EP PerMed
European Partnership
for **Personalised Medicine**

Task 5.7 – Tackling Ethics within EP PerMed

Training Sessions on Data Management

Paris

12.02.2026

AICIB

Technical References

Project Acronym	EP PerMed
Project Title	European Partnership for Personalised Medicine

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Work Package No.	WP5 – International, Transnational, Interregional and Over-arching Cooperation
Lead Beneficiary	AICIB

List of abbreviations

PM	Personalised Medicine
EP PerMed	European Partnership for Personalised Medicine

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The *Training Sessions on Scientific Integrity* is one of the actions planned in the context of the **Task 5.7 Tackling ELSA within the EP PerMed** (Lead: AICIB | Contributors: BBMRI-ERIC, TLS, EITH). It was the second of the training activities of this Task, specifically designed to the EP PerMed scientific community.

1 Background – importance of secure and ethical data management

In personalised medicine (PM), the collection, storage, sharing, and use of data are central to research and clinical innovation. Ethical and secure data management practices are fundamental to ensure data quality, reusability, transparency, and accountability towards the public, as well as to maintain the reliability and societal impact of biomedical innovations. Proper data management also contributes to building public trust and supports broader moral and social values, such as human rights, dignity, equity, and diversity.

Compliance with ethical and legal standards in data management is mandatory within the context of the European Union's Horizon Europe Framework Programme for Research and Innovation. All funded actions are required to adhere to the highest ethical standards and to applicable EU, international, and national laws and best practices. In this context, secure and responsible data handling reflects key European bioethical principles, including autonomy, dignity, integrity, and protection of vulnerable populations.

In PM, data management raises specific ethical and practical challenges. These include safeguarding patient privacy and data security, ensuring high-quality and diverse datasets, providing equitable access to healthcare, and addressing economic sustainability. Additional considerations involve potential psychosocial impacts, such as risks of discrimination, informed consent complexities, mistrust in biomedical research, accuracy of PM diagnostics, and evolving dynamics in the doctor-patient relationship. Ethical data management therefore requires balancing competing priorities, including individual privacy versus societal benefits, open access versus restricted access to genomic and health data, economic incentives versus altruistic data sharing, community oversight versus clinical/research oversight, inclusion versus exclusion, and confidentiality versus duty to inform.

2 General aim of the event

Outlined in the broader context of Task 5.7 – Tackling ELSA within the EP PerMed, the Training on Data Management was articulated with the other capacity development and documental support activities of this Taks, which main objective relates to the provision of training and advising supporting frameworks on Ethical, Legal, data protection, data sharing and reuse, and Social and economic Aspects,

targeting EP PerMed scientific community. Its main purpose was to enable a responsible and effective use of data, by endowing researchers, clinicians, and data professionals with the knowledge, skills, and best practices necessary to manage, share, and interpret complex biomedical data in a way that supports personalised healthcare solutions.

3 Specific training objectives

The Training was specifically tailored to the PM scientific community, such as researchers, clinicians and healthcare providers, who applied to EP PerMed and other potential PM funding schemes, and that in their daily work have to deal with the complexity of managing health data, in contexts of high security and vulnerability demands. Specific Training objectives related to the enhancement of data literacy and competency; promotion of FAIR (health) data principles; facilitation of regulatory and ethical compliance; improvement of research efficiency and reproducibility; and acceleration of translational research and innovation.

Topics selected for the Sessions:

- «**Data Reusability**» – secondary use of data.
- «**Data Collection**» – key RDM issues.
- «**Data Processing & Analysis**» – Galaxy platform.
- «**Data Preservation**» – key RDM issues.
- «**Data Sharing**» – human data deposition EGA
- «**Data Management Planning**» – DSW platform

4 Trainers

- **Daniel Faria** – ELIXIR (European Life Science Infrastructure for Biological Information) – PT Node | INESC ID | University of Lisbon

- **Jorge Oliveira** – ELIXIR (European Life Science Infrastructure for Biological Information) – PT Node | INESC ID | University of Lisbon

- **Korbinian Bösl** – ELIXIR (European Life Science Infrastructure for Biological Information) – NO Node | Bergen University

5 Summary and Key Messages

5.1 Summary

The Training took place, in a fully presential format, on the 5th and 6th of February 2026, in Paris (National Research Agency – ANR Headquarters), back-to-back with the ERA PerMed JTC2022 Midterm Seminar organized by WP2 of EP PerMed. Thirty (30) trainees were selected through an application and evaluation process, from which twenty-height (28) physically attended the sessions. The group, constituted by twenty-three (23) senior and five (5) junior elements, encompassed:
- significant global geographic reach (e.g. European and African countries);
- underrepresented countries: Latvia, Moldova, Tunisia and Türkiye);
- non-European countries: Tunisia, South Africa;
- a large professional spectrum: PhD students, established researchers, university professors, science, data and project managers, medical doctors, entrepreneurs.

The welcome and introductory notes were presented by Philippe Bouvet (ANR – Host Institution / Vice-Coordination of EP PerMed), Katja Kuhlmann (Coordination of EP PerMed) Matteo Gentili (TLS – Leader of WP5), and Carlos Almeida Pereira (AICIB – Leader of Task 5.7).

Matteo Gentili

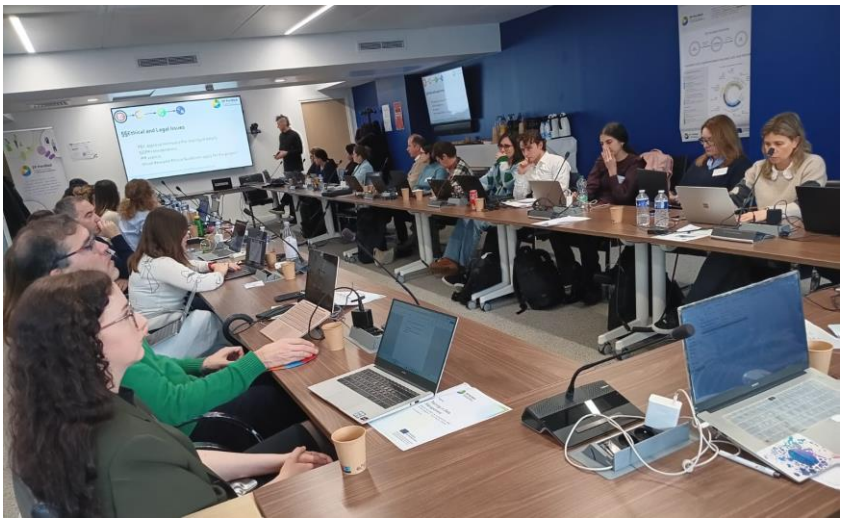
Carlos Almeida Pereira

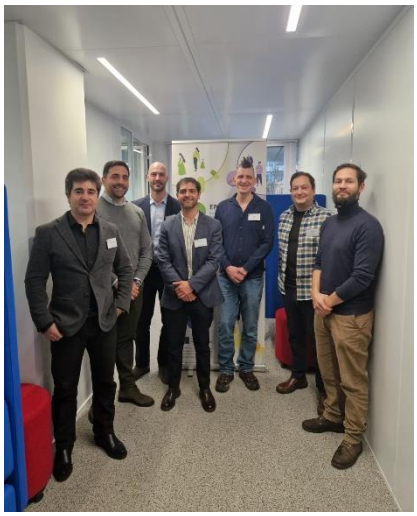
The Trainers focused their interventions on the goal of equipping the participants with practical skills and foundational knowledge in research data management, with a particular focus on the preparation and implementation of Data Management Plans (DMPs). The sessions combined structured presentations, interactive exercises, and group discussions, to create an engaging and participatory learning environment. Trainers made extensive use of digital training materials hosted on «GitHub». The «Ready4BioData Management Intensive Course» (ELIXIR Portugal) provided structured modules covering data management practices, tools, and case studies, while the ELIXIR Norway DMP Writing Workshop offered practical guides and templates for drafting high-quality DMPs. These resources were integrated directly into exercises, allowing participants to follow along, complete tasks in real-time, and access reference materials for further study. This digital integration ensured a consistent, reproducible, and accessible training experience, enabling participants to continue applying the methods after the session, also ensuring the content was aligned with internationally recognised standards and best practices in FAIR data management.

During the session, participants explored key concepts including data organisation, documentation, storage, sharing, and ethical considerations. Practical exercises guided participants through drafting their own DMPs, emphasising project-specific needs and challenges. Real-world examples were presented to illustrate common pitfalls and effective strategies in data management. The session also encouraged collaborative learning, as participants shared experiences, posed questions, and received immediate feedback from the instructors. This approach helped to reinforce comprehension, clarify uncertainties, and build confidence in applying DMP principles independently.

Feedback collected from participants indicated a high level of satisfaction with both the structure and content of the session. Participants highlighted the clarity of the materials, the practical relevance of exercises, and the effectiveness of the guided discussions in consolidating learning. The interactive elements, in particular, were noted as highly valuable for understanding how to adapt general DMP principles to specific research contexts. Based on the session, it is recommended that future trainings continue to integrate hands-on exercises with collaborative

discussions, and include examples drawn from participants' own research projects to maximise engagement and applicability.





5.2 Key messages

1. Practical Skills Development

Participants acquired hands-on experience in drafting Data Management Plans (DMPs) and applying FAIR data management principles to their own research projects.

2. Integration of High-Quality Resources

The session leveraged structured materials from the «Ready4BioData Management Intensive Course» and the «DMP Writing Workshop», ensuring alignment with internationally recognised best practices.

3. Interactive and Collaborative Learning

Exercises, discussions, and real-world examples promoted active participation, enabling participants to consolidate learning and address project-specific challenges.

4. Digital Accessibility and Sustainability

GitHub-hosted resources allowed participants to follow along in real time and provided reference materials for ongoing use beyond the session.

5. Positive Feedback and Impact

Participants reported high satisfaction with the clarity, relevance, and applicability of the session, highlighting the usefulness of interactive exercises and guided discussions.

6. Recommendations for Future Training

Continued emphasis on hands-on exercises, collaborative discussions, and project-specific examples is recommended to maximize engagement and learning outcomes.

6 Closing Remarks

The two half-days of intensive training brought together diverse perspectives and expertise, fostering critical discussions on research data management and the practical implementation of Data Management Plans (DMPs). Participants engaged actively with real-world examples and interactive exercises, which encouraged problem-solving and peer learning. The session highlighted the importance of structured planning, ethical considerations, and FAIR principles in ensuring high-quality, reusable research data. Access to well-curated digital resources supported ongoing learning beyond the training itself. Overall, the workshop reinforced participants' confidence and skills, providing a strong foundation for the effective management and sharing of research data in their respective projects.

7 Annex: List of Participating Institutions

Institution	**Country**
APHP (Assistance Publique – Hôpitaux de Paris)	France
Barcelona Supercomputing Center (ELIXIR-ES)	Spain
Instituto de Investigación Sanitaria Galicia Sur	Spain
Istinye University	Türkiye
IRCCS Maugeri Lumezzane	Italy
HOSPITAL UNIVERSITARIO ROYO VILLANOVA	SPAIN
Universitat Politecnica de Catalunya	Spain
ULS Santo Antonio	Portugal
IEO - Istituto Europeo di Oncologia	Italy
Fondazione IRCSS Istituto Nazionale dei Tumori	Italy
National Institute for Research in Medicine and Health, State Medical University	Moldova
Hospital Sant Joan de Déu	Spain
ProChild CoLAB	Portugal
Universidade de Coimbra - Faculty of Medicine	Portugal

Instituto Português de Oncologia do Porto FG, EPE (IPO-Porto)	Portugal
University of Marburg	Germany
Faculty of Medicine -University of Sfax	Tunisia
INMA/CSIC-UNIZAR-CIBER BBN	Spain
Prodigy Tech Innovations Unipessoal Lda	Portugal
GeneScape	Netherlands
Fondazione IRCCS Istituto Nazionale dei Tumori	Italy
Fondazione IRCCS Istituto Nazionale Tumori	Italy
IFOM ETS - The AIRC Institute of Molecular Oncology	Italy
Politecnico di Milano	Italy
Clinical Academic Center - Braga (2CA-Braga)	Portugal
South Africa	South Africa
Riga Stradins University	Latvia
IMT School for Advanced Studies Lucca	Italy