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PANELFIT

PARTICIPATORY APPROACHES TO A NEW ETHICAL AND LEGAL FRAMEWORK FOR ICT

The Panelfit's official Newsletter - 01 May 2019

PANELFIT: Science with and for Society.

The vertiginous transformations placed in the field of Information and Communications Technologies (ICT), and their impact on society, lead to significant changes in regulation landscape. The General Data Protection Regulation (GDPR), The Data Protection Law Enforcement Directive (EU) 2016/680 so called "police directive", or the Directive on Security of Network and Information Systems (NIS Directive), are just examples of this. Such normative, which has as a background, the defence of fundamental rights of European citizens who may be affected by inappropriate use of ICTs, requires an understanding and adaptation by all sectors at stake, which is not easy at all.

PANELFIT project, funded by the European Union Framework Program Horizon 2020, is designed to assist in this difficult process of adaptation with a set of editable, openly accessible guidelines. Once completed, these guidelines shall serve as operational standards, capable of reducing ethical and legal problems posed by information and communication technologies while fostering innovation and market growth.

Data commercialization, informed consent and security, are the three pillars on which PANELFIT will mainly concentrate. But the project intend to go further, it is moving to identify the key topics or issues on which a new or amended ethical and legal framework should focus on and uses these topics as concrete case studies to identify the key issues.

In the EU nomenclature, this project is inserted in the 'Science with and for Society' program (SwafS), it means that PANELFIT initiative 'will be instrumental in addressing the European societal challenges tackled by Horizon 2020, building capacities and developing innovative ways of connecting science to society´. That is why, all project´s outcomes will be developed in a broad, participatory co-creation process. Among these expected results, we can find:

- A compendium of the legal framework for data protection and informed consent,

data commercialisation and security and cyber-security issues.

- A critical analysis of the EU legal framework, in particular of ethical issues not adequately addressed in the General Data Protection Regulation and of open legal issues within EU regulations.
- The creation of an interactive platform for mutual learning to serve as a reference forum for researchers, stakeholders and policy makers.
- A series of activities dedicated to improving knowledge of the new legal framework and ethical and legal issues in selected communities - such as research and journalism - and among citizens in general. To this end, PANELFIT will develop handbooks, codes of conduct and information kits, and organise a variety of participation and dissemination initiatives, including monthly chats, MOOC courses, information and teaching events and public debates.

Coordinated by the University of the Basque Country (UPV/EHU), PANELFIT Consortium comprises twelve other European partner institutions from different fields; from of technology assessment to university and academic research, IT consulting, citizen science, research ethics, data protection, media and consulting.

The 'Science with and for Society' spirit of PANELFIT allows to involve many societal actors working side by side during the project journey. This transparent and responsible approach to research, we expect, will guide us to an enhanced the project´s outcomes taking into account ´the values, needs and expectations of European society´.

Aliuska Duardo

PANELFIT Project Manager

NEWS

PANELFIT hosts a talk on health data and clinic research at the CPDP2019 Conference

Federico Caruso PANELFIT EC&DB

On February 1st, a panel of experts in data protection from different fields gathered in Brussels to discuss challenges and opportunities brought by the use of new technologies in the research on health. The ethical and legal implications raised by the use of personal data for this purpose has been tackled by different points of view, starting with a fundamental question: is it ok to use people's data?

During the CPDP2019 Conference, which took place in Brussels earlier this year, a panel was organized by PANELFIT and Brussels Privacy Hub. The panel took place on February 1st and aimed to promote discussion of the key challenges involved in health data processing in clinics and research under the GDPR. The panel was chaired by Albena Kuyumdzhieva, programme manager at the Ethics and Research Integrity Sector, Directorate-General for Research and Innovation (European Commission). The moderator of the encounter was Gianclaudio Malgieri, doctoral researcher at the Vrije Universiteit LSTS in Brussels, while the invited speakers were Bernd Stahl (Professor of Critical Research in Technology at De Montfort University, UK), Zuzanna Warso (advocate and researcher at the Helsinki Foundation for Human Rights), Nicola

Orlandi (Novartis, CH) and Aliuska Duardo, (researcher at the University of the Basque Country, ES).

Lawfulness, transparency and accountability are important elements to consider when dealing with health data – as well as personal data in general. «In case of uncertainty», stated Kuyumdzhieva, introducing the talk, «we have to protect human rights». Uncertainty comes with the rapidly developing scenarios implied by new technologies, and their ever expanding fields of implementation. Lawyers try to provide helpful tools to deal with these changes, but comprehensive regulation is likely to fail in taking into account all possible cases and situations. In the case of health data, the matter is even trickier, and the questions that emerge are many: how to deal with the risks of using of new data-mining techniques in the context of clinics, and how to protect the rights and freedoms of data subjects? How to solve the conflict between private and public interests in the context of biomedical research? What are the main ethical, legal and governance issues related to AI in the context of health care, and how can these issues be solved?

Regarding lawfulness, one of the central issues concerns the limits of informed and free consent: problems arise when data is monetised, when secondary data subjects are involved, and when health-related data emerges from the processing of non-health-related data. A question about how to deal with such data was addressed to Aliuska Duardo, who stressed the importance of context: «If you use data for health, they are health data, and they should be treated like that». What about secondary data produced after the patient's consent, for which they could not give explicit authorization? «The subject who handles the patient's data has the duty to inform the latter of new data generated by information previously given by him, and specific consent should be asked of the patient before new data is generated», explained Duardo. Moreover, ethical issues arise when we consider the purpose for which data is collected: «If an incidental finding comes to light during research, the patient must be given the right not to know, if he doesn't want to». The researcher then warned of big-data tools which can be used to de-anonymize data, and classify people into groups by aggregating information not directly connected to health issues - data which people are not even aware exists. The questions addressed to Bernd Stahl were even more elementary, though unavoidable: is it ok to use people's data? Are there actual health and economic benefits arising from the massive use of data in medicine? «The only honest answer I can give is: we don't know», said Stahl. «We don't know about the benefits, if any, and it is unclear what the costs will be for this practice, and who will bear them»

The panel went on to provide different perspectives on other relevant issues. Zuzanna Warso spoke about the fundamental human rights which are at stake in health data research, while Nicola Orlandi explained how the regulatory framework can provide solutions for the numerous open questions, with specific reference to big companies dealing with private research. The full talk can be found here (https://www.youtube.com/watch?v=owGjO36mMSQ), together with all the other videos from CPDP2019.

H2020 FELLOW PROJECTS

On May 20, 10 AM CET, the SIENNA, PANELFIT and SHERPA projects will explain what we do, where the overlaps are, and how we intend to work together to improve ethical, human rights and legal frameworks for artificial intelligence, big data, smart information systems, and ICT in

general.

The webinar is open to anyone who is interested what we do. We use Zoom, and you will receive an e-mail with information and a link to the meeting when you register.

All three projects are funded by the European Union's H2020 programme. The webinar is hosted by SIENNA, in collaboration with PANELFIT and SHERPA.

Sign up for the webinar

EVENTS/FURTHER STEPS

PANELFIT Consortium´s meeting 23-24 May 2019 Brussels	The second meeting of the PANELFIT Consortium will take place in Brussels on May 23 and 24 at the Vrije Universiteit Brussel. Partners and members of PANELFIT Expert Advisory Board will meet for two days to analyse how the project has been developed and put common ideas on future actions.	**Expert workshop on governance of ICT** 22nd May 2019 Brussels	The expert workshop on governance of ICT data protection ELIs is going to take place in Brussels, on 22nd May, 2019. Participants will discuss the most important challenges in the area of ICT research and innovation.
		Workshops on data commercialization; Security and Cibersecurity, Data protection 3-5 June 2019 Bilbao	

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