EP PerMed
European Partnership
for **Personalised Medicine**

Task 5.7 – Tackling Ethics within EP PerMed

Training Session (Workshop) on Scientific Integrity

Berlin

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AICIB

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EP PerMed
European Partnership
for Personalised Medicine

Technical References

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Lead Beneficiary	AICIB

List of abbreviations

PM	Personalised Medicine
EP PerMed	European Partnership for Personalised Medicine

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The *Training Session (Workshop) 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 first of the training activities of this Task, specifically designed to the EP PerMed scientific community.

1 Background – importance of Ethics related to PM

Ethical and integrity principles and standards when conducting research and innovation activities are fundamental to develop PM approaches for example to guarantee data quality, re-usability, collaborative work, accountability towards the public, also ensuring the reliability of innovations with high impact on human health. In addition, R&I ethical and integrity norms facilitate the process of building public trust and inspire the development of other important moral and social values (Human rights, dignity, equity, diversity, etc.).
Compliance to ethical and integrity research principles is fundamental within the context of the European Union's Framework Programme for Research and Innovation Horizon Europe, which ensures that all its funded actions must be carried out in line with the highest axiological standards and the applicable EU, international and national laws and best practices. Ethics and integrity are, thus, a mandatory determination of the Horizon Europe, namely in what refers to the acknowledgement of central ethical principles of the European bioethics and bio-laws, as autonomy, dignity, integrity, and vulnerability.
In Personalised Medicine (PM), ethical and integrity norms and principles are many and multifaceted as research practice and clinical applications in this area arise axiological problematization, as the privacy and security of patients' data, data quality, data diversity, access to healthcare, economic sustainability, the possible challenges of PM (including psychosocial ones), such as for discrimination of certain groups, informed consent, mistrust in in biomedical research, issues with the diagnostic accuracy of PM, and changes in the doctor-patient relationship (besides many other potential ethics aspects, as the balance between: individual privacy *vs* social benefits; open access *vs* restricted access to genomic and health data; economic benefits/profit *vs* altruist donations; community oversight *vs* clinical/research oversight; inclusion *vs* exclusion; confidentiality *vs* 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 Workshop on Scientific Integrity was articulated with the other capacity development and documental support activities, such as targeting to provide training and an advising supporting framework on Ethical, Legal, data protection, data sharing and reuse, and Social and economic Aspects, to EP PerMed scientific community. Its purpose was to contribute to the dissemination of the notion that scientific research, once conducted ethically, accurately, and transparently, namely

through the adherence to principles of integrity, truthfulness, transparency, responsibility, confidentiality, fairness, and others, may increase public, scientific peers, and policy makers' trust, reliability and accountability. Training provided in this context focused on the promotion of the adherence of PM scientific community to ethical and integrity values and principles when developing, applying and reporting the results of their scientific activities.

3 Specific training objectives

The Workshop was specifically tailored to a PM scientific community, such as researchers, clinicians and healthcare providers, who did or could apply to EP PerMed and other potential PM funding schemes. These are then dealing with ethics and integrity compliance considerations, from the preparation via the submission to the execution phase of the successful scientific projects. It was designed for invited Trainers to provide pedagogical interventions to the target audience. The intensive, advanced training sessions on Scientific Integrity focused on:

- the most significant guidelines of the *European Code of Conduct for Research Integrity*;
- the key principles of research integrity;
- the crucial procedures of good research practice;
- the best practice when disseminating, communicating and exploiting the research results;
- the Ethics and Integrity Compliance under Horizon Europe.

The topics selected for this Workshop have been:

- «**Research Integrity & Impact**» – contributions of Research Integrity for Scientific Impact.
- «**Good Research Practice**» – reproducibility and integrity in biomedical research.
- «**Scientific Integrity & Responsible Research Communication**» – responsible dissemination of scientific results and the importance of effective communication.
- «**Responsible Research & Ethics**» – research ethics and compliance under Horizon Europe regulations.

4 Trainers

- **Maura Hiney** – ALLEA (European Federation of Academies of Sciences and Humanities)
- **Emanuela Oldoni**– EATRIS (European infrastructure for Translational Medicine)
  Sarah Morgan – EATRIS (European infrastructure for Translational Medicine)
  Saheli Datta Burton – UCL (University College London)
- **Susana Magalhães** – i3S (Institute of Research and Innovation in Health / University of Porto)

5 Summary and Key Messages

The Workshop took place, in a fully presential format, on the 12th and 13th of February 2025, in Berlin, back-to-back with the 1st conference of EP PerMed. 30 trainees, selected through an application and evaluation process, attended. The group, constituted by 25 senior and five junior elements, encompassed:

- significant global geographic reach: Morrocco, Czech Republic, Finland, Germany, Italy, Ireland, Turkey, Spain, Switzerland, Moldova, Tunisia, Lithuania, Portugal, Honduras, Bulgaria, Norway, South Africa;
- underrepresented countries: Morocco, Tunisia, Czech Republic, Moldova, Lithuania, Bulgaria, Turkey, Ireland;
- non-European countries: Morocco, Tunisia, Honduras, South Africa;
- a large professional spectrum: PhD students, established researchers, teachers, science and project managers, medical doctors, entrepreneurs, etc..

The welcome and introductory notes by Wolfgang Ballensiefen (DLR – Coordinator of EP PerMed), Matteo Gentili (TLS – Leader of WP5), and Carlos Almeida Pereira (AICIB – Leader of Task 5.7), were followed by the pedagogical interventions, as subsequently indicated.

Wolfgang Ballensiefen

Matteo Gentili

Carlos Almeida Pereira

5.1 Maura Hiney – European Code of Conduct for Research Integrity| Key Principles of Research Integrity

In her training intervention, and combining theoretical explanations with case studies, Maura Hiney explored the role of research integrity in ensuring scientific trustworthiness and impact. After a conceptual approach, in which the definition and challenges of research integrity were tackled, Hiney expounded on the impact of scientific misconduct on public trust and researchers' credibility. The types of misconduct (fabrication, falsification, and plagiarism, alongside questionable research practices) were expounded, as well as the prevalence of misconduct and the key drivers behind unethical behaviour. The role of the European Code of Conduct for Research Integrity and other policy initiatives in preventing misconduct and fostering research integrity was analysed. Finally, participants completed a case study examining the Wakefield case and its implications for society.

Key Message: cultural and systemic changes are needed to foster a research environment that prioritizes ethics and integrity.

Maura Hiney

5.2 Emanuela Oldoni | Sarah Morgan – Good Research Practice

In a joint effort, and in an interactive model that included a pedagogical game, Emanuela Oldoni and Sarah Morgan focused on the best practices in scientific research, emphasizing reproducibility and integrity in biomedical research and trustworthy Artificial Intelligence (AI). They started by problematizing "Good Research", and the ethical, methodological, and professional standards ensuring research validity and trust. Then, they approached the best practices in biomedical research, and the guidelines for improving reproducibility in preclinical research for personalised medicine. The challenges in reproducibility were, subsequently, addressed, namely how methodological flaws impact research reliability. Transparency in data science and AI was also a topic under discussion, namely the importance of open and well-documented data practices. In the end, the Trainers made some recommendations for robust preclinical models, namely regarding strategies to enhance translational research and to bridge the gap between preclinical and clinical phases.

Key Message: promoting reproducibility, integrity, and transparency in biomedical research and AI is essential for ensuring trustworthy, valid, and ethically sound scientific practices, especially in preclinical research and personalized medicine.

Emanuela Oldoni

Sarah Morgan

5.3 Saheli Datta Burton – Dissemination, Communication & Exploitation of Research Results

Saheli Datta Burton based her intervention on the responsible dissemination of scientific results and the importance of effective communication in science. One of Saheli's central topics was transparency in research communication, viewed as critical for building and maintaining public trust. Then, distinguishing research ethics from responsible innovation, she highlighted the relevance of aligning research with societal needs. Regarding the open science movement, the challenges and benefits of making research accessible were discussed, as well as the risks of poor scientific communication, that normally lead to public misunderstandings and therein contributing to weaker social acceptability of emerging science. Finally, some strategies for public engagement were presented, namely the inclusion of diverse stakeholders in iterative and continuous diaglogue with research(ers)

Key Messages: responsible dissemination of scientific results through effective, transparent and iterative dialogue with the diverse stakeholders is essential for aligning research with societal needs, building and maintaining public trust in science, and ensuring social acceptability of emerging science.

Saheli Burton

5.4 Susana Magalhães – Responsible Research under ALLEA | Ethics Compliance under Horizon Europe

As a topic requested by EP PerMed scientific community, compliance under Horizon Europe regulations occupied part of Susana Magalhães' training intervention. This combined conceptual moments with case studies (for instance, a case study on scientific fraud, consisting of a recent example of misconduct and its impact on the scientific community). The concept of "moral disengagement" in research was also discussed, as the causal substrate of the unethical behaviour of ethical individuals. Then, the intervention focused on potential strategies for fostering institutional integrity, while path to building an ethical research culture. Authorship abuse in scientific publishing was another topic tackled, namely ghost, guest, and honorary authorship issues. Ultimately, Magalhães reflected on the importance of ongoing ethical reflection and AI transparency in research, as well as in the role of codes of conduct in ensuring diversity, inclusion, and responsible research practices.

Key Messages: fostering an ethical research culture requires ongoing ethical reflection, institutional integrity, and transparency – especially in addressing misconduct, authorship abuse, and compliance with regulations in the context of responsible and inclusive research practices.

Susana Magalhães

5.5 Closing Remarks

The two half-days of intensive training brought together diverse perspectives and expertise, fostering critical discussions on transparency, ethical practices, and responsibility in research. Through interactive sessions, case studies, and expert-led interventions, participants gained valuable insights into the challenges and best practices shaping today's scientific landscape. By reinforcing a culture of integrity, accountability, and openness, the workshop highlighted the collective commitment to advancing trustworthy and socially responsive science in Personalized Medicine.

6 Annex: List of participating institutions

Institution	**Country**
Hospital del Mar Research Institute	Spain
IRCCS Maugeri	Italy
Innovative Medicine Centre	Lithuania
USMF	Moldova
charles univerzita ujep utb	Czech Republic
University of Bologna	Italy
ERCIYES UNIVERSITY	Turkey
University of Helsinki	Finland
AICIB	Portugal
Oslo University Hospital	Norway
Hospital del Mar Research Institute - Barcelona	Spain
Faculty of Medicine-University of Sfax	Tunisia
Prodigy Tech Innovations Unipessoal Lda	Portugal
Clinical Academic Center - Braga (2CA-Braga)	Portugal
Humboldt-Universitaet zu Berlin	Germany
Università Politecnica delle Marche/IRCSS INRCA	Italy
Humboldt University Berlin, Faculty of Life Science, Institute for Biology, Systems Medicine of the Liver	Germany
Selcuk University	Turkey

TUBİTAK	Turkey
University of Health Sciences	Turkey
Alliance for Public Health,Ukraine/FIND, Switzerland	Ukraine/Switzerland
Hospital del mar	Spain
Universidad Católica de Honduras	Honduras
IRCCS INRCA	Italy
Università Cattolica del Sacro Cuore di Roma	Italy
IRCCS Istituti Clinici Scientifici Maugeri, Milano	Italy
IRCCS AOU di Bologna, Policlinico di Sant'Orsola	Italy
South African Medical Research Council	South Africa
Humboldt University	Italy
UCD	Ireland