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Feedback from: European Federation of Nurses Associations (EFN)

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Submitted by

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Non-governmental organisation (NGO)

Organisation

European Federation of Nurses Associations (EFN)

Organisation size

Micro (1 to 9 employees)

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Belgium

Initiative[Digital health data and services – the European health data space \(/info/law/better-regulation/have-your-say/initiatives/12663-Digital-health-data-and-services-the-European-health-data-space\)](/info/law/better-regulation/have-your-say/initiatives/12663-Digital-health-data-and-services-the-European-health-data-space)

The nursing workforce, which is the largest healthcare professional of all, will be key in the deployment of the European health data space in healthcare settings. Its success in Europe will largely depend on end-users providing input to the health data space and using the data to better plan their services. Nurses will only do so when they were involved as co-designers of these technologies, trust the systems and see the added-value for EU citizens.

The cloud-based service that will potentially transform the way current healthcare systems operate and communicate are the interoperable EU Electronic Health Record, building on what Member States have developed already. The Electronic Health Record is the digital file containing citizens/patient's personal data (name, picture, address, age, etc.) and health history (existing diseases, previous surgeries, allergies, blood type, allergies, vaccinations, etc.) that nurses need to provide high quality and safe services.

It is key for EFN, representing 3 million EU nurses and 6 million European nurses, that frontline nurses are able to use the collected data to boost the continuity of care (e.g., cross border care). Frontline nurses need to become co-designers of future EU-wide systems of Electronic Health Records (EHR). Innovation in health data governance should empower patients/citizens and frontline nurses, moving towards an integrated care system based on proactive/empowered health-aware patient/citizen summary data, with the use of AI, to get better health outcomes.

Stakeholders should look at the national regulation of the growing volume of data, e.g. patient's health data. The creation of common data spaces should allow citizens, businesses and organisations to access non-personalized data from countries, pooled across different key sectors. Data protection and competition laws continue to be applied. Strengthening data quality, governance, security and interoperability are key to build that trust with the end-users: the frontline healthcare professionals. It is therefore essential to create fit-for-purpose innovations/solutions for healthcare ecosystems. Requirements and mechanisms co-designed with the end-user are key to ensure the utility and suitability of the developed solutions. It is important in the requirement phase to provide the IT developers with the nurses' views and expertise in making the solution fit-for-purpose.

Furthermore, an open, standardized and unique European extended-EHR is needed to preserve the European assets and professional ways of working, by addressing the current lack of interoperability and security, defining a set of integrated protocols and conformance criteria for mobile apps/software, supporting secure and portable local storage and backup, released as open specifications. Moreover, this exchange is organised by a superior authority – namely governments or hospitals. The idea is to give data's control back to the citizens and patients, by empowering them. Different scenarios can be worked out, namely 1) device-to-device, 2) a patient in an emergency situation, and 3) donating data for research; and make these happen, implemented throughout the EU. We need to stop hiding us behind subsidiarity: each

citizens/HCP needs to have the data for continuity of care at their fingertips!

In order to ensure that the European health data space is deployed successfully and safely across EU healthcare systems, it is key to:

1. Develop the co-creation of EU health policies.
2. Support the development of national electronic health records and improve the interoperability of health data.
3. Equip the nursing workforce with the necessary skill sets to maximise the positive impact of health data and conduct a comprehensive regulatory assessment of the healthcare professions gearing both the bachelor education and lifelong learning programmes towards digital literacy.

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