Formalizing Best Practices for Data Governance of Life Science Data in Central Asia

Committee

Faina Linkov

Chair

Faina Linkov is an Associate Professor at Duquesne University, Pittsburgh, PA. Dr. Linkov is a multidisciplinary researcher with research interests in molecular epidemiology, cancer, prevention, health systems research, global health, scientific communications, and research productivity. Dr. Linkov obtained her PhD in Epidemiology at the University of Pittsburgh, where she has been conducting research from 2005 to 2020. She has been active in initiating research work with several groups in Asia publishing on the public health challenges in Kazakhstan. Also, Dr. Linkov’s work helped to spread the word about the need for endometrial cancer prevention in Central Asia and specifically in Kazakhstan. Pipelle biopsy, commonly used diagnostic modality in the US for endometrial cancer detection and control, is rarely practiced in Kazakhstan. Dr. Linkov’s protocol for investigating various factors impacting Pipelle biopsy use were shared with cancer researchers at Nazarbayev University in Kazakhstan and became the focus on several recent publications. Dr. Linkov's research career has been extremely productive with over 100 original research publications and reviews. Dr. Linkov was named AAAS fellow in 2020, the first female faculty member to have such distinction at Duquesne University. Her H-index in Google Scholar is 25, indicating high degree of citation of her work.

Susan Aaronson

Member

Susan Ariel Aaronson is Research Professor of International Affairs at George Washington University (GWU). Aaronson is also co-principal investigator with the NSF -NIST (National Science Foundation and (National Institute of Standards and Technology Institute for Trustworthy AI in Law & Society, TRAILS, where she leads research on data and AI governance. Aaronson was recently named one of GWU's Public Interest Technology Scholars, where she works to encourage interdisciplinary research on technology. Susan is also director of the Digital Trade and Data Governance Hub at GWU. The Hub was founded in 2019 and educates policy makers, the press and the public about data governance and data-driven change through conferences, webinars, study groups, primers and scholarly papers. It is the only organization in the world that maps the governance of public, proprietary and personal data at the domestic and international levels. The Hub’s research has been funded by foundations such as Ford and Minderoo. Susan currently directs projects on AI overcapacity, public participation in AI governance, and AI nationalism as well as the Hub’s metric of data governance, which maps the governance of data in 68 countries and the EU. Aaronson also frequently writes on XR sets. She regularly writes op-eds for Barron’s and Fortune, and was a commentator on economics for NPR’s Marketplace, All Things Considered and Morning Edition, and for NBC, CNN, the BBC and PBS. Aaronson is the author of 6 books and more than 70 articles on data, AI, trade, corruption and good governance. She is also a senior fellow at the Canadian think tank, Centre for International Governance Innovation. Aaronson received her Ph.D. from Johns Hopkins University in 1993.

Damian O. Eke

Member

Damian Okaibedi Eke is an Assistant Professor at the School of Computer Science, University of Nottingham, UK. Dr Eke was the Data Governance coordinator for the EU Human Brain Project. He leads the IBI Taskforce on International data governance and is one of the PIs on the Wellcome Trust funded project BRIDGE (developing an international data governance framework for Neuroscience). He is the founder and director of the African Brain Data Network (ABDN). Damian has extensive experience in developing data governance strategies and frameworks for Neuroscience research and practice. He teaches Data Governance for Brain Research at the NIH funded summer school Neurohackademy hosted by the University of Washington, Seattle. His research interests cover critical philosophical issues at the intersection of Technology, Data and Society including Data Governance and Responsible Innovation.

Yann Joly

Member

Yann Joly, Ph.D. (DCL), FCAHS, Ad.E. is the Director of the Centre of Genomics and Policy (CGP). He is a James McGill Professor at the Faculty of Medicine and Health Sciences, Department of Human Genetics. Prof. Joly is also an associate member of the Bioethics Unit and at the Law Faculty at McGill. He was named advocatus emeritus by the Quebec Bar in 2012 and Fellow of the Canadian Academy of Health Sciences in 2017. Prof. Joly's research interests lie at the interface of the fields of data sciences, human rights law, and bioethics. He is the current Co-chair of the Regulatory and Ethics Work Stream (REWS) of the Global Alliance for Genomics and Health (GA4GH). He created the world's first international Genetic Discrimination Observatory (GDO https://gdo.global/en/gdo-description) in 2018. The Observatory is represented in 28 countries in five world regions including Ukraine, Kazakhstan, and China. He has published his findings in over 250 peer-reviewed articles featured in top legal, ethical and scientific journals. He served as a legal advisor on multiple IRBs in the public and private sectors. In 2012, he received the Quebec Bar Award of Merit for his work on data sharing and privacy.

Yann Joly is a Strategic Leadership Committee of the global data sharing organization Global Alliance for Genomics and Health (GA4GH). He is also currently involved in the publishing of an industry-based and industry-funded paper on data sharing.

Tatyana Novossiolova

Member

Tatyana Novossiolova is Senior Analyst at the Center for the Study of Democracy in Bulgaria specialising in research, training design, and project-management. Her work covers the cross-cut between international law and security with a focus on the geopolitics of CBRN (chemical-biological-radiological-nuclear) risk governance and emerging hybrid threats. She has served as an international consultant to the OSCE Project Coordinator in Ukraine on the development of a professional training program on biosafety and biosecurity risk management. Tatyana is a non-resident member of the Biological Security Research Centre at London Metropolitan University, UK where she contributes to research activities on biosecurity education. She is a member of the International Federation of Biosafety Association (IFBA) Board of Directors with a portfolio that covers the integration of Diversity, Equity, and Inclusion (DEI) issues with biosafety and biosecurity. Tatyana conducts training and outreach on the prevention of misuse of biotechnology and has worked with life science stakeholders in different regions to strengthen local biosecurity efforts. She has extensive experience with the design and delivery of training activities for academic and professional audiences and the application of innovative active learning methods and ICT technology in facilitation and training. Tatyana holds a BA (Hons) in International Relations and Security Studies and PhD in Politics and International Security, both earned at the University of Bradford, UK. In 2016, Tatyana served on the organizing committee of a NASEM regional workshop on "Teaching about Responsible Science, Biosafety, and Biosecurity: Resources in Arabic" for stakeholders from the MENA region.

Yerbol Suleimenov

Member

Yerbol Suleimenov is Independent Director of the Board of Trustees of KIMEP University in Almaty, Kazakhstan. He previously served as Rector at Eurasian Technological University in Kazakhstan. He has over 19 years of experience in designing and implementing complex state programs in Science, Technology, and Innovation (STI) development, including policy formulation, implementation and evaluation, and management of public authorities. This includes Kazakhstan's and Uzbekistan's National Innovation Systems and various science and commercialization laws. With a background in banking, he also has extensive experience in project management and fundraising, as well as strong academic and practical experience in public policy, systems analysis, and quantitative modeling in Kazakhstan and other former members of the Commonwealth of Independent States. He co-authored the 2004 United Nations Development Programme National Human Development Report analyzing Kazakhstan's education system and a 2006 analysis of the impact of new technologies on human development. He sat on the editorial board of the 2015 United Nations Educational, Scientific and Cultural Organization (UNESCO) Science Report, authored a section in the 2021 UNESCO Science Report surveying Central Asia, and serves as Chairman of the International Experts Board within the World Bank's "Modernizing Uzbekistan National Innovation System" project. He holds a Masters degree in Mathematics from the University of Manchester as well as PhD in Mathematics from the National University of Uzbekistan.