

MEMORANDUM OF AGREEMENT
between the
NATIONAL INSTITUTES OF HEALTH OFFICE OF THE DIRECTOR-OFFICE
OF DATA SCIENCE STRATEGY, US DEPARTMENT OF HEALTH AND
HUMAN SERVICES
and
ELIXIR EUROPE
2024-2028

This Memorandum of Agreement (MOA) involves the National Institutes of Health, of the Department of Health and Human Services and ELIXIR Europe (hereinafter referred to individually as “Participant” and collectively as “the Participants”).

Background

The National Institutes of Health (hereinafter “NIH”), a part of the US Department of Health and Human Services, is the medical research agency in the United States of America that makes and funds important discoveries that improve health and save lives. The NIH comprises 27 Institutes and Centres, and Offices (ICOs), each with its own research mission. NIH requires sharing of data collected using public funds to maximise the value of research data by facilitating innovation of research tools and methods, increasing statistical power, and improving research quality through validation and replication.

The Office of Data Science Strategy (hereinafter “ODSS”) is situated in the NIH Office of the Director. ODSS leads NIH’s efforts to modernise the NIH-funded biomedical data science ecosystem by collaborating with scientific communities to support the use of services, explore and implement standards, and promote the eventual long-term sharing of well-annotated data in a responsible manner. Through scientific, technical, and operational collaborations with the NIH ICOs, ODSS (1) develops and coordinates strategies to establish technical data standards, infrastructure, and resources related to data collection, storage, analysis, uses, and sharing; (2) addresses policy and ethical, legal, and social implications related to data science and emerging technology issues; and (3) fosters a talented and diverse data science workforce. ODSS also works with scientific communities to support clinical (e.g., Health Level Seven International [HL7] and Fast Healthcare Interoperability Resources [FHIR]) and other life sciences data (e.g., Research Data Alliance (RDA) and Research Software Alliance) standards and best practices to accelerate collaborative biomedical research.

ELIXIR Europe (hereinafter “ELIXIR”) is an intergovernmental organisation that brings together life science resources from across its 22 Members and three observer countries. With Headquarters in Hinxton, UK, ELIXIR is a distributed infrastructure with Nodes in each participating country. It connects over 250 national institutes that provide a wide range of services to users. These include databases, tools and workflows, registries, interoperability resources, compute, training, and data management support.

ELIXIR has well-established collaborations with several international initiatives, such as the Global Alliance for Genomics and Health (GA4GH) and the RDA. Additionally, it has developed collaboration strategies with national data infrastructures in key countries outside Europe, including the Australian Biocommons initiative. ELIXIR is represented by its Director Prof. Tim Hubbard.

Collaboration to date

Over the previous years, the Participants have collaborated through a number of ways, including: conducting joint workshops and conference sessions at ISMB/ECCB and Bio-IT World US and Europe; presented at reciprocal seminars to raise awareness of each respective initiative; collaborated on already funded projects such as GA4GH (i.e. driver projects) and RDA activities (infrastructure and software working/interest groups, ML working group); ODSS serves on editorial boards of the ELIXIR’s FAIR Cookbook and RDMKit; and co-authored manuscripts.¹

Principles

The objective of this MOA is to formalise these collaborations in order to better track and increase the visibility of these interactions and engagements.

The following considerations are intended to underpin the implementation of the MOA:

- Operating under the principles of open science;
- Considering the importance of collaboration in the area of life and health sciences, bridging the link between fundamental and health-focused research and the role that infrastructure plays in enabling these collaborations;
- Facilitating community building, establishing links, and raising the visibility of activities between the scientific communities in Europe and the US;
- Aiming to embed a long-term strategic collaboration between the Participants.

¹ <https://doi.org/10.1038/s41597-023-02166-3>

This MOA aims to stimulate mutually beneficial collaboration between the Participants for the benefit of advancing life and health science research internationally, whereby bioinformatics and health data science represent an indispensable source of knowledge for solutions in research data science, driving innovative solutions, further facilitating data sharing and data federation activities across respective Participants whilst complying with its own policies and international data protection regulations.

Scope of collaboration

There is a strong alignment between many thematic areas in the Goal and Objectives of the NIH *Strategic Plan for Data Science*² and the *ELIXIR Scientific Programme 2024-28*³.

The Participants identify three main areas of joint interest to strengthen ongoing activities for mutually-beneficial collaboration:

- Research data management best practices, including outreach in the US and Europe, to jointly disseminate best practices, work together to contribute and develop the FAIR Cookbook and RDMkit, and ensure a level of alignment between other related efforts in the field;
- Building relationship capital, capacity building and exchanging technical knowledge;
- Evaluation of community building activities to strengthen cross-sector international partnerships through common projects with expert community organisations, such as with the GA4GH, the RDA, Carpentries, the Galaxy and Bioconductor developer and user communities.

Potential mechanisms for realising this include, but are not limited to:

- Reciprocal invitations to a range of events, such as technical workshops, expert meetings and webinars;
- Joint 'contentathons' to advertise, enrich and expand the FAIR Cookbook and the RDMkit;
- Collaboration on already funded projects, such as GA4GH Driver Projects;
- Joint sessions at flagship conferences, such as the International Society for Computational Biology (ISBM) conference and the ELIXIR All Hands Meeting;
- Participating in mutual interest groups, such as the ELIXIR Focus Groups, for example ELIXIR's Machine Learning Focus Group;

² NIH Strategic Plan for Data Science, <https://datascience.nih.gov/nih-strategic-plan-data-science>

³ ELIXIR Scientific Programme 2024-28, <https://elixir-europe.org/sites/default/files/documents/elixir-programme-24-28-full.pdf>

- Applicable staff exchanges and scholar visits in areas of technical alignment;
- Conducting quarterly coordination calls between relevant NIH and ELIXIR staff to manage progress and coordinate ongoing activities.

Financial Responsibilities

Unless otherwise mutually decided in writing, each Participant intends to be responsible for paying all costs of participation, including travel costs for each Participant's own employees to maximise the scientific and operational benefits arising from interactions. Specific collaboration activities under this MOA are subject to the availability of personnel, funds, and other resources.

Data protection and sharing

The sharing of any personal data by either partner related to ongoing collaboration activities will be handled according to the relevant data protection laws, regulations and policies applicable to the partners, which for NIH, includes the Privacy Act of the United States, 5 U.S.C. § 552a,, and for ELIXIR, includes its internal data protection legal framework. Should the need arise, partners will deal with any data sharing protection matters regarding such collaboration activities in a separate arrangement.

Intellectual Property Rights and Confidentiality

Should any intellectual property arise from any of the collaboration activities, the Participants expect to deal with this in a separate arrangement. The Participants intend to treat as confidential any information that is labelled as such during the collaboration activities.

Promotional Material and Use of Logos

The use of a name or logo of either Participant in external activities requires prior consent of that Participant.

Settlements of Differences, Indemnification, and non-Endorsement

The Participants intend to resolve any differences arising under this MOA amicably through mutual consultations and negotiations. NIH does not endorse or recommend any commercial products, processes, or services and NIH websites may not be used for advertising or product endorsement purposes, as indicated on the NIH website under <http://www.nih.gov/web-policies-notice>. No indemnification for any loss, claim, damage, or liability is intended or provided by the Participants under this MOA.

Modifications, Commencement, Duration, and Discontinuation

The Participants plan to provide any additional information reasonably required by either Participant to assess the ongoing effectiveness of this MOA. The Participants may extend or modify this MOA by mutual written decision. Activities under this MOA are intended to commence upon signature of both Participants and may continue through 12/31/2028 to cover ELIXIR's Scientific Program 24-28. This MOA may be discontinued at any time by either Participant, which should endeavour to give at least ninety (90) days written notice to the other Participant.

This MOA is not intended to create any binding obligations under international law or under the domestic laws of the Participants.

Signed in duplicate in the English language.

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Tara A. Schwetz PhD

Date 04/09/2024

NIH Deputy Director for Program Coordination, Planning, and Strategic Initiatives
Division Director (DPCPSI)
National Institutes of Health

X 

Prof. Tim Hubbard
ELIXIR Director

Date 04/09/2024