

Privacy by default, security by design. Effects of GDPR on public health research. Monday 12 October, 09:00 - 12:00 CET

Organisers

- EUPHA section PHMR, Digital Health, EUPHA initiative for a section on Public Health and Law, EUPHA and EUPHA section on Health Service Research
- InfAct: Joint Action on Health Information
- Sciensano, Belgium
- Ministry of Health, Department for Policy in Health, Health Information and Research, Malta
- Gesundheit Österreich, Austria
- University Vita-Salute San Raffaele, Italy

Background

In 2018, the General Data Protection Regulation (GDPR) came into force, imposing new responsibilities on organizations which process data of EU citizens. The Regulation seeks to harmonize data privacy laws, to protect EU citizen's data privacy and to reshape the way that organizations approach data privacy. However, different interpretations of the regulations have led to a diversity in implementation of GDPR in countries, this having an impact on public health research and digital health products development and use worldwide. While the so called "digital transformation of healthcare" is aimed at empowering citizens and building a healthier society, how can this process evolve in synergy with effective data protection? Was the GDPR developed taking into consideration the technical basis and underlying concepts of digitalization.

This pre-conference will focus on specific problems which arise in the context of the regulation's application to public health research and digital health products and how to deal with these problems. The pre-conference will start by setting the scene. A technical introduction on legal aspects with regards to the GDPR will be given. Additionally, the results of the European Commission's and InfAct's study on Member States' primary and secondary use of health data, respectively, in light of the GDPR will be summarized. Then an interactive panel discussion will be held where experiences with countries on dealing with the GDPR at national level will be shared. Participants will be able to vote reflecting their position. The second part of the pre-conference will have a stronger focus on digital health. It will focus on the implication of GDPR entering into force for digital health tools, development, implementation, use and monitoring. More specifically, interactive presentations will provide: i) the perspectives of digital health solution developers, ii) the perspectives of public health researchers', and iii) citizens' perspectives.

Objectives

- Familiarize the audience with the legal implications of the GDPR on public health research and digital health worldwide.
- Share experiences of how the GDPR has had an impact on linkage or exchange of health data.
- Provide EU and non-EU participants practical examples of how countries have been translating the GDPR at national level and how it could support them in their efforts.
- Provide insights into different approaches how to balance the public good and personal privacy and their pros and cons.

Main messages

- GDPR theory and practice: how can we overcome the barriers? Sharing experiences of secondary use of health data.
- Effective compliance to GDPR might foster the potential offered by digital health tools to public health research, practice and policy.

Programme

Time	Topic	Speaker
9.00-9.05	Welcome and opening: Privacy by default, security by design. Effects of GDPR on public health research.	Petronille Bogaert, EUPHA PHMR, InfAct, Sciensano, Belgium
Section I: Setting the scene		
9.05-9.11	Introducing GDPR from a theoretical, legal point of view	Petra Willson, Health Connect Partners, Belgium
9.11-9.25	Implementation of the GDPR across Europe	Eline Verhoeven, Netherlands Institute for Health Services Research, the Netherlands
9.25-9.40	The impact of GDPR on secondary use of health data	Jakov Vukovic, Croatian Institute of Public Health, Croatia
9.40-9.50	Discussion	Moderated by Petronille Bogaert, EUPHA PHMR, InfAct, Sciensano, Belgium
Section II: PRO-CON discussion		
9.50-11.00	“GDPR is not hampering research and adding transparency” VS “GDPR is building new barriers”	<ul style="list-style-type: none"> - Neville Calleja, Ministry of Health, Malta - Vesna Vizintin National institute of Public Health, Slovenia - Melissa Van Bossuyt, Sciensano, Belgium - Hanna Tolonen, National Finnish Institute for Health and Welfare, Finland - Claudia Hahl, Public Health Institute Gesundheit Österreich GmbH, Austria
11.00-11.15	Break	
Section III: Digital Health and GDPR		
11.15-11.25	The perspective of digital tools for health producers and developers	Andrea Tognoni, Cambre Associates, Brussels
11.25-11.35	The perspectives of the private sector	Robin Ohannessian Télémédecine 360, France
11.35-11.45	The perspective of a young public health professional	Juan Rachadell, Lisbon University Institute, Portugal
11.45-12.00	Wrap up and key messages	Stefan Buttigieg, University of Malta, EUPHA Digital Health, Digital Health Malta, Malta Petronille Bogaert, EUPHA PHMR, InfAct, Sciensano, Belgium

Speakers

Petronille Bogaert, EUPHA section on Public Health Monitoring and Reporting, InfAct and Sciensano, Belgium



Petronille Bogaert is president of the EUPHA section on Public Health Monitoring and reporting. She is project researcher and functional head of unit EU health information systems at Sciensano, the Belgian Federal Public Health Institute in Brussels. Her work primarily focusses on the Joint Action on Health Information (InfAct) which aims to prepare the transition towards a sustainable EU health information system infrastructure for both public health and research purposes. She is a graduate from the European Master of Public Health, a double master degree in the University of Sheffield (UK) and Jagiellonian University (Poland). She specialised in health economics and governance of health systems. She also holds a Bsc and Msc in Biomedical Sciences at the Katholieke Universiteit Leuven and is PhD candidate at Tilburg University.

Eline Verhoeven, Netherlands Institute for Health Services Research, the Netherlands



Eline Verhoeven is a researcher at Nivel, Netherlands Institute for Health Services Research. She has a background in Global Health and Environmental Science. At Nivel Eline is part of the EUHealthSupport team, which provides scientific support to the European Commission. Recently Eline and colleagues have conducted research on the impact of the GDPR on the use and exchange of health data in and between EU Member States. Next to this she is also working on patient safety in Dutch independent treatment centres.

Jakov Vukovic, Croatian Institute of Public Health, Croatia



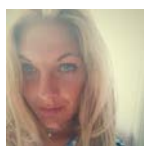
Jakov is a medical doctor and works as a Public Health Resident at the Croatian Institute of Public Health. His previous professional experiences include clinical medicine (general practitioner) and clinical trials (sub-investigator).

Neville Calleja, Ministry of Health, Malta



Prof Neville Calleja is a medical doctor and qualified in Medical Statistics and Public Health. He is a specialist in public health medicine and was awarded Membership of the Faculty of Public Health in the UK in 2011. In 2013, Neville completed his PhD studies on the statistical correction of misclassification of disease status between self-reported and examined health surveys. He has been employed at the Directorate for Health Information and Statistics within the Ministry responsible for Health since 2001 and also served as Acting Chief Medical Officer. Prof Calleja has fifteen years of experience lecturing medical statistics, epidemiology and public health to all health care professionals, together with ethical and scientific review of projects at local and international level. He is also active at European level in the field of Health Information for both the European Commission and WHO (Europe) and in InfAct.

Vesna Vizintin National institute of Public Health, Slovenia



Vesna Vižintin Šporn, a university graduate in law and a master of science in human resource management, has been employed in public health for 15 years. Areas of work include legislation in health sector, GDPR, as well as employment legislation and HRM. She is head of the Legal and system affairs at NIPH.

Melissa Van Bossuyt, Sciensano, Belgium



Dr. Melissa Van Bossuyt is information security coordinator and lead data protection officer (DPO) at Sciensano, the Belgian public health institute. After completing a PhD in Pharmaceutical Sciences and working as a toxicologist at Sciensano, she became increasingly interested in data protection aspects of public health research. She holds a DPO certificate of the national leading data protection institute and is involved in several projects and working groups aiming to harmonise (personal) data protection implementation measures across the national and EU public health research landscape. Her background as a scientist enables her to better understand the needs and obstacles researchers may face when processing personal data.

Hanna Tolonen, National Finnish Institute for Health and Welfare, Finland



Adjunct Professor (public health) Hanna Tolonen has a PhD in public health and epidemiology, MSc in Statistics and Specialist Qualification in Management degree. She is working as a Research Manager in the Department of Public Health Solutions in the Finnish Institute for Health and Welfare and serves also as a deputy health of the unit. She is coordinating the European Health Examination Survey (EHES) Network. Currently she is leading a national project Projections of the burden of disease and disability in Finland – health policy prospects (2017-2021) and the member of the ethical board in the European Human Biomonitoring Initiative (HBM4EU), and partners in InfAct and EU/H2020 project Science and Technology in childhood Obesity Policy (STOP).

Claudia Hahl, Public Health Institute Gesundheit Österreich GmbH, Austria



Claudia is working in the field of health care and health policy for 25 years. After working in hospital administration she joined the Austrian Public Health Institute Gesundheit Österreich GmbH (GÖG) in 1998 where she worked on a number of topics in the field of health and social care focusing on big data, public health, health systems performance, health policy, medicines and medical devices. Her current position is Head of International Affairs and Consultancy at GÖG. She contributes to the JAs InfAct and eAction. She is also in charge of GDPR implementation in her institution. Claudia is consultant to EU and WHO for a number of topics, including digital health, health information and pricing of pharmaceuticals – just to mention the current ones. An important [publication](#) is the Study on Big Data in Public Health, Telemedicine and Healthcare done for DG SANTE

Andrea Tognoni, LL.M, Senior Consultant – Cambre Associates, Brussel



Andrea is an EU law and policy expert, with a specific focus on public health, internal market, trade and investment issues. At Cambre, he advises public and private clients on EU health policies and connected issues, notably on market access and trade for medical products, public procurement, cancer policy and much more. Thanks to a consolidated experience working on regulatory issues and policy communications, he focuses on integrated campaigns around economic, technical and political negotiations within the EU, notably within the European Parliament. Prior to joining Cambre, he worked at the EU Delegation to the United Nations and other international organisations in Geneva, specifically the WHO, as an independent researcher, as a lawyer, and as a free-lance editor and translator. He has also gained experience on international affairs working with global NGOs and think tanks focused on human rights, corporate governance and international law. A qualified lawyer in Spain, he holds a J.D. from Barcelona University, and an LL.M in Public International Law from Leiden University.

Juan Rachadell, Lisbon University Institute, Portugal



Juan Rachadell is a Lisbon based luso-venezuelan medical doctor currently specializing in Public Health and pursuing a master's degree in public policy at ISCTE – Lisbon University Institute. He is passionate about the fields of evidence-based medicine, health policy and digital health. In the latter field, he's been specifically interested in the crossroads between new technologies and public health, how they influence each other and how that interaction can be beneficial for public health goals.

Robin Ohannessian, Télémedecine 360, France



Dr Robin Ohannessian MD MPH is a medical doctor from Paris, France specialised in public health. He is the co-founder and director of Télémedecine 360 (TLM360 SAS), a global consulting company dedicated to support the international development of telemedicine with TelemedStart, TelemedAudit and TelemedEval services. He is as well an academic researcher on telemedicine with several publications on teleneurology and telestroke, and also published a global call to action for the organized use of telemedicine to fight Covid-19 pandemic

Stefan Buttigieg, University of Malta, Digital Health Malta, Malta



Dr Buttigieg is the Vice-President of EUPHA Digital Health Section and a Specialist in Public Health Medicine with an avid interest in Clinical Informatics, Social Media and Digital Health. He currently lectures at the University of Malta Faculty of Health Sciences on the topics of Digital Health and Social Media in Healthcare. He is also an Author, Tutor and Digital Health Consultant focused on creating transformative and effective change. Within the World Federation of Public Health Association Governing Council, he represents the voices of Students and Young Professionals in Public Health and he is the co-founder of Digital Health Malta.