

## Addressing Open Access in Personalised Medicine

Guidelines for PM research projects to implement Open Access Policies and data integration of research data on European databases

**OPEN ACCESS** is a key aspect of the Responsible Research and Innovation approach. It provides online, free, reusable and shared access to scientific information (peer-reviewed scientific research articles and research data). This helps to disseminate the latest research and innovation advances, with the following objectives:

- ✓ To improve the quality of the results
- ✓ To enhance efficiency
- ✓ To facilitate innovation
- ✓ To engage better citizens and society
- ✓ To avoid duplicity in public funds expenses
- ✓ To increase the impact and visibility of research

European Commission (EC) establishes [The Guidelines on Open Access to Scientific Publications and Research Data](#), to all scientific peer reviewed publications of the research projects funded or co-funded under H2020. EC facilitates Open Access through different initiatives:

- ✓ [European Open Science Cloud \(EOSC\)](#), promoting the access and reuse of research data from publicly funded research.
- ✓ [Horizon Results Platform \(HRP\)](#), promoting Key Exploitable Results to stakeholders.

ICPerMed aimed to train PM researches about the importance to implement Open Access and data management best practices, and cooperate as well with ELIXIR and 1+ Million Genomes, in order to promote the linkage of data management and different repositories (genomics, omics and medical records).

**OPEN SCIENCE** promotes a transparent, more efficient, accessible science and collaboration and immediate dissemination of research results.

The EC has established Open Science as a policy priority for research programmes under H2020 and Horizon Europe, for international calls (funded by EC) as well for national and regional funding PM research calls. It is organised according to eight ambitions:

- ✓ Open Data
- ✓ To foster the European Open Science Cloud (EOSC)
- ✓ New Generation Metrics
- ✓ Rewards
- ✓ Future of scholarly communication
- ✓ Research integrity
- ✓ Education and skill
- ✓ Citizen science

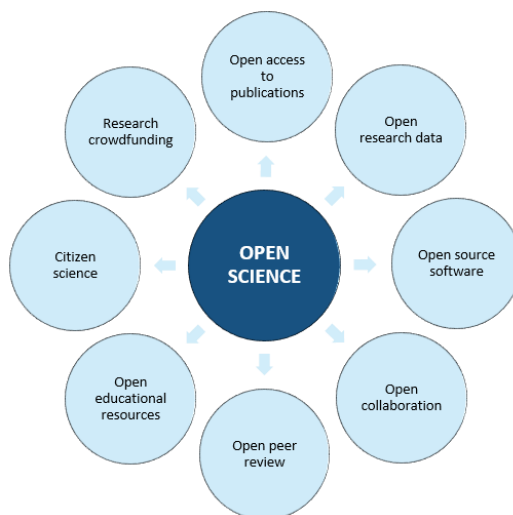
Research Funders, and specifically those funding PM research projects, should provide more information and training to their own funded researchers at national and regional level.





## Open Science englobes a whole set of different issues




The EC requires that all peer-reviewed publications and research data generated in projects funded under Horizon 2020 programme, be deposited in Open Access

**Open Data.** Research data should be freely accessed, used, modified and shared by anyone for any purpose, following the FAIR Principles: Findable, Accesible, Interoperable & Re-usable



EU Funding Programme for research & innovation	Description
<p><b>Open Access to publications and Data in Horizon 2020</b></p> 	<p>Open Access is encouraged in two political declarations: the <a href="#">Budapest Declaration</a> and the <a href="#">Berlin Declaration</a>.  <u>Researchers must ensure open access to their publications via:</u></p> <ul style="list-style-type: none"> <li>Green Open Access: researchers can deposit their final peer-reviewed manuscript or the published article providing access to scientific data. Useful listings of repositories are: Registry of Open Access Repositories (ROAR) and <a href="#">Directory of Open Access Repositories</a> (OpenDOAR).</li> <li>Gold Open Access: researchers can publish an article immediately in open access mode.</li> </ul> <p><u>Open Access to research data</u> generated in projects funded under the Horizon 2020 programme must be deposited in open access repositories that comply with European Commission mandates, as <a href="#">Article 29.3</a>. All research data should be FAIR: Findable, Accessible, Interoperable and Reusable.  <a href="#">The Practical Guide to the International Alignment of Research Data Management</a> present the requirements for data management plans.</p> <p><i>In calls at international and national level, e.g. in ERA PerMed calls, open access for the publication of the scientific outcomes and achievements of the funded PM projects can be included as mandatory.</i></p>
<p><b><u>Open Science in Horizon Europe</u></b></p> 	<p>The next steps in Open Science promotes by Horizon Europe are:</p> <ul style="list-style-type: none"> <li>To ensure that beneficiaries retain intellectual property</li> <li>To require research data to be FAIR</li> <li>To promote the adoption of open science practices</li> <li>To engage and to involve civil society</li> </ul>






Open Access to research publications & Research Data Management	Description
<p><a href="#">Open Access infrastructure for research in Europe (OpenAIRE)</a></p> 	<p>This infrastructure is the recommended entry point for scholars from any research discipline to determine which repository to choose. It offers the possibility to import their Project publications into the EU's Participant Portal and disseminate their Project results to collaborators. Tools developed by OpenAIRE:</p> <ul style="list-style-type: none"> <li>▪ <a href="#">National Open Access Desks</a> (NOADs) aims to develop capacity at a local level, to put in place the relevant support structures for open science practice and to provide expert advice on infrastructures.</li> <li>▪ <a href="#">Zenodo</a>, a catch-all repository for EC funded research.</li> <li>▪ <a href="#">AMNESIA</a> provides better anonymization of the research data.</li> <li>▪ Argos facilitates Research Data Management (RDM) activities related to the implementation of Data Management Plans (DMPs).</li> </ul>
<p><a href="#">Open Research Europe (ORE)</a></p> 	<p>A platform for the publication of research stemming from Horizon 2020, Horizon Europe and/or Euratom funding across all subject areas. ORE facilitates and encourages data re-use.</p>
<p><a href="#">European Open Science Cloud (EOSC)</a></p> 	<p>This initiative provides a set of services related to research data infrastructures (data management, data sharing, data storage, data security), based on the <a href="#">European Data Strategy</a>. It aims to create a single market for data within the EU, to benefit businesses, researchers and public administrations.</p> <p><i>ICPerMed has established collaboration with several biomedical science research infrastructures that are part of the <a href="#">EOSC-Life</a> and has developed a guidance document on services for PM purposes.</i></p>
<p><a href="#">FAIRsFAIR-Fostering Fair Data Practices in Europe</a></p> 	<p>It is an infrastructure on academic quality data management, procedures, standards, metrics and related matters, based on the FAIR principles and aims to supply practical solutions. Also, it provides a platform for using and implementing the FAIR principles in the day to day work of European research data providers and repositories.</p>



European Research Infrastructures and European Initiatives	Description
<p><b><a href="#">ELIXIR</a> Resources for data integration and Open Science</b></p> 	<p>It offers a wide variety of resources to life science researchers across Europ, such as:</p> <ul style="list-style-type: none"> <li>▪ <a href="#">ELIXIR Deposition Databases for Biomolecular Data</a>: list of repositories for publishing open data in life science research.</li> <li>▪ <a href="#">ELIXIR Core Data Resources</a>: a set of European data resources for long-term preservation of biological data.</li> <li>▪ <a href="#">Interoperability Platform</a>: which promotes interoperability best practices for data providers and data integrators.</li> </ul> <p>It offers as well a great deal of guidelines and training material for researchers:</p> <ul style="list-style-type: none"> <li>▪ <a href="#">RDMKit</a>: guide to establish good data management practices in research projects from beginning to the end.</li> <li>▪ <a href="#">FAIR cookbook</a>: recommendations for making research data FAIR.</li> <li>▪ <a href="#">Data Stewardchip Wizard</a>: guide to manage data planning.</li> </ul> <p>Also, the <a href="#">European Genome-Phenome Archive</a> (EGA) archives and shares of all types of personally identifiable genetic and phenotypic data from biomedical research projects.</p>
<p><b><a href="#">BBMRI</a> The Biobanking and BioMolecular resources Research Infrastructure</b></p> 	<p>Research infrastructure for biobanking, which brings together all the main players from the biobanking field: researchers, biobankers, industry and patients, in order to boost biomedical research. BBMRI improves the accessibility and interoperability of existing comprehensive collections, either population-based or clinical-oriented, of biological samples from different populations of Europe or rare diseases. These collections include the associated data on factors such as health status, nutrition, lifestyle and environmental exposure of the study subjects. BBMRI also offers quality management services and support with ethical, legal and societal issues.</p>
<p><b><a href="#">The 1+Million Genomes Initiative (1+MG) and The Beyond 1 Million Genomes Project (B1MG)</a></b></p>  	<p>1+MG aims to create a cross-border and secure access to a cohort of at least one million sequenced genomes in EU, with different local databases with data protection rules and standards. Currently, more tan 20 European countries are enrolled. In addition, B1MG promotes a network of genetic and clinical data across Europe.</p>



Health Data Platforms	Description
<p data-bbox="137 364 482 426"><b><u>European Health Data Space (EHDS)</u></b></p> 	<p data-bbox="534 327 1312 530">This initiative offers a secure health data sharing framework for using health data by patients and for research and innovation, policy making, patient safety, statistics or regulatory purposes. Patients and society have easy access to their own data, being able to share and control them. The availability of electronic health data could offer better and more personalised medicine.</p>
<p data-bbox="122 627 496 689"><b><u>European Health Research and Innovation Cloud (HRIC)</u></b></p>  <p data-bbox="251 723 458 764"><b>HEALTHYCLOUD</b> Health Research &amp; Innovation Cloud</p>	<p data-bbox="534 592 1312 762">HRIC is a cornerstone piece of the EHDS. This initiative facilitates the science exchange by setting a <a href="#">Glossary</a> of commonly used terms in the field of health data research. This glossary represents a living document that will be regularly updated with new terms and any modifications to existing terms, if needed.</p>
<p data-bbox="144 859 475 922"><b><u>European Health Data and Evidence Network (EHDEN)</u></b></p>  <p data-bbox="265 946 412 988"><b>EHDEN</b> EUROPEAN HEALTH DATA &amp; EVIDENCE NETWORK</p>	<p data-bbox="534 824 1312 1015">This platform involves new insights and evidences to support patients, clinicians, payers, regulators, governments and the industry in understanding wellbeing, disease, treatments, outcomes and new therapeutics and devices. In other words, it provides a new paradigm for the Discovery and analysis of health care data in Europe.</p>

