RDA webinar on data visitation

From policy to implementation technologies

The EOSC-FUTURE/RDA AIDV-WG's outputs framing Lifetime Omics data visitation technologies

Tuesday 17 December 2024
14:00 to 15:00 UTC; 15:00 to 16:00 CET; 9:00 to 10:00 am EST
Register here for the Zoom meeting

Organised by the
European Open Science Cloud – Future (EOSC-Future) & Research Data Alliance (RDA)
Artificial Intelligence and Data Visitation Working Group (AIDV-WG)
with RDA TIGER Support

Contents

RDA webinar on data visitation 1

From policy to implementation technologies The EOSC-FUTURE/RDA AIDV-WG's outputs framing Lifetime Omics data visitation technologies 1

- Webinar description 2
- Webinar agenda 2
- Webinar methodology 3
- Webinar impact 4
- Target audience 5
- Biographies 5

Webinar description

Join us for an insightful webinar, 'From policy to implementation technologies: The EOSC-FUTURE/RDA AIDV-WG's outputs framing Lifetime Omics data visitation technologies', where we delve into the latest advancements in ethical and technological frameworks for data visitation. This webinar highlights the integration of AIDV-WG's global policy outputs with Lifetime Omics' FAIRLYZ platform. Central to this discussion are the AIDV's landmark policy documents: *Guidance for Ethics Committees Reviewing Artificial Intelligence and Data Visitation*, *Guidance for Informed Consent in the Context of Artificial Intelligence and Data Visitation*, and the *AI Bill of Rights Recommendation*. These frameworks empower researchers to navigate the complexities of secure, ethical, and compliant data visitation practices. Attendees will learn how these policies, can be operationalized through Lifetime Omics' FAIRLYZ's cutting-edge technology that features AI-driven quality control, gamified curation, and FAIR compliance.

This event bridges the gap between policy development and real-world application by focusing on the intersection of open science, data governance, and cutting-edge technology. A demonstration of the FAIRLYZ platform will show how ethical and legal guidance can be used to support actionable tools for data visitation. The webinar will address critical needs for secure and ethical data sharing through reliable data visitation infrastructure. The FAIRLYZ platform's technologies enable researchers to manage, curate, and share sensitive datasets efficiently within a framework of the FAIR Data Principles. Although currently in its pilot stage, FAIRLYZ has the potential to transform the way we share data for AI. By adhering to the rigorous standards of the RDA AIDV policies, we're ensuring that FAIRLYZ ongoing development is both innovative and responsible.

Webinar agenda

Time	Topic	Presenter
00:00	**Welcome and opening remarks**	**Professor Perihan Elif Ekmekci** MD, PhD, Head of History of Medicine and Ethics Department, Deputy Dean of the School of Medicine, Head of the Institutional Review Board, TOBB University of Economics and Technology; Co-Chair, EOSC-Future/RDA AIDV-WG; Ankara, Turkey
00:05	**The EOSC-Future/RDA AIDV's deliverables as framing documents for data visitation tools** 1. Guidance for Ethics Committees Reviewing Artificial Intelligence and Data Visitation 2. Guidance for Informed Consent in the Context of Artificial Intelligence and Data Visitation 3. AI Bill of Rights Recommendation	**Professor Natalie Meyers** Professor of the Practice Lucy Family Institute for Data & Society, University of Notre Dame, USA & CODATA Working Group on the role of integrity in

Time	Topic	Presenter
		data and AI science, ethics, and policy (Integrity-WG)
00:15	**From policy to implementation in the digital space**	**Francis P. Crawley** Co-Chair & Principal Investigator, EOSC-Future/RDA AIDV-WG Chairman, Leuven, Belgium
00:20	**Data visitation** **Effective methodologies & technologies** Including a hands-on demonstration of FAIRLYZ technologies and the Lifetime Omics data visitation platform.	**Dr. Patricia Buendia, PhD** Founder & CEO Lifetime Omics
00:40	**Open discussion**	**Professor Perihan Elif Ekmekci**
00:55	**Summary of the webinar**	**Moderators** **Professor Perihan Elif Ekmekci** **Professor Natalie Meyers**
01:00	**Close of the webinar**	

Webinar methodology

This webinar is designed to engage a diverse global audience of researchers from across all disciplines who are engaged in data collection, data curation, data analysis, and data sharing in the context of the FAIR Data Principles as well as within scholarly communication and open science practices. It focuses on the role of ethics, governance, and technical innovation in achieving EOSC sustainability goals through data visitation.

This webinar is structured to provide a comprehensive and interactive experience, bridging theoretical frameworks with practical applications in data visitation. It adopts a structured approach to explore the intersection of ethical, legal, and technological dimensions of data sharing. The webinar integrates expert-led presentations, a live demonstration of cutting-edge technologies, and an open discussion to facilitate knowledge exchange and collaborative dialogue.

The event aims to contextualize and operationalize the *EOSC-Future/RDA AIDV-WG*'s landmark policy outputs, such as the *Guidance for Ethics Committees Reviewing Artificial Intelligence and Data Visitation*, the *Guidance for Informed Consent in the Context of Artificial Intelligence and Data Visitation*, and the *AI Bill of Rights Recommendation*. These deliverables serve as the foundation for understanding secure and ethical data visitation and how they align with open science principles and the FAIR Data framework.

Specific goals

The webinar's agenda is crafted to achieve specific goals through a targeted methodology. The session opens with expert presentations to introduce the foundational policy frameworks, their relevance, and their role in guiding ethical AI and data visitation practices. It progresses into an exploration of how these policies transition from theoretical constructs to actionable tools within the digital landscape, led by experienced thought leaders in the field.

A pivotal component of the methodology is the hands-on demonstration of Lifetime Omics' FAIRLYZ platform. This practical segment highlights how technologies like AI-driven quality control, gamified curation, and FAIR compliance are applied to enhance data sharing and curation. The live demonstration provides attendees with a tangible understanding of how these technologies operationalize ethical and legal principles in real-world scenarios.

The event includes an open discussion and summary session, encouraging active engagement and fostering a collaborative exchange of ideas. This interactive format ensures that participants leave with actionable insights into the integration of ethical and legal frameworks with advanced technologies, empowering them to apply these learnings to their own data-sharing ecosystems. By aligning with the goals of the Research Data Alliance (RDA), the webinar supports global data sharing practices while promoting inclusivity and innovative solutions for cutting-edge research ecosystems.

Webinar impact

This webinar is expected to deliver several significant impacts across the RDA data sharing and open science communities having the following impacts:

1. **Enhanced understanding of data visitation frameworks**
   Attendees will gain a clear understanding of how the *EOSC-Future/RDA AIDV-WG*'s policy outputs translate into actionable tools. This empowers researchers and stakeholders to navigate the complexities of ethical and legal challenges in data visitation practices.
2. **Promotion of advanced data visitation technologies**
   The demonstration of the FAIRLYZ platform will showcase cutting-edge technologies for data curation, AI-driven quality control, and compliance with FAIR principles. This practical insight equips participants with the knowledge to implement these tools in their own institutions, advancing data sharing practices and increasing the reliability and reusability of shared datasets.
3. **Support for ethical and inclusive open science**
   By emphasizing ethical and legal frameworks, the webinar fosters a culture of accountability and transparency in data sharing. It supports the equitable participation of underrepresented regions and diverse research communities, aligning with global priorities like the United Nations' Sustainable Development Goals (SDGs).
4. **Capacity building and skill development**
   Through expert-led discussions and interactive segments, the webinar strengthens the capacity of participants to adopt and implement advanced data visitation methodologies. This contributes to developing the human capital needed for managing Open Science infrastructures and leveraging AI responsibly.
5. **Catalyzing collaboration and policy innovation**
   The webinar encourages international cooperation and dialogue among researchers, policymakers, and technologists. By addressing global challenges in data governance and

AI integration, it paves the way for collaborative innovation and the development of interoperable standards that support Open Science ecosystems like EOSC.

6. **Driving adoption of RDA and EOSC principles**
   The session reinforces the RDA's mission to globalize data-sharing practices and align them with the FAIR Data Principles. It also highlights EOSC's priorities, such as building trust in digital research environments, fostering sustainability, and promoting ethical AI innovations.

Overall, the webinar will contribute to a stronger, legally-framed, and ethically-driven data sharing practices within open science communities, equipping participants to leverage data visitation technologies effectively while adhering to global standards and priorities.

Target audience

The target audience for this webinar includes researchers, policymakers, data governance professionals, and technology developers engaged in Open Science, artificial intelligence (AI), and data-sharing ecosystems. It is particularly relevant for members of the Research Data Alliance (RDA), European Open Science Cloud (EOSC) stakeholders, ethics committee members, and professionals involved in legal, ethical, and technical aspects of AI and data visitation. The session also appeals to those focused on aligning research practices with global standards like the FAIR Data Principles and the United Nations' Sustainable Development Goals (SDGs). By addressing the intersection of policy, technology, and ethical frameworks, the webinar is designed to attract a diverse, multidisciplinary audience committed to advancing equitable and responsible data-sharing practices.

Biographies

Dr. Patricia Buendia, PhD, Founder & CEO, Lifetime Omics, USA

Patricia is a bioinformatics scientist with over 20 years of experience in biomedical research and has been awarded several contracts and grants from the Centers for Disease Control and the National Institutes of Health. She earned her Master's degree in computer science from the Technical University of Munich and her PhD. in Bioinformatics from Florida International University. Her research and career activities are focused on assisting the biomedical community with access to quality data and computational tools that improve and accelerate knowledge discovery in all aspects of medicine and health care. In her research, she combines data integration methods with algorithmic, statistical, and machine learning approaches to discover or extract medical/biological knowledge from clinical/health records, imaging data, and high-throughput biomedical data, such as NGS and omics data. She has developed computational tools for phylogenetic and machine learning analysis of RNA viruses such as HIV-1 and Hepatitis C viruses and published several infectious disease papers. She works in collaboration with renowned experts in biomedical translational research, PhDs in academia, and MDs doing clinical trials, and appreciates the mutual exchange of ideas that leads to discoveries, biomarkers, and treatments.

Professor Perihan Elif Ekmekci M.D. Ph.D, Head of the History of Medicine and Ethics Department and Deputy Dean at TOBB University Medical Faculty, the Head of the International Chair in Bioethics/WMA Cooperation Center

TOBB ETU Medical Faculty. Dr. Perihan Elif Ekmekci is a member of the CODATA International Data Policy Committee (IDPC) and Co-chair of the EOSC-Future/RDA Artificial Intelligence and Data Visitation Working Group (AIDV-WG). She has expertise in the fields of medicine, ethics, and history of medicine. She holds an M.D. and Ph.D. and is currently affiliated with the Department of History of Medicine and Ethics at TOBB University Medical Faculty, Ankara, Turkey. Dr. Ekmekci's educational background includes a medical

degree from Ankara University Faculty of Medicine, as well as a Ph.D. in Medical Ethics and History of Medicine from Ankara University. She has held positions as an Assistant Professor and currently serves as the Head of the History of Medicine and Ethics Department and Deputy Dean at TOBB University Medical Faculty, the Head of the International Chair in Bioethics/WMA Cooperation Center (formerly UNESCO Unit for Bioethics) o, member of Open Science Committee of TOBB ETU, and as the Chair of the Institutional Review Board (IRB) of TOBB University Medical Faculty. Dr. Ekmekci is affiliated and is an active member of several professional societies and scientific boards, including the World Association for Medical Law, the European Network of Research Ethics Committees, European Open Science Cloud Task Force, the International Forum of Teachers (IFT) of the International Bioethics Chair in Bioethics, and the Research Data Alliance.

Professor Natalie Meyers, Professor of the Practice Lucy Family Institute for Data & Society, University of Notre Dame, USA

Natalie Meyers serves as a Professor of the Practice in the Lucy Family Institute for Data & Society at the University of Notre Dame in the USA and holds an appointment as a Computational and Data Science Research Specialist at the San Diego Supercomputer Center University of California San Diego (UCSD) USA. Meyers' research focuses on FAIR data management and software preservation for model driven research. Prior to joining Notre Dame, she was co-owner of Content Innovations, LLC, a California certified woman-owned small business in San Francisco. Meyers was previously a programmer analyst and GIS specialist at UC Berkeley where she also received her Masters in Library and Information Systems (MLIS) with a concentration in Systems Analysis and Database Design. She also holds an MA in English from University of Wisconsin, Milwaukee.

Francis P. Crawley, Co-chair and Principal Investigator of the EOSC-Future/RDA Artificial Intelligence and Data Visitation Working Group (AIDV-WG)

A philosopher specialized in research ethics, integrity & methodology as well as in data/AI ethics & law. Expertise in EU, US, international and country-specific ethics, law, and patient and community interests in health-related research. Strong experience working closely with patients, communities, researchers, and policymakers across disciplines. domains, and geographic regions in establishing consortia, developing patient registries, contributing to the development of biobanks, drafting data management and data protection plans, and contributing to building data repositories. His currently Chair of the CODATA International Data Policy Committee (IDPC), FORCE11 working group on 'Developing research assessment criteria for the use of AI in scientific and scholarly publications (RA4AI)', and Co-chair and Coordinator of CoARA-ERIP: Coalition for Advancing Research Assessment (CoARA)'s Working Group on 'Ethics and Research Integrity Policy for Responsible Research Assessment in Data and Artificial Intelligence (ERIP)': https://coara.eu/coalition/working-groups/. He is a Global Fellow in Medicines Development Program (GFMD) and currently a member if the Ethics Working Group of the International Federation of Associations of Pharmaceutical Physicians and Pharmaceutical Medicine (IFAPP).