

Carina Dantas, Karolina Mackiewicz (2022): Are we ensuring a citizen empowerment approach for health data sharing? In: Proceedings of the International Conference on Privacy-friendly and Trustworthy Technology for Society – COST Action CA19121 - Network on Privacy-Aware Audio- and Video-Based Applications for Active and Assisted Living

Are we ensuring a citizen empowerment approach for health data sharing?

Carina Dantas^{1,2}, Karolina Mackiewicz¹

¹European Connected Health Alliance, ²SHINE 2Europe

carina@echalliance.com, carinadantas@shine2.eu; karolina@echalliance.com

Abstract

Today, almost all (if not all) societal activities, especially in the health field, involve the collection and processing of large amounts of data. Technological advancement, with an emphasis on the exponential increase of eHealth apps, implies that the data collected in this field will quickly become very extensive, up-to-date and timely. However, some major ethical and technical challenges arise when using big data to support health predictions, such as data protection and privacy, safe storage and analysis, scalability, potential security breaches and the capability to protect citizens rights, among others.

These concerns are already widely perceived by the European policy makers and are being addressed in communications, regulations and initiatives of several Member States, as well as EU projects, such as CA19121 – GoodBrother [1].

Being a fairly new area with many open questions, data sharing is a subject that is far from being discussed by the common citizen and a clear elicitation of its potential benefits will be key to active engagement. Besides an increase in trust, clear explanations on how and what data is collected, namely in video and audio-

based applications, how can data sharing work in practice, what direct benefits can be achieved by the individual and by society and what are the low hanging fruits that can be collected are essential for the involvement of citizens in the data sharing movement.

Background

Europe has already passed the point where healthcare and social care systems are able to respond to all upcoming needs and inequalities related to access to healthcare in a traditional way. Thus, these issues need to be addressed through a coordinated approach that builds on the use of new technologies and health data for diagnosis, treatment and care. The outbreak of COVID-19 made the need for health and health-related data much more visible [2] and raised discussions about data sharing schemes, citizens' control over their data and potential data governance models, mainly due to the tension between public health interest vs citizens privacy and security of data [3], [4].

To guarantee sustainability of the healthcare systems it is necessary to invest in prevention and predict the upcoming challenges with enough time to address them with the minimum resources [5]. This is in line with the United Nations Sustainable Development Goals [6], as well as the whole-of-society and whole-of-government approaches. However, this raises additional challenges such as the eSkills of healthcare professionals, digital health literacy of the population and the need for capacity building of local, regional and national authorities.

Research must invest in predictive analytics - determining the biggest at-risk factors by analysing the factors taken from different sources over the course of people's lives, thus preventing health problems from developing. This predictive research is now quite fallible due to the small samples of data available that are used to extrapolate results. Big data is often discussed in the context of improving medical care, but it could have an even more relevant role in preventing disease, by increasing the effectiveness of interventions to help people achieve healthier behaviours in healthier environments [7].

However, some very relevant challenges arise when using big data to support health predictions. Especially, when considering audio and video-based Ambient Assisted Living (AAL) products and services, ethical and technical concerns are extensive and require improved methods and larger discussion [8, 9].

Data protection and privacy still entail further developments and high investment in order to positively impact trust and citizen reliability on digital

services and tools. Data protection becomes more challenging to ensure as information is multiplied and shared around the world through multiple technological devices. Information regarding individual's health, location, online activity, among so many others, raises reasonable concerns about profiling, discrimination, exclusion and loss of control.

Also, safe storage and analysis, scalability, potential security breaches, the capability to protect citizens rights, prevent cyberattacks and misuse, are all very important issues that still need further developments.

These concerns are already widely perceived by the European policy makers and are being addressed in communications, regulations and initiatives of several Member States [10, 11].

A practical example of how to address these societal and ethical challenges in the development of video or audio-based AAL services is the use of ethical dialogue iterations with the relevant stakeholders, leading to an interactive process of co-creation throughout the development and deployment of the product [12]. The ethical dialogue starts with a contextual explanation of how the product or service work, (e.g. surveillance by sensors, cameras, storage of personal information etc.), followed by an open discussion on the perspectives of the participants involved regarding the effects of the technology, the specific aspects of implementation and what should be changed, adapted or improved based on stakeholders' feedback. The participation of the quadruple-helix of stakeholders in this dialogue process includes end-users, caregivers, health professionals, payers, policy makers and any others that may be relevant to the product or service at stake. Most user engagement methods foresee involving only the end user, but not the whole range of stakeholders that are somehow of relevance. However, the whole value-chain is essential to ensure that products and services are answering user needs and also adjusted to professionals demands, reimbursement models and fit to the different national markets. This interactive and iterative discussion between different actors brings several more challenges (and potential solutions) to the table, thus enriching the potential results and market feasibility for the future.

This method is already being used by the AAL Association in a batch of pilots within their approved projects for funding for the last two years and the assessment is so far very positive.

Towards a citizen empowerment approach

Besides the support and boost of European industry competitiveness, it is a priority for Europe that citizens and patients have the right to and should be empowered to determine when and how their health data can be shared, by having secure and authorised access to it and being able to securely provide these to authorised parties. By enabling this, it becomes possible to reengineer today's practices on citizen consent in a fully informed way and specific to the context of sharing, even in the most challenging situations such as for re-using data for research purposes.

For example, the Data Governance Act [11] brings forward the concept of Data Altruism as “data that is made available without reward for purely non-commercial usage that benefits communities or society at large, such as the use of mobility data to improve local transport” which underlies a strong and beneficial societal purpose. However, when being implemented, it should not be a legal expedient to justify accessing all data sources potentially needed for research, without the need for citizen consent. This would again break the trust chain with the citizens. For purposeful and large-scale data sharing Europe needs an educational pathway that is long-term and implies a cultural shift and an empowerment perspective in terms of literacy, citizenship and democratic participation. Even if shorter-term solutions are needed to enable data sharing, data altruism should be a holistic and beautiful vision of a committed society and not only a legal opportunity or an ethical obligation to share data.

For citizens' and patients' full empowerment however, it is important to rethink the way health data is captured, stored and organized, especially when concerning video and audio-based AAL tools. It needs to become easily discoverable, consistent across several health information providers and over time, shared across communities securely and lawfully through systems and apps that support interoperability.

But mostly, it also needs to ensure users that their intimacy and private life are not disclosed. There is the fear that some data platforms, especially those marketed directly to citizens, may poorly protect against cyber security risks as well as risks of privacy breaches, due to lack of supervision. To overcome these barriers, efforts must be strengthened and escalated in all areas of interoperability, data quality, clinical and co-operative governance.

In this context of citizen-controlled data governance, it is essential to further understand and experiment with digital empowerment models that are in use in

Europe and beyond, framed to examine innovative and ground-breaking initiatives that may be benchmarked and adopted to overcome the challenges.

Being a fresh new area, data sharing is indeed a subject that is far from being discussed and comprehended by the common citizen. However, this knowledge, understanding of the process and a clear elicitation of the potential benefits connected to data sharing will be key to active engagement and the use of digital applications for health.

Side by side with the need for more trust in the process, public campaigns and clear explanations of how data sharing can work, what direct benefits can be achieved by the individual and by society and what are the low hanging fruits that can be collected – e.g., privileged access to research results – will be essential for the involvement of citizens in the data sharing movement, as future works to be developed.

Acknowledgments

This work was partially developed within the DigitalHealthEurope project, funded by the European Commission under the Grant Agreement: 826353 (<https://digitalhealtheurope.eu/>) and based upon work from COST Action GoodBrother 19121 – Network on Privacy-Aware Audio- and Video-Based Applications for Active and Assisted Living, supported by COST (European Cooperation in Science and Technology).

References

- [1] COST action 19121, Network on Privacy-Aware Audio- and Video-Based Applications for Active and Assisted Living. Accessed: March 18th, 2022. Available: <https://goodbrother.eu/>
- [2] WHO on behalf of European Observatory on Health Systems and Policies, “Quarterly EUROHEALTH”, 2020. [Online]. Accessed: March 18th, 2022. Available: <https://apps.who.int/iris/bitstream/handle/10665/336263/Eurohealth-26-2-2020-eng.pdf>
- [3] Organisation for Economic Co-operation and Development, “Recommendation of the Council on Health Data Governance, OECD/LEGAL/0433”, 2019. [Online]. Accessed: March 18th, 2022. Available: <https://www.oecd.org/health/health-systems/Recommendation-of-OECD-Council-on-Health-Data-Governance-Booklet.pdf>
- [4] World Health Organization, “Ethical considerations to guide the use of digital proximity tracking technologies for COVID-19 contact tracing. Interim guidance”, 2020. [Online]. Accessed: March 18th, 2022. Available: https://www.who.int/publications/i/item/WHO-2019-nCoV-Ethics_Contact_tracing_apps-2020.1

- [5] C. Dantas, W. van Staaldouin, M. van der Mark, A. L. Jegundo, J. Ganzarain. “Framing Paper Thematic Network 2018 Smart Healthy Age-Friendly Environments”. <https://en.caritascoimbra.pt/wp-content/uploads/sites/3/2018/11/Framing-Paper-SHAFF-20181121.pdf>
- [6] United Nations. “Take actions for the sustainable development goals”. Sustainable development goals. <https://www.un.org/sustainabledevelopment/sustainable-development-goals/>
- [7] M. A. Barrett, O. Humblet, R. A. Hiatt, and N. E. Adler, “Big Data and Disease Prevention: From Quantified Self to Quantified Communities,” *Big Data*, vol. 1, no 3, pp. 168-175, Sep. 2013, doi: <http://doi.org/10.1089/big.2013.0027>
- [8] E. Vayena, T. Haeusermann, A. Adjekum, and A. Blasimme, “Digital health: meeting the ethical and policy challenges”, *Swiss medical weekly*, 2018, doi: 10.4414/smw.2018.14571
- [9] UNGlobalPulse, “Data privacy, ethics and protection: guidance note on big data for achievement of the 2030 agenda” 2017. [Online]. Accessed: March 18th, 2022. Available: https://unsdg.un.org/sites/default/files/UNDG_BigData_final_web.pdf European Commission, “A European strategy for data”. *Shaping Europe’s digital future*. [Online]. Accessed: March 18th, 2022. Available: <https://digital-strategy.ec.europa.eu/en/policies/strategy-data>
- [10] Dantas, C., Hoogendoorn, P., Kryspin-Exner, I., Stuckelberger, A. & Tijink, D. “AAL Guidelines for Ethics, Data Privacy and Security”, 2020. Ambient Assisted Living Association. Available: <http://www.aal-europe.eu/wp-content/uploads/2020/07/AAL-guideliens-for-ethics-final.pdf>
- [11] European Commission, “Proposal for a regulation of the European parliament and of the council on harmonised rules on fair access to and use of data (Data Act)”, 2022. [Online]. Accessed: March 18th, 2022. Available: <https://digital-strategy.ec.europa.eu/en/library/data-act-proposal-regulation-harmonised-rules-fair-access-and-use-data>
- [12] A. M. Vicente, W. Ballensiefen, D. Donertas, M. Eklund, A. Ivask, J. Jönson, K. Kulmann, A. Lawrence, M. O’Driscoll, E. Richer, and G. Trivella, “The ICPeMed vision for 2030. How can personalised approaches pave the way to Next-Generation Medicine?”. ICPeMed International Consortium, Sep 2019. [Online]. Accessed: March 18th, 2022. Available: https://www.icpermed.eu/media/content/Vision_Paper_2019.pdf