EMIF

EMIF Ethical Advisory Board

Responsibilities & members

Responsibilities

The Ethical Advisory Board (EAB) of the European Medical Information Framework (EMIF) is the body responsible for setting up EMIF's appropriate governance structures and for addressing the ethical, legal, and privacy aspects pertaining to the re-use of human health data within the EMIF project.

The EAB serves as an independent and external advisory board to the EMIF project. Its primary responsibility is to formulate and review the EMIF Ethical Code of Practice (ECoP) and advise on updates as needed.

The ECoP is a set of requirements with which each organisation participating in EMIF (as a data source or a data user) must comply through their local SOPs (existing ones or supplementary ones created to comply with EMIF Ethical Code of Practice (ECoP)). The ECoP covers the use of different types and levels of aggregation of data in the framework of EMIF throughout various R&D phases included in the project. In addition, the ECoP defines a sustainable governance framework. The ECoP is expected to be published more than once during the project lifetime, in order to incorporate both experience of use and additional constraints that may be required by the EU Data Protection Regulation.

EAB's further responsibilities include

- advising on current and emerging legislation and ethical codes and practices with which EMIF should comply;
- tracking the development of EMIF solutions and ensure alignment between these and the ECoP;
- providing input on key stakeholders' concerns on ethical perspective as they might apply to EMIF's activities, objectives, and reputation;
- providing specific advice on an as-needed basis about issues, concerns and decisions that may arise within the EMIF consortium;
- advising and assist EMIF in public engagement and communications messages relating to ethical matters;
- providing brief reports to facilitate reporting duties of the EMIF consortium.









Members

The EMIF EAB currently has 6 members:

- Prof. Luciano Floridi, Professor of Philosophy and Ethics of Information, Oxford Internet Institute, University of Oxford and Turing Faculty Fellow, The Alan Turing Institute, London (chair of the EAB)
- Prof. Effy Vayena, Professor of Health Policy, University of Zürich
- Prof. Burkhard Schäfer, Professor of Computational Legal Theory, University of Edinburgh and Director of its SCRIPT Centre for IT and IP law
- Prof. Christophe Lütge, holder of the Peter Löscher Chair of Business Ethics, Technical University of Munich
- Prof. Peggy Valcke, Professor ICT and media law, KU Leuven
- Prof. Ugo Pagallo, Professor of Jurisprudence at the Faculty of Law, University of Turin



Luciano Floridi is Professor of Philosophy and Ethics of Information at the University of Oxford, where he is the Director of Research of the Oxford Internet Institute. Among his recent books, all published by Oxford University Press: The Fourth Revolution - How the infosphere is reshaping human reality (2014), The Ethics of Information (2013), The Philosophy of Information (2011). He is a member of the EU's Ethics Advisory Group on Ethical Dimensions of Data Protection, and of Google Advisory Board on "the right to be forgotten".



Effy Vayena is Professor of Health Policy at the University of Zurich, where she leads the Health Ethics and Policy Lab. She is visiting faculty at the Harvard Center for Bioethics, Harvard Medical School and faculty associate at the Berkman Center for Internet and Society at Harvard Law School. From 2000-2007 she was a technical officer at the World Health Organization (WHO). Her current scholarship focus is on ethical and policy questions in precision medicine and digital health. She brings to the EAB high level expertise in bioethics and health policy, extensive knowledge of health research regulation and vast experience in working within interdisciplinary and intercultural contexts.



Burkhard Schafer is Professor of Computational Legal Theory at the University of Edinburgh, and Director of its SCRIPT Centre for IT and IP law. With a background in logic, computer linguistics and law, his main interest is the potential of embedding legal and ethical norms directly in computer code, law compliance by design and the ethical and legal consequences of taking humans out of the loop when designing data governance structures.











Christoph Luetge studied business informatics and philosophy. He obtained his doctorate in philosophy in 1999 at the Technical University of Braunschweig and his habilitation at the University of Munich in 2005. Since 2010, he holds the Peter Löscher Chair of Business Ethics at Technical University of Munich. He has also held visiting professorships in Taipei, Kyoto and Venice. Luetge is director of the Experimental Ethics Lab (EEL) and one of the first ethicists to apply the method of laboratory experiments to ethics. His conception of "order ethics" emphasizes the role of the order framework for ethical behavior. For the EAB, he provides expertise from a business ethics point of view. Among his major recent publications are: "Order Ethics or Moral Surplus: What Holds a Society Together?" (Lexington, 2015), "Experimental Ethics" (Palgrave Macmillan, 2014), the "Handbook of the Philosophical Foundations of Business Ethics" (Springer, 2013) as well as 20 other books and more than 120 articles. He has commented on political and economic affairs on Bloomberg, Financial Times and numerous other media.



Peggy Valcke is professor ICT and media law at KU Leuven in Belgium, visiting professor at Tilburg University in the Netherlands, and research leader at iMinds. In 2014, she was part-time professor at the European University Institute in Florence, Italy, and in 2006, she was visiting professor at Central European University in Budapest, Hungary. Peggy has a broad experience with international and interdisciplinary research projects funded by the European Union or national actors dealing with IT innovation in communications, health, the public sector, police and criminal justice, and online commerce. Peggy has been an assessor of the Belgian Competition Authority and a member of the Flemish Media Regulator since 2008. She was a member of Google's Advisory Council on the Right to be Forgotten and is currently a member of Digital Minds for Belgium, a working group convened by Belgium's Minister for Telecommunications and Digital Agenda (A. De Croo).



Ugo Pagallo is Professor of Jurisprudence at the Faculty of Law, University of Turin, since 2000, faculty at the Center for Transnational Legal Studies (CTLS) in London and faculty fellow at the NEXA Center for Internet and Society at the Politecnico of Turin. Chief editor of the *Digitalica* series published by Giappichelli and co-editor of the AlCOL series by Springer, he is vice-president of the Italian Society on legal informatics. In addition to numerous essays in scholarly journals, he is the author of eight monographs. His main interests are Al & law, network theory, robotics, and information technology law (specially data protection law and copyright).





