

Open Research Data to Support Sustainable Health Initiatives

24 April 2018

Hotel Renaissance, Brussels

09:00 - 16:30 followed by a networking reception

Frontiers is pleased to host its second Annual Data Services Workshop. The event aims to draw lessons from recent successes in the application of big data technologies and artificial intelligence (AI) to data-intensive health research, and to discuss policy challenges and actions necessary to unleash the full potential of open research data in health for the benefit of society. It will feature panellists from leading institutions and companies specialising in this field, together with representatives from academic libraries, patient advocacy groups, research funders, universities and the European Commission.

Organised by



In collaboration with



SwissCore

Contact Office for European Research
Innovation and Education

Agenda

09:00–09:05

Welcome

Frederick Fenter – Executive Editor, Frontiers, Lausanne, Switzerland

09:05–09:10

Opening

Michel Goldman – Director, Institute for Interdisciplinary Innovation in HealthCare (I3h), Brussels, Belgium; Field Chief Editor, Frontiers in Medicine

09:15–10:45

Session 1: Breakthroughs in data-intensive health research

Moderator: Charlotte Geerdink – European Advisor for Innovation, Swiss Contact Office for European Research, Innovation and Education

- **Integrating omic technologies into public health research:** Paolo Vineis – Professor of Environmental Epidemiology, Imperial College London, UK; Field Chief Editor, Frontiers in Public Health
- **Open drug discovery:** Lee Wen Hwa – Director, Disease Foundations Network, Strategic Alliances, Structural Genomics Consortium, Oxford, UK
- **Text & data mining and health states modelling:** Michael Rebhan – Senior Investigator, Novartis Institutes for BioMedical Research, Basel, Switzerland

10:45–11:15

Coffee

11:15–13:15

Session 2: Cutting-edge technologies and services for data-intensive health research

Moderator: Frederick Fenter – Frontiers Executive Editor

- **FAIR data and knowledge management:** Samuel Kerrien – Section Manager Data and Knowledge Engineering, Blue Brain Project/EPFL, Lausanne, Switzerland
- **Data infrastructure:** Christine Durinx – Associate Director, Swiss Institute of Bioinformatics, Lausanne, Switzerland
- **Research data and knowledge management:** Ian Potter – Global Business Development Manager, Publishing & Associations, Clarivate Analytics, UK
- **Artificial intelligence in open access publishing:** Mattia Albergante, Lead Product Manager, Frontiers, Lausanne, Switzerland
- **Text and data mining:** Lucas Anastasiou – Project Officer, Knowledge Media Institute (KMI), The Open University, UK

13:15–14:15

Lunch

14:15 – 16:20

Session 3: Achieving open research data in health – overcoming the EU policy, institutional, and regulatory challenges

Moderator: Monica Dietl – Senior Advisor, Science|Business

This session brings together policymakers and stakeholder representatives to identify the key challenges that Europe faces in expanding and leveraging open research data in health, and the policies necessary to address these.

Aspects likely to be covered include:

- Designing the next EU Research & Innovation programme to ensure it best supports big data research in health according to the FAIR principles (whereby research results – publications and data – are Findable, Accessible, Interoperable and Reusable)
- Specific considerations necessary for open research data in health with respect to privacy, security and public benefit (including the Public Sector Information Directive)
- Achieving balance between data protection and openness to foster innovation (including the General Data Protection Regulation and the EU Copyright Reform)
- Applications of the European Open Science Cloud (EOSC) in health research, and the actions necessary to realise these opportunities
- Developing the researcher skills base necessary to ensure all EU member states can undertake and benefit from big data research in health
- Engaging patients and citizens in data intensive health research for the benefit of society

Opening Keynote:

Cornelius Schmaltz, Head of Unit for Strategy, European Commission, DG Research and Innovation, Brussels, Belgium

Panel:

- **DG CONNECT:** Saila Rinne – Programme Officer, Unit Data Policy and Innovation, DG CONNECT, Luxembourg
- **Open Science Policy Platform (OSPP):** Eva Mendez – Young European Research Universities (YERUN), OSPP, Madrid, Spain
- **Public research funders & performers:** Stephan Kuster – Secretary General, Science Europe, Brussels, Belgium
- **Patient groups:** Tamás Bereczky – Coordinator EUPATI Germany, Patient Cluster lead IMI Big Data Project Harmony, Berlin, Germany
- **Research libraries:** Jeannette Frey – Director BCU Lausanne, Vice-President LIBER, Lausanne, Switzerland
- **DG Research and Innovation:** Cornelius Schmaltz – Head of Unit for Strategy, European Commission, DG Research and Innovation, Brussels, Belgium

16:20–16:30

Closing remarks

Frederick Fenter – Executive Editor, Frontiers, Lausanne, Switzerland

16:30–18:00

Networking Reception

Biographies



MATTIA ALBERGANTE
Lead Product Manager, Frontiers
Lausanne, Switzerland

Mattia Albergante is Lead Product Manager at Frontiers, currently overseeing the development and launch of Data Products in the Frontiers ecosystem. He joined the Open Access publisher in 2014, supervising the development of new journal and article pages. More recently, he led the development of the Digital Editorial Office, a cutting-edge product that enables Chief Editors to efficiently monitor the status of their journal and manuscripts in review. He obtained his PhD in Physics with a thesis on numerical modelling of Nuclear Fusion devices in 2011 before starting his career in software development in Lausanne, Switzerland and Berlin, Germany.



LUCAS ANASTASIOU
Project Officer, Knowledge Media Institute (KMI)
The Open University, UK

Lucas Anastasiou is an Open Access Publishing Project Officer. He is a graduate of National Technical University of Athens (Electrical and Computer Engineering) and University College London (Information Security). He has been employed by the Knowledge Media Institute where he has been involved as a research assistant in various academic projects, e.g. LTfLL (<http://www.ltfll-project.org/>), Stellar (<http://www.teleurope.eu/>), CORE (<https://core.ac.uk/>), eCloud (<https://pro.europeana.eu/project/europeana-cloud>), OpenMinTed (<http://openminted.eu/>). His main interests span from Recommender systems for research, to scholarly literature aggregations, text and data mining (TDM) and interoperability. He is a strong advocate and enthusiast of open access and the promotion of open science for the advancement of research.



TAMÁS BERECZKY
Coordinator EUPATI Germany, Patient Cluster lead IMI Big Data Project Harmony
Berlin, Germany

Tamás Bereczky currently works as the communications advisor of the European Patients Academy for Therapeutic Innovation (EUPATI), a flagship pan-European project in patient education. He is also member and former board member of the European AIDS Treatment Group, the largest European network of individuals living with HIV. HIV-positive since 2003, he served as co-chair of the European Commission's Civil Society Forum on HIV/AIDS between 2013 and 2015. Originally a linguist (ELTE University of Budapest) and psychologist (Open University), Tamás is set to defend his PhD based on research into the significance and perspectives of patient organizations in Europe in 2018. In addition to his work in communications, he also works as an advisor to EACS, UNAIDS and ECDC in matters concerning HIV, HCV, men having sex with men, substance use and health policy. Currently he is involved as the patient cluster coordinator for HARMONY, a key big data project of IMI in haematological malignancies. Tamás has been producing HIV and hepatitis C advocacy videos, websites and blogs in his native Hungarian. Some upcoming publications of Tamás discuss, amongst others, the standing and possibilities of patient organisations in neoliberalism and a training manual for patient organisations on the methods and processes in medicine pricing, the affordability of medicines, and practical advocacy for more affordable medicines. You can read some of his work at www.atk.academia.edu/TamasBereczky.



MONICA DIETL (Moderator)
Senior Advisor, Science|Business

Monica Dietl is senior advisor for the Healthy Measures initiative at Science|Business. She is a neurobiologist who conducted research at the University Pierre and Marie Curie in Paris (UPMC), the University of Vienna, Sandoz in Basel, and Collège de France with Rhone Poulenc Santé in Paris. Before joining Science|Business she was director of the Brussels office of France's CNRS (Centre national de la recherche scientifique). Monica has also worked at the European Commission DG Research and Innovation on building up the European Research Council (ERC) and was director of the COST Association.



CHRISTINE DURINX
Associate Director, Swiss Institute of Bioinformatics, Lausanne, Switzerland

Christine Durinx is the Associate Director of SIB Swiss Institute of Bioinformatics since 2014. At SIB, Christine is responsible for the communications and training departments, the director's office and the technology group. She is member of the executive board of BioMedIT, establishing a coordinated nationwide network of secure IT infrastructures at Swiss universities to support biomedical research in Switzerland. Christine is co-lead of the ELIXIR Data platform which has developed a process to identify ELIXIR Core Data Resources. These are European data resources that are of fundamental importance to research in the life sciences and are committed to the long-term preservation of data. Christine has a Pharmacy degree and a PhD in Pharmaceutical Sciences from the University of Antwerp, Belgium. Before joining SIB, she worked in the pharmaceutical industry for more than 10 years.



FREDERICK FENTER
Executive Editor, Frontiers, Lausanne, Switzerland

Frederick Fenter is Executive Editor at Frontiers. He worked in environmental research before moving to the scientific-publishing business, and thanks to a number of projects that have also involved libraries, document repositories, data bases and open-access publishing initiatives, he has participated in many facets of the publishing revolution that is sweeping through academia. Frederick studied in the USA and Switzerland, finishing with a PhD in Chemistry from Harvard University (Cambridge, USA); he subsequently worked at the CNRS (University of Bordeaux) and the EPFL (Lausanne). His career in publishing started with his appointment as manager of the Inorganic Chemistry Program of Elsevier Science (Lausanne) in 1996. Since then he has been founder of a start-up in publishing technology (FontisMedia SA, Lausanne); and publisher for a Swiss-based English-language University Press (EPFL Press). Fred has been Executive Editor at Frontiers since August 2013.



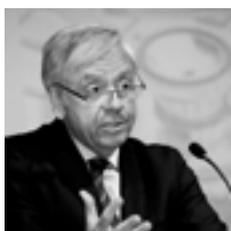
JEANNETTE FREY
Director BCU Lausanne, Vice-President LIBER, Lausanne, Switzerland

Born April 13, 1962 in Kirchberg, BE, Switzerland, Jeanette Frey first studied Ancient History, Archeology and Egyptology at University of Fribourg, Switzerland, then worked in the field of academic publishing at Redaction LIMC (Lexicon Iconographicum Mythologiae Classicae) in Basel. In 1992, she moved to the Swiss national museum in Zurich as Head of Photographic Collection. Her first experiences in digitization of photographic collections were in the years 1992-1998, after which she headed the Federal Archive for Historic Monuments in Bern, where other projects for digitization of photographic collection take place. After 2002, Jeanette worked in the private sector as Head of Information & Communication, studying in parallel Computer Science and Mathematics at the University of Fribourg. In 2004 she changed to be the Head of Periodicals and Electronic Resources at BCU Lausanne, where she has been Director since 2008. Her main project in 2016 was the extension of the main building of the university library and implementation of new ILS for the Renouvaud network of libraries of Vaud canton (120 libraries). She is Vice-President of LIBER and a member of the Board of EUROPEANA since 2014.



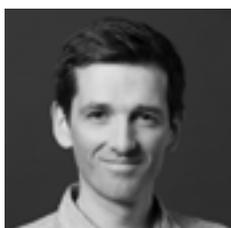
CHARLOTTE GEERDINK (Moderator)
**European Advisor for Innovation, Swiss Contact Office for
European Research, Innovation and Education**

Charlotte Geerdink is a senior European advisor for Innovation at SwissCore. She has been working in Brussels for nearly 8 years and has built up expertise in European science, research and innovation topics. By coincidence, she started moderating high level events and found out that she loved doing it. Anything related to the current European research and innovation programme Horizon 2020 and its successor programme FP9, as well as relevant EU research and innovation policy, are at the heart of her professional and personal interest – for investments in science and innovation bring prosperity, growth and help to provide evidence-based policymaking. Charlotte is a Dutch national, fluent in English, German and with a good command of French. Her style of moderating can best be described as informal, relaxed, and witty. It is her aim to bring across complex material in an understandable way, and make the speakers, panelists and audience feel at ease. In this sense, proper preparation of an event is already 70% of making an event successful, the other 30% is pure entertainment and show time!



MICHEL GOLDMAN
**Director, Institute for Interdisciplinary Innovation in HealthCare – I3h,
Brussels, Belgium; Field Chief Editor, Frontiers in Medicine**

Michel Goldman is a Belgian medical doctor specialised in immunology and internal medicine. He is the Executive Director of the Institute for Interdisciplinary Innovation in healthcare (I3h) and Full Professor at the Université libre de Bruxelles (ULB). From 2009-2014, he was the first Executive Director of the Innovative Medicines Initiative Joint Undertaking (IMI), a €2 billion partnership between the European Federation of Pharmaceutical Industries and Associations and the European Commission. Michel is a member of the Board of Directors of the Canadian Consortium for Precompetitive Pharmaceutical Research (CQDM), the European Tuberculosis Vaccine Initiative and the French National Institute of Health and Medical Research (INSERM). His scientific achievements resulted in a recognition as ISI Highly Cited Scientist by the Thomson Institute. He shared the Lucien Steinberg Prize with Pr. Peter Piot in 1992. He was also the laureate of the Quinquennial Prize of the Belgian National Fund of Scientific Research for Clinical Sciences (2000) and he held the Spinoza chair at the University of Amsterdam (2001). In 2007, Michel Goldman was awarded the degree of Doctor Honoris Causa of the Université of Lille.



SAMUEL KERRIEN
**Section Manager Data and Knowledge Engineering – Blue Brain Project/EPFL
Lausanne, Switzerland**

Samuel Kerrien is the section manager of the Neuroinformatics Software Engineering section in the Neuroinformatics Division headed by Professor Sean Hill. He has extensive experience with the Java and big data ecosystems, data integration in life science as well as making software development teams more effective using agile processes. He is mainly focused on developing Blue Brain Nexus platform that lies at the heart of the Blue Brain core activities. Previously, Samuel was a Senior Data Engineer and ScrumMaster at Jagex, a games developer and publisher in Cambridge, UK. He also worked at the European Bioinformatics Institute in the area of proteomics (molecular interactions) and data standardisation, as the technical lead of the IntAct project. Making the most of life in Switzerland, Samuel enjoys skiing, hiking and photography, as well as yoga and cooking.



STEPHAN KUSTER
Secretary General, Science Europe
Brussels, Belgium

Stephan Kuster has been with Science Europe since its founding in 2011. Since his appointment as Secretary General in February 2018, he acts as spokesperson for Science Europe, and leads the development of joint initiatives, positions, and approaches by the Science Europe Member Organisations. Before joining Science Europe, he worked as European Advisor for the Swiss National Science Foundation and the Swiss Contact Office for Research, Innovation and Education in Brussels, SwissCore.

Science Europe

Science Europe is the Brussels based association of 43 major European public Research Funding Organisations (RFO) and Research Performing Organisations (RPO). It promotes the collective interests of its Member Organisations and supports them in their efforts to foster European research. It helps to strengthen the European Research Area (ERA) through its engagement with key partners and EU institutions. Science Europe carries out initiatives for its Members and provides advice on policy issues such as the European Research Area, EU and national research funding, Open Access and Open Science, Cross-Border Research Collaboration, Gender and Diversity issues in research, Research Infrastructures and Research Careers and Mobility.



EVA MÉNDEZ
Young European Research Universities (YERUN), OSPP
Madrid, Spain

Eva Méndez holds a PhD in Library and Information Sciences and is an expert in metadata. She defines herself in her Twitter profile as an open knowledge militant (@evamen). She has been a lecturer at Universidad Carlos III de Madrid since 1997 and Tenured Professor since 2008. She has also taught and carried out research at other universities and institutions. She has been an active member of several international research teams on various standards for the Web: She is member of the US Academy Louis Round Wilson-Knowledge Trust, the Advisory Committee of the DCMI (Dublin Core Metadata Initiative), the Advisory Board of OpenAire, as well as an active member in other initiatives such as Metadata2020 (steering committee) and RDA (Research Data Alliance) where she is one of the creators the RDA Iberia. In 2005-06 she was awarded a Fulbright Research Scholarship, as part of the European Union postdoc programme, at the University of North Carolina at Chapel Hill (USA). She has taken part in and led several research projects and acted as advisor to many more in the fields related with standardization, metadata, semantic web, open data, digital repositories and libraries, in addition to information policies for development in several countries. Since 2006 she has been participating as an independent EC expert on the assessment and monitoring of various projects for a number of programmes in different fields such as Digital Libraries and Open Science. From 2009 to 2012 she was Director of the University Master's degree in Digital Libraries and Information Services. She is one of the creators of The Hague Declaration on Knowledge Discovery in the Digital Age. In 2015 she won the Young Researcher of Excellence award of her University. Besides her current position as Deputy Vice President for Scientific Policy- Open Science at Universidad Carlos III de Madrid she has been also Deputy Vice-president of Infrastructures and Environment (2011-2015) and for Strategy and Digital Education (2015-2017) at the same university. In November 2017 she was named "Open Data Champion" by SPARC Europe. She is currently member of the EU-OSPP (European Open Science Policy Platform) on behalf of YERUN (Young European Research Universities Network).

**IAN POTTER****Global Business Development Manager, Publishing & Associations
Clarivate Analytics, UK**

Ian Potter began his career in research at the University of Liverpool followed by a PhD at the University of Edinburgh, UK, investigating the molecular mechanisms of cellular growth in plants, following by post-graduate work at the University of Connecticut, USA, where he also became involved in several publication and media initiatives. On returning to the UK, Ian worked initially as technical editor for a leading society journal and then moved to Blackwell Publishing to hold a series of production and technology roles. Ian joined ScholarOne in 2003, which was acquired by Thomson in 2006. Ian has held several roles at Thomson, latterly Clarivate Analytics, and now works with the sales and product teams across the Publishing & Associations business.

**MICHAEL REBHAN****Senior Investigator, Novartis Institutes for BioMedical Research
Basel, Switzerland**

After a PhD on the biology of disease (1996, in Germany), Michael Rebhan did a postdoc in bioinformatics (creating GeneCards, at the Weizmann Institute, Israel, until 1998), and then joined industry as a scientist in AstraZeneca during the early days of omics and 'big data' technology (Boston, USA). After some time in a biomedical startup in Germany (2000-2002), he helped to build up 'big data' for disease biology research capabilities in Singapore (2002-2004, Biopolis). In 2004 he moved to Basel, Switzerland, to join Novartis as a research scientist. His focus is on understanding the real-world complexity of disease, including biological, medical and other aspects. As we reinvent the way how we investigate it in R&D, Precision Medicine is an overarching theme in his interests, including translational challenges. Michael is also interested in indications related to Regenerative Medicine. He recently published an Open Science approach to 'connect the dots' in how we develop solutions for chronic diseases, which includes a more central role for computational modelling in crowd-based learning.

**SAILA RINNE****Programme Officer, Unit Data Policy and Innovation
DG CONNECT, Luxembourg**

Saila Rinne has had a long career in the European Commission. For the past five years she has been working as a Programme Officer in the Directorate General for Communications Networks, Content and Technology, DG CONNECT. Her unit is the Data Policy and Innovation unit that supports the data economy in the Digital Single Market and advances the Commission open data policy and the use and re-use of public data. As a member of the Research Sector of the unit, Saila manages a portfolio of H2020 research and innovation actions with an emphasis on health data applications, such as privacy-preserving technologies for health data and a large-scale pilot action on big data in healthcare. She also takes part in the inter-service work of the Commission on digital transformation of health and care.

**CORNELIUS SCHMALTZ****Head of Unit for Strategy, European Commission
DG Research and Innovation, Brussels, Belgium**

Cornelius Schmaltz received his MD and his training as a board-certified paediatrician from the University of Freiburg, Germany. Following a postdoc at Dana-Farber Cancer Institute in Boston, USA, and a fellowship in Pediatric Hematology/Oncology at Memorial Sloan-Kettering Cancer Center in New York, USA, Cornelius joined the Volkswagen Foundation in Germany as programme manager in medicine. Since 2006 he has been an official at the European Commission's Research and Innovation Directorate General, where he is currently Head of Unit for Strategy in Health Research. In 2012 he obtained a (distance-learning) MA in International Relations from the Free University in Berlin, Germany. He is the co-author of 11 original papers in peer-reviewed journals, including Nature Medicine and Nature Genetics.



PAOLO VINEIS

**Professor of Environmental Epidemiology, Imperial College London
UK; Field Chief Editor, Frontiers in Public Health**

Paolo Vineis is professor of Environmental Epidemiology at Imperial College London, School of Public Health, UK. He is a leading researcher in the field of molecular epidemiology and his latest research focuses on examining biomarkers of disease risk, complex exposures and intermediate markers from omic platforms in large epidemiological studies. He also studies the effect of climate change on non-communicable diseases. He is Head of the Unit of Molecular and Genetic Epidemiology at the Italian Institute of Genomic Medicine in Torino, Italy. Paolo is coordinator of the European Commission funded Exposomics (on air pollution) and Lifepath (H2020, on socio-economic inequalities and ageing) projects, and is a principal investigator or co-investigator of numerous international projects. He has more than 900 publications in journals such as Nature, Science, Lancet, and Lancet Oncology. He is the author of "Health without Borders. Epidemics in the Era of Globalization", Springer 2017. (see also https://en.wikipedia.org/wiki/Paolo_Vineis).



LEE WEN HWA

**Director, Disease Foundations Network, Strategic Alliances
Structural Genomics Consortium, Oxford, UK**

Lee Wen Hwa directs the Disease Foundations Network at the Structural Genomics Consortium (SGC), based at the Nuffield Department of Clinical Medicine, University of Oxford. He is trained in Biology, Molecular, Structural and Computational Biology and Drug Discovery in diverse places such as Brazil, USA and France. Joining SGC in 2004, he has been involved in the planning of scientific strategies, communications and alliances with external collaborators and partners. He has been working with multiple institutions to facilitate the exchange of expertise and establishment of joint research programmes with SGC's international partners, including charities, academia, industry and government agencies – always exploring the potentials of Open Science. Lee co-led the establishment a new SGC laboratory in Brazil – the first node of an international effort on novel kinases. He is now committed to create new frameworks and partnerships with patient and disease foundations to bridge basic science and patient-driven drug discovery efforts.

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