

EAPM EXPERT PANEL (VIRTUALLY): EU Health Data Space

Securing European citizens' trust in the European Health Data Space as an aid to healthcare

Tuesday, June 7th, 2022

10.00 – 13.00 CET

Background.

Deriving the full benefits of the European Health Data Space will depend as never before on Europe making a conscious decision to act in concert, with the right legislation and the right policy decisions, so as to take the chance that is on offer.

Success requires that data can flow more freely, rather than being trapped in traditional silos or constrained by artificial borders. Success also depends on something less tangible: readiness by everyone involved to make use of the data that will become available. This will require buy-in by EU and national policymakers, by health authorities at all levels, and by stakeholders – patients and citizens – who stand to gain most, and who are also determinant in how far further benefits will be conferred on future generations of Europeans. Individuals are both the sources for and the beneficiaries of this wealth of data. And for once, it is individuals who are in a position to influence the outcome. In very real terms, this time the future is in their hands.

The short answer therefore is that Europe is able – in principle – to seize the chance for wide healthcare progress. But its willingness needs the input of all stakeholders.

EAPM Expert Panel Event

This expert panel will take place on Tuesday, June 7th, 2022, bringing together policy makers with thought leaders from healthcare, academia, industry, and patient organisations, to learn from each other and discuss the current state of play and a joint approach forward to developing widespread development and adoption best practice.

Together we have the opportunity to facilitate the appropriate use of genomics and genomic data that will maximise the benefit to health systems and patient care.

Expected outcomes

The main outcome will feed into activity that will support the discussion at the EU and member state level regarding the 'Proposal for a regulation - The European Health Data Space'.

Participants

Attendees will be drawn from key stakeholders whose interaction will create a cross-sectoral, highly relevant and dynamic discussion forum. These participants will include public health decision makers, representatives from the European Commission, Members of the Parliament, patient organisations, and umbrella organisations representing interest groups and associations actively engaged in the field. Each session will comprise panel discussions as well.



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10:00 -11:30 Framing the discussion

Setting the Scene:

Martin Dorazil, Deputy Head of Unit, Unit B.3, European Reference Networks and Digital Health, DG Health and Food Safety (10 minutes)

5 minutes Discussion

Framing the discussion

EATRIS: Marian Hajduch, Director at Institute of Molecular and Translational Medicine, Faculty of Medicine & Dentistry, Palacky Universit, Czech Republic & National Representative for EATRIS. (10 minutes) (Confirmed)

5 minutes Discussion

BigData@Heart: Marilena Vrana, Manager for Patients and Research, European Heart Network (10 minutes) (Confirmed)

5 minutes Discussion

Diabetes: Jeannette Soderberg, Ph.D., Director, JDRF (Confirmed)

5 minutes Discussion

EHDEN: Nigel Hughes, Scientific Director, Observational Health Data Analytics/ Epidemiology, Janssen Research and Development, Belgium (10 minutes) (Confirmed)

5 minutes Discussion

Prostate Cancer: Muhammad Imran Omar, Vice Chair Methods Committee, European Association of Urology Guidelines Office (10 minutes) (Confirmed)

5 minutes Discussion

11:30 -13:00 **View from Stakeholders**

Public Health: Fidelia Cascini, Assistant Professor Hygiene and Public Health, Università Cattolica del S. Cuore. Digital Health Expert engaged by the DG for the Digitalisation, Ministry of Health. Telemedicine Working Group Member, Agenas. GDHP member (10 minutes) (Confirmed)

5 minutes Discussion



HTA: Oriol Solà-Morales, *President Fundació HiTT & CEO at HITT (10 minutes)*
(confirmed)

5 minutes Discussion

INTEL: Mário Romão – *Global Director for Digital Health Policy, INTEL (10 minutes)*
(confirmed)

5 minutes Discussion

Neurology: Frédéric Destrebecq, *CEO, European Brain Council (10 minutes)* (confirmed)

5 minutes Discussion

Screen4Care project. Edith Sky Gross, *Health & Social Science Senior Manager, EURORDIS*
- *Rare Diseases Europe 10 minutes* (Confirmed)

5 minutes Discussion

Value of Diagnostic Information: Verena Thaler, *Manager Digital Health, MedTech*
Europe (10 minutes) (Confirmed) (10 minutes)

5 minutes Discussion

Discussion

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End of Meeting