TOWARDS A TRUSTWORTHY DATA GOVERNANCE FOR HEALTHCARE TECHNOLOGIES

WEBINAR, 18 September 2020

10:00am – 12:30pm CET
4:00pm – 6:30pm SGT
1. Background and Rationale

This webinar is organized by Prof. Effy Vayena and Agata Ferretti (Health Ethics and Policy Lab, ETH Zurich), together with Prof. Tamra Lysaght (Centre for Biomedical Ethics, National University of Singapore). The webinar is within the scope of the Future of Health Technology (FHT) Program and addresses critical challenges in developing a future-oriented Mobile Digital Health concept and technologies. The aim of the FHT Program is to build an evidence-based mobile digital health technology environment to transform healthcare systems through prevention and a community-based and patient-centric model, leveraging on scalable digital technologies.

Prof. Vayena and Prof. Lysaght are the PIs responsible for the FHT module focused on “trustworthy data governance”. This concept aims to define a best practice protocol that is compatible with cross-border regulatory frameworks in Switzerland and Singapore for the protection of privacy, data ownership and accountability, while also enabling modern analytics across a variety of health-related data that populates the FHT microcosm. The well-defined and controlled “small-world system” of data and users - part of the FHT program - is sufficiently holistic and interdisciplinary to mimic the complexity of real-world health systems.

This webinar is an opportunity to explore the “trustworthy data governance” concept with experts in data governance. Our goal is twofold. First, we aim to better understand the similarities and differences, strengths and weaknesses, between and within existing data governance frameworks. Particularly, we will focus on Switzerland and Singapore regulations concerning data collection, linkage and uses. Second, we will reflect on lessons learned from the application of these frameworks: how could these frameworks be revised, combined and updated in order to achieve a more trustworthy health-related data governance? What are the critical features that health-related data governance should have to become useful in the FHT ecosystem, where most of the data are collected by mobile health devices rather than physicians in hospitals? Is there a need for a global data governance framework that could be applied across borders?
2. Agenda

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<td><strong>10:00 – 10:10 CET</strong></td>
<td><strong>Welcome and Introduction</strong></td>
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<td><strong>10:10 – 11:10 CET</strong></td>
<td><strong>Panel 1: Existing data governance frameworks and their limitations</strong></td>
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<td><em>What are the existing mechanisms of data governance for data generation, use and linkage? Which ethical challenges and gaps exist within these models? Are there specific similarities among the Swiss and Singaporean health-related data governance frameworks?</em></td>
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|                  | **Panelists** | James Scheibner (ETH)  
Hannah Lim (NTU)  
Andrew Morris (HDR UK)  
Elettra Ronchi (OECD) |
|                  | **Moderator** | Effy Vayena (ETH) |
| **11:10– 11:20 CET** | **Break** | |
| **11:20 – 12:20 CET** | **Panel 2: Desirable developments and possible solutions for a trustworthy data governance** | |
|                  | *Are there valuable aspects of the existing data governance models that should be improved and further developed? Which best-practices cannot be missed in a framework for trustworthy data-governance? Is there a need for a global data governance framework that could be applied across borders?* | |
|                  | **Panelists** | Vicki Xafis (NUS)  
Alessandro Blasimme (ETH)  
Sharon Kaur (University of Malaya)  
Angela Ballantyne (NUS) |
|                  | **Moderator** | Tamra Lysaght (NUS) |
| **12:20 – 12:30 CET** | **Conclusions** | Effy Vayena (ETH) |
3. How to join the webinar

Meeting ID: 913 3982 7130

Computer, tablet or smartphone

Follow the link: https://ethz.zoom.us/j/91339827130

For support about how to join a Zoom meeting see:
https://www.youtube.com/embed/hIkCmbvAHQQ?rel=0&autoplay=1&cc_load_policy=1

Telephone

Find your local number: https://ethz.zoom.us/u/aboAOsk3WH

Join by SIP: 91339827130@zoomcrc.com

Skype for Business: https://ethz.zoom.us/skype/91339827130
4. Rules for the attendees

Panel Sessions

Each panel session will be composed of:

5 minutes presentation per panelist
30 minutes panel discussion
10 minutes questions from the audience

Questions and Discussion

If you have a question for a presenter, or if you want to interact with the panelists, please raise your hand using the “🤚” Zoom feature. This way, the organizers will know you have an input for the discussion. Alternatively, you can write your question in the chat box, and the organizers will read it on your behalf.

In case you encounter an issue, you can always contact Agata Ferretti for support through the chat box.

To know more about these features, please see:
https://www.youtube.com/watch?v=5e8eg4_rgwg
https://support.zoom.us/hc/en-us/articles/205761999-Webinar-Chat#attendees
5. Participants’ biographical notes

Angela Ballantyne (National University of Singapore)
Associate professor Angela Ballantyne's academic interests include research ethics (especially issues of justice and vulnerability), medical ethics education, the ethics of pregnancy and reproductive technologies and data ethics. She has worked in schools of Medicine, Primary Health Care and Philosophy in New Zealand, Australia, England and the United States; and as the Technical Officer for Genetics and Ethics at the World Health Organization in Geneva. In 2008 and 2018 she was a Visiting Scholar at the Yale University Interdisciplinary Center for Bioethics. She is currently a Visiting Senior Research Fellow at the National University of Singapore and her permanent position is in the Department of Primary Health Care and General Practice at the University of Otago Wellington.

Alessandro Blasimme (ETH Zurich)
Dr. Alessandro Blasimme is a Senior Scientist (permanent) at the Health Ethics and Policy lab of ETH Zurich. He holds a degree in philosophy and a master in bioethics from La Sapienza University of Rome (Italy), as well as a PhD in bioethics from the University of Milan – European School of Molecular Medicine (Italy). He has held research appointments at the French National Institute of Health and Medical Research (INSERM) as well as the University of Zurich (Switzerland), before joining Swiss Federal Institute of Technology (ETH Zurich) in 2017. In 2013 he received a Fulbright-Schuman Scholarship to undertake research at Harvard University (USA). His activities revolve around ethical and regulatory issues in biomedicine and biotechnology. His work covers areas such as genomics, stem cell research, cell therapy, gene therapy, precision medicine, digital health, the use of artificial intelligence in medicine, and ageing.

Agata Ferretti (ETH Zurich)
Agata Ferretti is a PhD candidate at the Health Ethics & Policy Lab, Department of Health Sciences and Technology at ETH Zurich. Agata has a background in philosophy and bioethics – from the University of Milan (Italy) and KU Leuven (Belgium). Prior to joining ETH she completed a MSc degree in Global Health Policy from the London School of Economics (UK). Her PhD, supported by the Swiss National Science Foundation, focuses on the BEHALF project, which aims to provide a framework for an ethically aligned use of big data in biomedical research and healthcare. Her current research interests include the ethics and governance of health-related big data, the social and ethical impact of using artificial intelligence in medicine, the need for quality
assurance standards to guide health-apps development and implementation, the promises and challenges of using digital health to ensure global health.

Sharon Kaur (University of Malaya)

Dr. Sharon Kaur is a senior lecturer at the Faculty of Law, University of Malaya where she teaches Medical Law and Medical Ethics to undergraduate as well as graduate students. She also teaches on the Masters of Health Research Ethics programme at the Faculty of Medicine, University of Malaya. Her research interests primarily revolved around medical research ethics and issues of competency and consent. She recently spent a year as a Visiting Research Fellow at the Centre for Biomedical Ethics at the National University of Singapore where she developed an interest in issues relating to Global Health Ethics and the rights of marginalised populations.

Hannah Lim (Nanyang Technological University)

Professor Hannah YeeFen Lim is an internationally recognised legal expert in Technology & Internet law and is the author of over a hundred scholarly papers and six scholarly books on law and technology published by leading international publishers such as Oxford University Press – her two most recent books are on data privacy and AI, ethics and autonomous vehicles. Formally trained in both Computer Science and Law from the University of Sydney, where she went on to complete postgraduate studies under a Telstra Scholarship, all her research have been interdisciplinary and have examined cutting edge technology and how such technology should be regulated from both the lenses of law and ethics, especially as they impact upon society. Her research has been cited with approval by senior judiciary, most notably by the High Court of Australia. Hannah has also assisted UNCITRAL and UNIDROIT as a legal expert in reviewing the impact of digital developments on the efficacy of existing international legal frameworks.

Tamra Lysaght (National University of Singapore)

Dr Lysaght is Director of Research and Phase Director of the Health ethics, Law and Professionalism (HeLP) program at the Yong Loo Lin School of Medicine at the Centre for Biomedical Ethics, National University of Singapore. She has expertise in empirical bioethics and experience in using both qualitative and quantitative research methods to inform normative questions pertaining to science policy and ethics. Her work focuses on emergent health and biomedical technologies, including stem cell research and regenerative medicine, precision medicine and genomics, Big Data and AI in healthcare. She is Module Head of the Swiss ETH-National Research Foundation Future Health Technologies Programme, and is Principal Investigator of the Social Science Research Thematic Grant examining trustworthy governance models for sharing health-related data, and the National Medical Research Council-funded Science Health and Policy-relevant Ethics, Singapore initiative. She also serves on the Expert Panel of the AI and Data Ethics Advisory Council, the Oversight Board of the Singapore Network.
of Biorepositories, the Executive Committee of the Stem Cell Society, Singapore, and the Committee for Ethics, Law and Society of the Human Genome Organisation.

Andrew Morris (Health Data Repository UK)

Professor Andrew Morris became the inaugural Director of Health Data Research UK in August 2017. He is seconded from his position as Professor of Medicine, and Vice Principal of Data Science at the University of Edinburgh, having taken up the position in August 2014. Prior to this Andrew was Dean of Medicine at the University of Dundee. Andrew was Chief Scientist at the Scottish Government Health Directorate (2012-2017) and has served and chaired numerous national and international grant committees and Governmental bodies. His research interests span informatics and chronic diseases. He has published over 330 original papers, attracted over £50 million in grant funding and was the principal investigator of several programme grants including the Wellcome Trust United Kingdom Case Control Collection for Type 2 Diabetes, Generation Scotland, a study of the genetic health in 50,000 Scots, the Wellcome Trust funded Scottish Health Informatics Programme (SHIP), and the Farr Institute in Scotland. In 2007 he co-founded Aridhia Informatics, which uses high performance computing and analytics in health care. Andrew was previously Governor of the Health Foundation (2009-2017), a leading UK charity that supports quality improvement in health care, and chaired the Informatics Board at UCLPartners, London (2014-2017). He is a Fellow of the Royal Society of Edinburgh and the Academy of Medical Sciences.

Elettra Ronchi (OECD)

Elettra Ronchi, PhD, MPP, is Senior Policy Analyst at the OECD. Since 2015 she has been Head of Unit in the Division for Digital Economy Policy, where she coordinates work on privacy, risk management and data governance. She is currently leading the development of a draft recommendation on general principles on Enhancing Access and Sharing of Data. She is also leading the review of the implementation of the OECD Guidelines on the Protection of Privacy and Transborder Flows of Personal Data. Elettra Ronchi has more than 20 years of experience as policy analyst, evaluating the instruments available to governments to improve the public benefits from investments in health, science and technology. Since 2006 she has also contributed to the organisation’s work on digital health, including the development of the 2016 OECD Council Recommendation on Health Data Governance. Elettra started her policy career in 1993 as consultant for the United Nations Development Programme, before which she held academic research and teaching positions in the U.S. and France.
James Scheibner (ETH Zurich)

Dr. James Scheibner is a postdoctoral research fellow at the Health Ethics & Policy Lab, ETH Zürich. James completed his PhD with Professor Dianne Nicol, Dr Jane Nielsen and Associate Professor Michael Charleston at the University of Tasmania. James’s PhD examined intellectual property law, institutional economics and open source licensing for bioinformatics software. James conducted his PhD research using comparative doctrinal methods to examine intellectual property laws in the United States, Europe, Australia, and New Zealand. As a postdoctoral research fellow, James is studying the need to protect genomic and health data within personalised medical research as part of the Data Protection and Personalised Health (DPPH) project. This project aims at implementing a country wide system for the exchange of health records between hospitals and research institutes in Switzerland. In addition, James has continued the research into intellectual property and open innovation examining the right to science under international law.

Vicky Xafis (National University Singapore)

Dr. Vicky Xafis is a Senior Research Fellow at the Centre for Biomedical Ethics (CBmE), NUS. She is Programme Director for the NMRC-funded SHAPES (Science, Health and Policy-relevant Ethics in Singapore) Initiative. The SHAPES Initiative provides support and ethics expertise in biomedicine to policymakers, government agencies, clinician-scientists, and other stakeholders. Vicki received her MBioethics from Monash University, Australia, and her PhD (Ethics-Law) from The University of Adelaide, Australia. She also holds qualifications in linguistics and English language teaching. Current SHAPES projects include the Big Data Ethics Project, the Gene Modifying Technologies Project, and empirical research.

Effy Vayena (ETH Zurich)

Dr. Effy Vayena is a Professor of Bioethics at the Swiss Institute of Technology (ETHZ) and founder of the Health Ethics and Policy Lab. Her work focuses on important societal issues of data and technology as they relate to scientific progress and how it is or should be applied to public and personal health. In her work she tackles pressing questions that arise through technological advances such as genomic technologies in healthcare and research. She has been appointed a Visiting Professor at the Center for Bioethics at Harvard Medical School and a Faculty Associate at the Berkman Klein Center for Internet & Society at Harvard University, where she was previously a Fellow. She has previously worked with the Wellcome Trust, OECD, Commonwealth Fund, Chatham House, and academic institutions and governments around the world.