

European Health Data Space cannot compromise on data protection



(31 March 2023) The European Commission has described its European Health Data Space (EHDS) proposal as a 'quantum leap forward' for healthcare provision in Europe. Not everybody shares this optimism. As the proposal moves through the legislative cycle, trade unions, employers, health care professionals, patients and beyond have shared their concerns. If the EU truly wants to bridge the innovation gap it has with both the US and China, then it must do so with a proposal that does not compromise on the quality of public services and the protection of individual data rights. As it stands, the proposal fails to live up to its potential.

The possibilities and concerns posed by the proposal were debated in a webinar on Tuesday, 28 March. The webinar was organised by the Austrian Federal Chamber of Labour (AK EUROPA), the European Federation of Public Service Unions (EPSU) and the Austrian Trade Union Federation (ÖGB).

Jan-Willem Goudriaan, General Secretary, EPSU opened by highlighting unions' concerns with the current proposal. The pre-existing issues faced by health and care workers - such as burnout, unsafe staffing levels and administrative burden - will not be fixed by the EHDS. Instead, the proposal has the potential to worsen these issues by increasing workloads and radically changing the work environment of health workers. In order for the EHDS to be a success, it must involve unions to overcome these issues and build the necessary trust within society.

Daniela Zimmer, AK Vienna, stressed the differences between the primary uses of health data and the proposed secondary uses. While the primary uses are generally not objectionable, the proposed secondary uses go against the data protection principles established by GDPR. The EHDS proposal envisages data being pooled and accessible to any third party under an overly broad definition of health purposes, which will open the door to sensitive personal data being exploited for purely commercial purposes. The individual's right to opt-out from their health data being used for secondary purposes must be enshrined in the EHDS, and these secondary uses must be narrowed to only include non-commercial health research in the public interest.

Jan Penfrat, European Digital Rights (EDRi), noted digitising health and care service will be challenging given the pre-existing disparities and inequalities between Member States. There is a risk that the short implementation timeframe will lead to rushed and half-finished technology leaking sensitive data. Penfrat pointed out that anonymisation of data is insufficient to ensure privacy as any dataset with highly personalised data will be easily traceable back to the owner of the data. Moreover, the EHDS will undermine the confidentiality crucial to the patient-doctor relationship, as doctors will be forced to share patients' data without asking them. For this reason, Penfrat endorsed an opt-in system for secondary uses. Finally, Penfrat made a plea to avoid contracting out the implementation of the EHDS to a private company, as this would both be costly and less accountable.

Sara Roda, Standing Committee of European Doctors (CPME), shared doctors' concerns that the quality of healthcare provision will suffer due to increased administrative burden. More time doing administrative work may mean doctors have less time to care for their patients. The proposal fails to mention of medical liability, meaning that doctors and other healthcare professionals risk being held liable for issues arising from health data. Moreover, due to fragmentation in health care systems, there needs to be a flexibility of implementation on a national level. Roda concluded by highlighting the huge challenge that implementing the EHDS will represent, both in terms of closing the digital gap that currently exists between different states' healthcare systems but also in making data interoperable between already digitalised states.

MEP **Petar Vitanov** (S&D, Bulgaria), shadow rapporteur for LIBE, underlined the need for the EHDS to not just comply with GDPR but to go beyond it. Otherwise, our personal medical data has less protection than we have from cookies on the internet. Vitanov stressed that the issue of data protection is not just legal or technical, but a social one, and that the EHDS must respect the preferences of individuals and society. He emphasised his opposition to any delegated or implementing acts that would allow the Commission to amend the priority list of health data. **Lidiya Simova**, Parliamentary Assistant to MEP Vitanov, noted that states such as Bulgaria will have real difficulty in implementing the EHDS, expecting that it would take close to a decade to have the system properly up and running.

Speakers shared a consensus on that the proposal should be more restrained, comprehensive and clear to protect both health professionals and quality public services.

Further information:

[EPSU Position on the European Health Data Space](#)

[EPSU amendments to the European Health Data Space proposal](#)

[AK EUROPA Position Paper: Regulation on the European Health Data Space](#)

European Health Data Space: Data protection gaps and additional burden on the health system or opportunity for research and innovation? ([EN](#) - [DE](#))

[Video Webinar EPSU-AK EUROPA-ÖGB: "The European Health Data Space: a risk or](#)

an opportunity?"

[Standing Committee of European Doctor's \(CPME\) Position on the European Health Data Space](#)

[European Digital Rights \(EDRI\) Position Paper on the European Health Data Space](#)

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