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AEIP statement on the EU Health Data Space

With the beginning of the discussions at the European Parliament on the European Health Data Space (EHDS) on 8 November 2022, paritarian healthcare insurers and provident funds members of the European Association of Paritarian Institutions - AEIP reiterates their support to co-legislators for the achievement of this important initiative.

Through the EHDS, the European Commission aims to form a key element of the European Health Union that should promote a more effective use of health data, necessary to address diseases impacting often vulnerable communities. The proposal aims to allow for a better exchange of data used for the care of citizens across the Union (primary use of health data) and to allow further uses of such data for research and policy purposes (secondary use of health data). Particularly, AEIP is glad to see that the EHDS proposal is built on data portability, interoperability and data infrastructures and technology.

AEIP fully supports the principle embedded in the European Pillar of Social Rights, according to which every individual has the right to timely access affordable, preventive and curative health care of good quality. As non-for-profit social protection providers, paritarian institutions are a key stakeholder for citizens who benefit of their coverage and services, in addition to those offered by their social security systems.

Enable secondary use of data in a “secure processing environment” to adapt and improve treatments

AEIP strongly supports the proposal's Article 41, which makes health data available for not-for-profit entities. Making health data more available by fostering their use and re-use could help healthcare providers to adapt the treatments to the needs of beneficiaries, hence improving the service they provide. Yet, health data are very sensitive, and their use can be easily manipulated for commercial and economic interest. Therefore, we welcome that only the reuse of anonymous data in a “secure processing environment” is allowed and that researchers, innovators and policymakers have to apply for a permit to be able to reuse health data. By detecting “high-risk” customers, for-profit healthcare insurers might decide to cut them out of their coverage, by leaving this responsibility entirely to other non-for-profit schemes. This represents a major challenge for systems based on solidarity, such as the paritarian institutions represented by AEIP.

Adequate resources and infrastructures for the EHDS governance

One of the challenges with the implementation of the EHDS will be for Member States to put in place adequate resources and infrastructures at national level so that its governance framework becomes a reality. We fully support the proposal of the European Commission to deploy the data infrastructures, tools and computing capacity for the European Health Data Space and to scale up cross-border exchange of health data. This should prompt MSs to better assess their internal capacity and, if needed, increase the

funding in this area. This would be highly beneficial to paritarian health insurers, who face a rapid increase of demand of e-health services but often lack the IT and financial resources to put them in place.

Digital Health Literacy

The creation of the EHDS will lead to increased use of health data and related digital technologies. This also leads to a series of issues regarding the correct use, management and accessibility of such data. Therefore, it is crucial to establish digital health literacy programs aimed at all categories of users such as citizens/patients, professionals and new health authorities.

AEIP regrets that the European Commission's proposal does not contain any articles dedicated to digital health literacy. AEIP urges the decision-makers to invest and promote the equitable development of a basic understanding of digital health literacy for all parties involved, in order to make citizens aware of their rights, professionals aware of the legal framework and to avoid creating inequalities in the access to services for vulnerable classes.

Next steps

AEIP will closely follow the legislative debate and engage with relevant stakeholders in the process. For this reason, we welcome the appointment of rapporteurs and co-rapporteurs to the LIBE Parliamentary Committee in October and look forward to the publication of the priorities of the upcoming Swedish Presidency of the Council of the European Union.

AEIP and its members remain available to provide further information and feedback in relation to this dossier.

Contact person on behalf of AEIP:

Giuseppe PERRETTI, Policy Advisor Healthcare & Provident Funds

giuseppe.perretti@aeip.net

www.aeip.net