

Overcoming barriers with a citizen-centered digital health data infrastructure in Europe

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Nowadays the work of health care professionals is widely digitized – supported by hospital information and practice management systems, connected to health insurances, and becoming bit-by-bit interoperable between institutions. But the patients, or more generally the citizens, seldom experience a benefit from this digitization. Even when 9 out of 10 healthcare providers offer a patient portal along with their professional system (Green, 2018), the citizens cannot gather that information from different systems in one place or bring it together with their own health data from wearables or personal health applications.

Any business-to-business approach at some point will face the federal barriers and conflicting interests between businesses, hospitals, insurances, federal states, or countries. Therefore, we follow a business-to-consumer approach to set up a European health data infrastructure for citizens. The General Data Protection Regulation (GDPR, 2016) gives each European citizen the right to request data about them from any institution. We believe that, when citizens are empowered by a digital toolset to claim their rights, these barriers can be overcome. The Smart4Health project follows a citizen-centered approach which puts the citizen in the position to retrieve their personal health data from prospectively any health-related context within Europe. They collect this data in one secure citizen-centered health data platform in Europe. The infrastructure realizes maximum privacy and privacy-by-design, where only the citizen can access the data and decides to share this data directly with health care professionals or others in a controlled and targeted manner. In this way the cross-border exchange of health data can be realized without the need to connect health care providers. In addition, Smart4Health enables the citizen to voluntarily make this data available to the scientific community in anonymized form, which enables all citizens to gain personalized insights about their health and which supports societal wellbeing.

The objective of this article is to explain the high-level architecture of the Smart4Health platform addressing different barriers to realize a health data platform for all European citizens such as security, interoperability, connectivity, cross-border exchange, or language. We set the focus on the services provided to the citizens such as retrieving the data from health care providers and sharing with health care professionals. Also, we discuss the need of standards to realize scalable cross-border interoperability.

Smart4Health (www.smart4health.eu) is a project of the European Union with the aim to realize a platform for electronic health records and far-reaching value-added services for EU citizens throughout Europe. The Smart4Health consortium consists of 18 partners from medical, social and technical sciences, and industry. Smart4Health is funded through the European Union's Horizon 2020 research and innovation program under Grant Agreement No 826117 with a maximum of €21.8 million over 50 months.

References

- GDPR (2016). Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (General Data Protection Regulation), OJ 2016 L 119/1.
- Green, J. (2018). An objective comparison of the best EHR patient portals. [online] Available at: <https://www.ehrinpractice.com/best-ehr-patient-portals-comparison.html> [Accessed 11 Sept. 2019].