

Combined report from the session at the Health Data Forum

28 Oct 2020, 12:30-14:00 CET

Trust, citizen empowerment and the role of digital literacy on health data sharing

The aim of this session was to present the conclusions for health data sharing developed within the [DigitalHealthEurope project](#) (DHE) and engage into the discussion with a group of stakeholders to define the way towards a common pathway, strategically speaking, despite any different organisation types, perspectives or approaches.

The session was chaired by Bleddyn Rees, ECHAlliance, The Digital Health Society and included the following experts:

- [Karolina Mackiewicz](#), ECHAlliance
- [Carina Dantas](#), ECHAlliance
- [Diogo Martins](#), SPMS
- [Carola Schulz](#), empirica
- [Dipak Kalra](#), i~HD
- [Mara Diaconu](#), Norway Health Tech
- [Ana Silva](#), CHPVVC
- [Juliana Sá](#), CHP
- [Samuel Jacinto](#), SPMS

To set the scene and create a ground for discussion, two presentations were shared:

- Diogo Martins gave an overview on the DigitalHealthEurope project's Work Package (WP) 4: Multi Stakeholder Communities on "Citizens' secure access to and sharing of health data"
- Karolina Mackiewicz / Carina Dantas presented the summary of the challenges defined and next steps suggested in the project's deliverable "Recommendations and guidelines on citizen-controlled health data sharing governance".

In his presentation, Diogo Martins reminded the participants of the session about the aims of the work developed under this theme in DHE, which are:

- To establish a functional **multi-stakeholder community** on key aspects of the **first Digital Transformation in Health Care (DTHC)** priority;
- To bring together **EU, national, regional initiatives, relevant projects**, key stakeholder representatives, to widen citizen access to data relevant to their health through **health empowerment tools**;
- To build on **identified enabling factors** (e.g. digital literacy, citizen trust, etc.);
- To **facilitate the adoption** of a European electronic health record exchange format;
- To provide an instrumental contribution to the **implementation of EU policy** on the **first DTHC** priority.

Besides the already mentioned “Recommendations and guidelines on citizen-controlled health data sharing governance”, the outputs of WP4 also include the “White paper on better citizen access & control of data” and the “Recommendations for facilitating adoption of interoperability standards” which were further discussed in detail during the session.

The work developed brought the following diagnosis of the current situation:

- Many citizens have limited access to their health data;
- Health data are often not traceable;
- Health data are scattered in different places

At the same time, the European Data Strategy calls for the improvements in the following spheres:

- Citizens should have secure access, anywhere in the EU, to a comprehensive electronic record of their health data;
- Citizens should remain in control of and be able to share their health data securely with authorised parties;
- In line with data protection legislation.

The issue of the access and control over the health data can be discussed from multiple perspectives:

- Citizen’s, which includes the rights and responsibilities, control, ownership
- Government’s, which includes the governance, architecture, infrastructure, investments
- Technical, which includes interoperability, portability, safety and security.

The DigitalHealthEurope project conducted the in-depth analysis of the projects and initiatives in Europe, with relation to the citizens’ secure access and sharing of health data. It also connected with initiatives, collecting the information through desk research and via stakeholders’ engagement via survey and interviews.

Based on the results of the research and discussions with stakeholders, we drew the following conclusions:

- To make use of health data it is important to respect that people want more control over their health data and its uses; feedback on the sharing and uses of their data should be provided. There is the need to increase citizens’ awareness in regard to the rights to control their data and introduce them to governance models that ensure trust and privacy by design, and dynamic models of consent and data sharing.
- What is the governance model that is transparent, ethical, provides the incentives for data sharing and protects the privacy? How is this model sustainable?
- This needs further experience: learn through trial and error, by implementing, and developing large-scale field testing and assessing results and impacts of different models.
- When the discussion is on sharing the complete health data with several stakeholders, trust is a big challenge to overcome. In order for patients and citizens to trust the wide sharing and reuse of their complete health data, they will expect transparency about who will have access to their data and how it will be used. Furthermore, privacy and security should be strengthened. As citizens are increasingly aware of the importance of their data, they also want to know what, how and what it is used for. Improve informed consent guidelines to make it readable, clear and easy.

- In principle, giving data subjects more control over their data is a good thing. But a huge amount of education is required. Digital education is necessary – namely to ensure the role of citizens and the dual role of healthcare professional as drivers for change.

It is important to remember that there are several challenges to overcome on the way to the implementation of the vision described above. Those are:

- What is the policy and societal framework needed to better assess and develop on citizen-centred data sharing governance models?
- What are the needs in terms of digital literacy of citizens and professionals to ensure participatory models?
- How can citizen-led data governance models respond to current challenges?
- Which best practices and initiatives may be used as reference for benchmarking, adaptation and adoption?

Based on the introduction that set the scene, the panelists engaged in the discussion that circulated around the following themes:

1. DIGITAL LITERACY

This is seen undoubtedly and unanimously as an absolute prerequisite for the digital transformation in the access and citizen's control over their health data. It is clear that no data sharing programmes or campaigns will succeed without a solid investment in digital literacy. It should be primarily seen as a public investment.

We know that better health literacy leads to better health outcomes. E.g. the more digitally literate patients and citizens are, the better they can handle the challenges of COVID-19. There is also evidence that confirms the health professional's viewpoint on the issue. However, the day-to-day clinical practice does not usually allow time and resources for focusing on the health-literacy enhancing interventions.

However, the involvement of professionals in building trust and transparency is crucial. This is why the digital literacy aspects should be brought to the health professionals early in their career, during their studies and shortly after the graduation. They should be involved in the design and development of the functionalities and other usability aspects of the digital solutions, to stay familiar with those tools from a very early stage. Simultaneously, patients and citizens should be engaged in the development work, to make sure the tools address their real needs and are user friendly.

The panel proposed that a way to ensure that health professionals will have the basic digital skills is to define minimum requirements on digital health literacy for professionals. As for patients and citizens, health and education agencies should provide strong investment to develop digital literacy skills. Also, patient organizations and health bodies should be involved. "Public investment in education should be the first priority", one expert highlighted. It is important to also highlight that the European Strategy for Data (19 Feb 2020) calls for a common EU skills data space. This fact demands an EU-wide digital literacy acceleration, including digital health literacy.

While advocating for those investments, the experts involved in the session see opportunities for further improvements in digital health literacy laying in the community work. It was mentioned that the healthcare sector should look outside the healthcare system and promote digital literacy in collaboration with other institutions. In that sense, the needed transformation can be accelerated in collaboration with e.g., municipalities or schools.

2. HEALTH DATA SHARING AND INCENTIVES

The debate in this sub-theme started with considerations on the control and ownership of data. Do citizens own their data or do they control it? The former implies that when the data is being shared, the ownership is transferred to the other entity, and the citizen loses the rights to this data. Here we can speak about data donation. The latter implies that the citizen controls their own data and can grant full or limited access to it. Here we speak about data sharing or data exchange. The incentives, monetary or other, are valid for the two models. The experts agree the debate should be about control, not ownership.

The other dichotomy applies to the companies' and citizens' primary interests. Although not consensual, it was brought up in the discussion that while the companies primarily aim at profit (even if they can be socially responsible), the citizens focus on better health and better quality of life. This can be connected to some of the results of the survey conducted by the DigitalHealthEurope project, but is possible an area in need of further discussion and awareness, namely that people expect that their data will be used for better diagnosis and development of better health services that will help them and the others to live healthier lives. The monetary incentive appears to not play the major role, despite some age differences (it is more appealing to the younger respondents). Some suggested schemes include:

- yearly lump sum payment for every citizen participating in the data exchange,
- monetarily awarded through regular payments or medicine discounts,
- a subscription-type model to access growing data sets.

There is obviously a great challenge on how people can share their health data in a controlled and coordinated way. On one hand, there is a massive amount of health data produced every second, on the other hand, the health sector lacks the quality data. There are already some models emerging and being tested, among others data banks, data collectives, data unions, data wallets etc.

3. NEED TO DEFINE OR RE-DEFINE WHAT THE "CITIZEN-CENTRED" MEANS

It is important to notice that the "citizen-centred" can mean different things for people coming from different background and with a different agenda when it comes to the use of health data. Does "citizen-centred" mean giving most decision power to the citizens or benefiting the largest number of citizens as possible? Also, what does it mean from the perspective of the citizens themselves: personal control or personal benefit?

This is not only a philosophical debate. The distinction is important for decision on opt-in and opt-out model for data access and sharing. As one panelist noted, this means: if we think about the benefit as a top priority, the choice will be opt-out. If control, then the opt-in model should be applied.

However, to proceed with this discussion, we need to ensure that the citizens have the best understanding possible on what kind of data they share, what they mean, what kind of benefits they can get or are possibly entitled to, and what kind of risks sharing their data brings if done in an uncontrolled way. This brings us back to the debate on digital literacy and also health literacy. This also means that the successful campaigns on data sharing should make citizens aware what is the impact of their data, and why it should be shared. Also, the body that manages or accesses the data should be fully transparent on what the data is being used for. This can create confidence and trust among citizens. In other words, demonstrating how the data is being used, what kind of impact this has on the patient's health and the health ecosystem, could be a good way to progress to the next level.

This needs to be demonstrated to citizens in an agile way, and as health data sharing is being decided at a European level, it has less immediate impact on peoples live and death and thus it is less understandable on how it may improve or not their health and wellbeing.

There is still a lot of experiments to be implemented and lessons to be learned, on both the governance and infrastructure levels, to develop digital literacy and create the ideal model for health data sharing.

In summary, the panel concluded that digital literacy empowers citizens by giving them a better understanding on where their data is going and being used, increases their trust in health data managing and providing bodies, thus, unlocking the potential of data.

The discussion carried out within the scope of the DigitalHealthEurope project will continue at the Digital Health Society Summit in November and MyData Online 2020 Conference in December 2020.