage with stakeholders to identify user journey of health data research projects, understanding their limitations and capabilities in the context of EOSC.

**Outcome:** Expert recommendations on how to address user journey challenges when processing health data research projects.

Activity 2: Explore and Identification of gaps, redundancies, and possible synergies regarding different user journeys of researchers in EHDS and EOSC. Explore on European, national and local (data source institutions) level. Explore EOSC-related activities on Trusted Research Environments and how they match Secure Processing Environments defined by EHDS. Consider parallel activities and efforts, e.g. GDI, EUCAIM and EU Research Infrastructures, that might benefit and complement efforts in the connection of EOSC and EHDS for the use of health-related data for research and policy-making purposes.

Outcome: Deliverable 1.

Activity 3: Defining strategic view of involvement of EOSC with health data and EOSC supporting establishment and operations of EHDS.

Outcome: Deliverable 2.

#### 2.5 Deliverables and Timetable

The initial timeframe of the TF is 24 months starting from June 2024 after which the EOSC-A Board will evaluate the progress and decide if the TF needs to be extended.

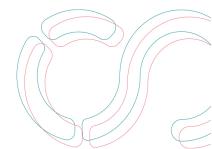
#### Deliverables

Month	Type of outcome	Title
Q4 2024	Milestone	EOSC-A Health Data TF strategy & workplan
Q2 2025	Deliverable 1	Identification of gaps, redundancies, and possible synergies regarding different user journeys of researchers in EHDS and EOSC
Q2 2026	Deliverable 2	Strategic view of EOSC supporting the adoption of EHDS

# 2.6 Working Methodology

The day-to-day collaboration of the Task Force will happen through the mailing list.







Regular video conference calls will be used to coordinate the work. The EOSC-A Health Data Task Force will solicit input from the community at large through workshops. We envisage to arrange workshops, preferable co-located with high profile events where the community at large is represented.

Decisions in the EOSC-A Health Data Task Force will be based on respectful and fair discussion within the TF and the principle of rough consensus to be determined by the Task Force Co-chairs and confirmed on the list.

# 3 Supporting Documents

The day-to-day operation of the Task Force is described in the EOSC-A Task Force Operational Handbook<sup>2</sup>.

#### 4 Relevant links

The relevant links for the Task Force can be found in TF EOSC Forum Group which will include

- Mailing list:
  - o newhealthdatatf@eosc.eu
- Meeting Minutes and action list is to be shared on EOSC Forum (Final Documents):
  - o <a href="https://forum.eosc.eu/group/tf-health-data/pages/page">https://forum.eosc.eu/group/tf-health-data/pages/page</a>
- Google Drive Folder (For working Documents):
  - o 3. Health Data
- Website entry:
  - o <a href="https://eosc.eu/advisory-groups/health-data-task-force/">https://eosc.eu/advisory-groups/health-data-task-force/</a>
- TF Framework:
  - EOSC-A Task Force Operational Handbook.
  - Articles of the Association





<sup>&</sup>lt;sup>2</sup> https://forum.eosc.eu/document/search/recent?previewDocument=66d848913d4e2de563affbd2