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Editorial

The European Health Data Space: an Opportunity to Empower Citizens

This month's newsletter is dedicated to the European Commission's proposal for a regulation to set up the European Health Data Space (EHDS), published on May 3rd, 2022. The EHDS regulation aims to provide a common framework across EU Member States for accessing and sharing of health data to support healthcare delivery, such as electronic health records, patient registries, and genomic data, and to facilitate health research, policymaking, and legislation. For this endeavour to be truly successful, as highlighted in this month's articles, the EU must do more to **promote digital health literacy** and to put safeguards in place to protect its citizens' health data.

The [EHDS proposal](#) intends to **empower citizens to take control of their own personal health data**, for example, by giving them access to their electronic health records. It is, however, crucial to ensure that people have internet access as well as adequate digital and health literacy. Recent data demonstrate that over 4 out of 10 EU citizens lack basic digital skills, and while the EU has launched several initiatives to address this issue, these all aim to equip workers with necessary digital skills for their workplace. Therefore, a **clear focus on digital skills** for the use of rapidly growing digital health tools is lacking and the EU must prioritise digital health literacy as a key issue for modern-day public health.

The secondary use of health data for research and innovation, as described in the EHDS regulation, has the potential to help discover new and more efficient treatments for many rare diseases. "Secondary use" of data refers to any application of data beyond the reason for which they were first collected, and it may include personal electronic health data originally collected to, for example, treat patients. However, for high quality health data to be collected and used for research purposes, **building citizens' trust through transparent and clear communication** about how their health data will be stored, accessed and (re)used is essential. The Commission also must ensure sufficient safeguards that would prevent health data from being misused or leaked, which is particularly of importance for vulnerable communities such as undocumented migrants, ethnic minorities, LGBTIQ+, as well as people living with certain medical conditions such as HIV/AIDS.

For years now, EPHA has been [advocating for an inclusive approach to digital health](#) tools. As pointed out in a [previous article](#) that EPHA published on the EHDS, the implementation of the regulation without fully understanding the users' concerns and needs could result in mistrust, in both governments and digital technology. It is thus important that the EU reaches out to ordinary citizens more, as well as to civil society groups representing them, throughout the different implementation stages.



Filip Karan

Junior Policy Manager for Digital Transformation, EPHA

This Month's Top Stories



By France Assos Santé

A French perspective on the European Health Data Space: health users as stakeholders

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By EPHA

Digital Skills...for All?

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By EPHA

The European Health Data Space: promises and obstacles ahead

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EPHA Events



This event launched a new study by independent researchers from CE Delft on the best alternative to diesel vehicles. Policy and industry specialists will discuss the study's findings, and what needs to happen to make Europe the first diesel-free continent.

30 June 2022

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EPHA Updates



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News From Members

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The ERS Congress is the once-a-year occasion when the world's respiratory experts come together, to present and discuss the latest scientific and clinical advances across the entire field of respiratory medicine. It welcomes a global audience of respiratory focused professionals inclusive of clinicians, scientists and researchers, and allied healthcare professionals.

4–6 September 2022 | Barcelona, Spain

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in health care settings as
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SHAAP

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Scotland? A qualitative
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SFP Welcomes the Commission's Proposal to Ban Flavours in Heated Tobacco Products

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European Cancer Organisation

New action report on *Men and Cancer: Raising the issues*.

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European Oncology Nursing Society

Join the EONS15 – Quality cancer care: pathways to clinical excellence in cancer nursing

10-12 September 2022 | Paris, France

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IDF Europe

IDF Europe welcomes the publication of the Healthier Together – EU NCD Initiative, a toolkit to help Member States reduce the burden of diabetes and other Non-communicable Diseases

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EPHA (AISBL) is the European Platform bringing together public health organisations representing health professionals, patients groups, health promotion and disease specific NGOs, academic groupings and other health associations. The European Public Health Alliance has received funding under an operating grant from the European Union's EU4Health Programme (2021-2027). The content of this email represents the views of the author only and is his/her sole responsibility; it cannot be considered to reflect the views of the European Commission and/or the European Health and Digital Executive Agency (HaDEA) or any other body of the European Union. The European Commission and the Agency do not accept any responsibility for use that may be made of the information it contains. Transparency Register Number: [18941013532-08](#)

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