ESIP feedback to the roadmap on a Legislative framework for the governance of common European data spaces

The European Social Insurance Platform (ESIP) welcomes the roadmap on a Legislative framework for the governance of common European data spaces, towards the creation of a Single Market for data in crucial sectors such as healthcare. This would particularly benefit people in cross-border situations. We therefore support the European Commission's initiative to increase accessibility, usability and interoperability of data, while lowering the costs of data transactions. The COVID-19 pandemic revealed the importance of sharing data in a timely, effective manner, namely on health and social-security, across EU Member States. We also welcome the creation of sectoral stakeholders' groups, namely on e-health – experts can and will provide essential contributions to design legal and technical frameworks for data exchange.

Transparency and Confidentiality

ESIP acknowledges that the roadmap focuses amongst others on increasing and improving the use of data held by the public sector e.g. national competent authorities and social security institutions, for research and innovative uses. We advocate for implementation of a harmonised and legally binding regulatory framework, providing for exchange of publicly accessible data across Member States, in full respect of the principle of Open Science. Transparency and traceability should remain the priority principles; confidentiality should also be respected. Regarding compliance with the GDPR, the legislative framework on common European data spaces should not neglect the right to be forgotten and to withdraw consent from data use to avoid unethical use of data. This is of utmost important especially when it comes to highly sensitive personal data, such as healthcare data. Transparency on the one hand and confidentiality on the other would promote facilitated and responsible access to data, increase acceptance of innovative digital tools amongst EU citizens, and foster cooperation with the scientific community.

Patient and Insured-centered Data Spaces

Exchange of quality and transparent personal data will lower barriers to R&I and offer public sector bodies the essential instruments to ensure cross-border and cross-sectoral data sharing in crucial domains, such as healthcare and social security. Public authorities – importantly statutory health insurance and social security institutions – should not solely be considered as data deliverers, but rather as key actors in building European data spaces. Data spaces should be designed to benefit all relevant stakeholders who could provide added value for patients, by improving (cross-border) healthcare provision and financial sustainability of healthcare systems. This would ensure a level playing field for all actors involved and purposeful use of public sector data for the benefit of EU citizens. Indeed, there is a need for a shift from an industry perspective to a patient and insured-centered perspective when building data spaces.

Best Practices and Standards

ESIP also recommends and supports the establishment of European structural enablers for data-sharing. These instruments should serve as coordination bodies to support the exchange of best practices and promote guidelines for common practices. Harmonised standards on data formats are essential to promote data comparability, compatibility and interoperability. Competent authorities in the health sector and social security institutions should be fully involved in exchange of best practices, in setting standards as well as in formulating priorities and conditions for the use of data. (A) European Coordination body/ies should on their side supervise a purposeful processing, transformation and flow of data, while ensuring quality and interpretability, transparency and confidentiality.

Finally, we call for a strategic use of investments in digital programmes. In this regard, we express our concerns on the significant cuts made to key programmes, including Digital Europe, despite digitalisation being identified as a strategic priority in the Council 2019-2024 Strategic Agenda and by the Commission.