



European health data space

EuroHealthNet's input to the European Commission's feedback, February 2021

EuroHealthNet welcomes the European Commission's initiative to establish a European Health Data Space with the purpose of promoting access to health data for research and innovation on new preventive strategies, as well as on diagnosis and treatment of diseases to improve health outcomes, while ensuring that citizens have control over their own personal data.

In line with its mission, EuroHealthNet monitors and advises on digital health strategies from a health equity perspective. Digital innovation in the field of health, when developed together with programmes enhancing inclusion, literacy and protection, can have significant positive effects on the efficiency and sustainability of health systems and improve health outcomes across the population, especially among people in fast changing vulnerable groups.

The **European Health Data Space** aims for *"making the most of the potential of digital health to provide high-quality healthcare and **reduce inequalities**"*. Improved safe health data collection and use could certainly improve monitoring and prevention systems, as well as enhance the ability of people to better understand and engage in their own wellbeing via multiple applications and tools. However, there are significant challenges to be addressed and safeguards to be ensured:

- Standardisation of data is a key for the deployment of the EHDS and use of health data across the EU. Regulators should take an active role in ensuring that standardisation includes high levels of data protection and anti-discrimination principles. Digital tools collecting these data should also be standardised and regulated to ensure they are safe, comprehensible, easy to use and (therefore) accessible to everyone. The ISO/IEC effectivity and reliability criteria for health and wellness can be considered in developing European standards
- The development of sound digital infrastructures should ensure the collection of high-quality data that add value to health systems in a non-discriminatory way. This includes ensuring that AI algorithms are designed reflecting the needs, preferences and expectations of people in vulnerable circumstances and priority needs. This means that people with lower digital or health literacy, less education, low income, migrants, disadvantaged older people, people with physical or mental disabilities etc., are systematically and well included in the underpinning research and planning. Health equity impact assessments are also vital processes
- Data/Digital Health Literacy programmes should be an integral part of the EU actions on the European Health Data Space. Improving data literacy across the population would allow people to not only actively manage their personal health and care, but also to increase their understanding of the quality and suitability of apps (including mHealth apps), their marketing, what their data is being used for, how they can control it and other relevant issues. Improved data/digital health literacy would also increase trust in digital innovation in health, care and related sectors as well as general media, which is an essential component as the COVID-19 syndemic has demonstrated
- The deployment of the European Health Data Space should go hand in hand with training and capacity building programmes for professionals (including through up- and re-skilling) . This would help them deliver better quality of care and also create a safer environment. For instance, a large part of cyber threats to health systems start off with phishing events at workstations, which could be prevented with better data and digital literacy

EuroHealthNet is a not-for-profit partnership of organisations, agencies and statutory bodies working on public health, disease prevention, promoting health, and reducing inequalities. Its core mission is to tackle health inequalities and to improve and sustain health between and within European States through action on the social determinants of health.