



Aalborg Universitet

AALBORG UNIVERSITY
DENMARK

Nordic Citizens' Willingness to Share Digital Health Data

Eriksen, Jeppe; Hjerimitslev, Camilla Bidstrup; Reponen, Jarmo; Hardardottir, Gudrun Audur; Tuulikki, Vehko; Faxvaag, Arild; Nøhr, Christian Gradhandt

Published in:

Digital Health and Informatics Innovations for Sustainable Health Care Systems

DOI (link to publication from Publisher):

[10.3233/SHTI240359](https://doi.org/10.3233/SHTI240359)

Creative Commons License

CC BY-NC 4.0

Publication date:

2024

Document Version

Publisher's PDF, also known as Version of record

[Link to publication from Aalborg University](#)

Citation for published version (APA):

Eriksen, J., Hjerimitslev, C. B., Reponen, J., Hardardottir, G. A., Tuulikki, V., Faxvaag, A., & Nøhr, C. G. (2024). Nordic Citizens' Willingness to Share Digital Health Data. In *Digital Health and Informatics Innovations for Sustainable Health Care Systems* (Vol. 316, pp. 120-124). IOS Press. <https://doi.org/10.3233/SHTI240359>

General rights

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the public portal -

Take down policy

If you believe that this document breaches copyright please contact us at vbn@aub.aau.dk providing details, and we will remove access to the work immediately and investigate your claim.

Nordic Citizens' Willingness to Share Digital Health Data

Jeppe ERIKSEN^{a,1}, Camilla Bidstrup HJERMITSLEV^a, Jarmo REPONEN^b, Gudrun Audur HARDARDOTTIR^c, Vehko TUULIKKI^d, Arild FAXVAAG^e and Christian NØHR^a

^a*Department of Sustainability and Planning, Aalborg University, Denmark*

^b*Research Unit of Health Sciences and Technology, University of Oulu, Finland*

^c*Directorate of Health, Iceland*

^d*Finnish institute for health and welfare, Finland*

^e*Department of Neuromedicine and Movement Science, Norwegian University of Science and Technology, Norway*

Abstract. The quality of the digital healthcare systems relies on citizens' willingness to share their digital health data. This makes citizens' use, perceptions, and attitudes towards digital healthcare systems pivotal. The study presented here examines Nordic citizens' willingness to share digital health data with healthcare providers and for research purposes. A cross-sectional study design was applied to obtain answers from citizens in Denmark, Finland, Iceland, Norway, and Sweden. The results are based on answers from 5078 citizens across the five countries. Results based on descriptive statistics indicate that the majority of Nordic citizens are willing to share health data that has clinical relevance with healthcare providers and for research purposes. The odds ratio analysis reveals that citizens' odds of sharing health data decreases with age and increases with the level of education. Conclusively, this study shows that most Nordic citizens are willing to share their health data, influenced by age and level of education. Awareness of and efforts to support citizens who are unable or unwilling to actively use and engage with the digital healthcare system is recommended.

Keywords. Digital healthcare, sharing of digital health data, citizen perspective, citizen survey, Nordic countries.

1. Introduction

In current digital healthcare systems, the sharing of health data across providers and stakeholders is essential underscored by the theme's significance in digital health strategies and policies on a global, European, and Nordic level.

In the "Global strategy on digital health 2020-2025" published by the World Health Organization (WHO), the sharing of health data is described as something that has the potential to positively affect the "quality of processes, the outcomes of health services and the continuity of care for patients" (primary use) and improve the quality of healthcare and research effectiveness (secondary use). Additionally, the accumulation of

¹ Corresponding Author: Jeppe Eriksen; E-mail: je@plan.aau.dk.

patients' health data is essential to develop digital solutions based on Artificial intelligence (AI) and Big Data [1].

On a European level, the sharing of health data is a key element in the design of the European Health Data Space (EHDS), to fulfil the aims of empowered individuals and a genuine single market for medical devices, electronic health records (EHR) and AI systems (primary use of data) and to enable the use of high-quality health data for research, innovation, policy-making and regulatory activities (secondary use of data). Thus, the European Commission wish to enable the sharing and accumulation of health data across national borders to facilitate improved access and use of digital health data; subsequently, supporting the improvement of treatments, research, and products. In other words, the idea is "to truly harness the power of health data" [2].

In a Nordic context, where the study presented in this paper took place, sharing and better use of digital health data, AI, and Big Data are perceived as ways to improve the quality, coherence, and effectiveness of the healthcare system and facilitate increased patient participation and self-management [3-7].

Even though the use of citizens' digital health data might improve continuity of care, quality, and efficiency when utilized appropriately potential gains rest on the citizens' willingness to engage with the digital healthcare system and share their digital health data with their healthcare providers [8]. Hence, the patient perspective in this context is focal, which is why Nordic citizens' willingness to share digital health data with healthcare providers and for research is examined in this study.

2. Method

The results reported here are based on a cross-sectional study design as the aim was to scrutinize Nordic citizens' use, perceptions, and attitudes towards digital healthcare.

The study and the development of the questionnaire were handled by the Nordic eHealth Research Network (NeRN) [9], which is a group of researchers supported by the Nordic Council of Ministers, whose mission it is to develop indicators to measure the effect of political eHealth initiatives on the healthcare systems; especially, from the perspectives of healthcare professionals and citizens. NeRN consists of members from Denmark, Finland, Iceland, Norway, and Sweden, which are also the countries where the study was conducted.

The questionnaire used in this study consists of 25 questions:

- Age, gender, education, place of residence (region) and need for assistance when using technology (Questions 1 to 5).
- Access and competencies (Questions 6 to 8).
- Use of digital healthcare services (Questions 9 to 11).
- Collection and use of health data (Questions 12 to 14).
- Sharing of health data (Questions 15 and 16).
- Effects and consequences of digital healthcare (Questions 17 to 25).

The research consultancy MEGAFON handled the survey, which was conducted from February 2nd to March 4th, 2023. Answers are based on internet interviews (90%) and phone interviews (10%), with members of MEGAFON's citizen panel, above 18 years of age living in Denmark, Finland, Iceland, Norway, or Sweden. Further details on recruitment and participant characteristics are available in the report "A Nordic survey to

monitor citizens' use and experience with eHealth" [10]. Table 1 provides an overview of the responses by country.

Table 1. Number of respondents per country.

Countries	Denmark	Finland	Iceland	Norway	Sweden
Number of respondents	1017	1015	1013	1016	1017

Besides background variables, the analysis is based on question 15, "In the case of the need for personal treatment in another Nordic country, which digital health data would you then accept to share across healthcare providers (e.g. hospitals, outpatient clinics, etc.) in the Nordic Countries?" and question 16, "In the case of the need for personal treatment in another Nordic country, which digital health data would you accept to share for research across the Nordic Countries?" [10]. In this study, digital health data refers to data typically available in Electronic Health Records (EHRs) and data collected/generated by the citizen/patient, also known as Patient-Generated Health Data (PGHD).

The analysis is based on descriptive statistics and Odds Ratio analyses conducted using SPSS and R.

3. Results

This section first provides a general overview of citizens' willingness to share data and then examines how age and education influence citizens' willingness to share data.

Figure 1 is based on questions 15 and 16, displaying the types of data and the number of citizens who wish to share their health data in the Nordic countries. Respondents were allowed to choose between multiple response options.

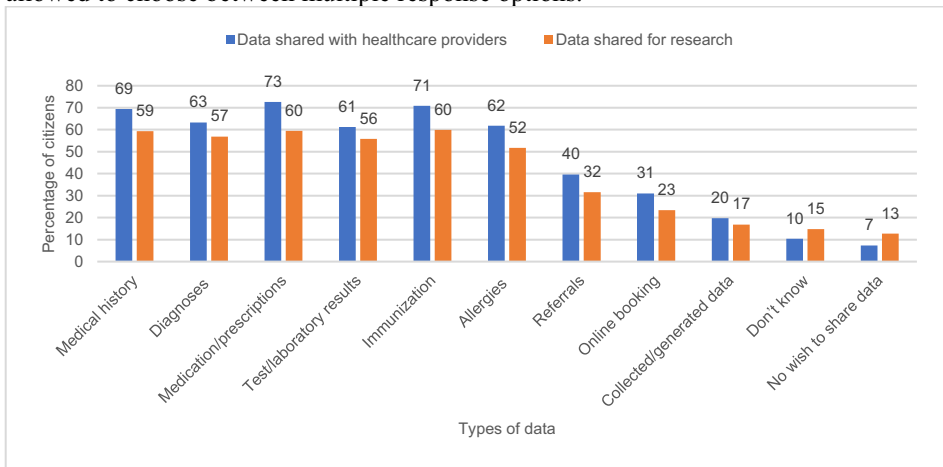


Figure 1. Percentage of citizens willing to share their health data (n=5078).

In the case of the need for personal treatment in another Nordic country, the majority of the citizens agree to share their data on "Medical history", "Diagnoses", "Medication/prescriptions", "Test results/laboratory data", "Immunization" and "Allergies", with healthcare providers and for research. Fewer are interested in sharing data on "Referrals" and "Online booking". This difference is noteworthy, indicating that citizens are more likely to share health data that have clinical relevance.

Based on the first eight response options (“Medical history” to “Online booking”), calculations disclose that an average of 8,9 percentage points of the citizens are more willing to share digital health data with healthcare providers compared to situations where data is used for research purposes. 20% (with healthcare providers) and 17% (for research) of the citizens were interested in sharing collected/generated health data

Table 2. Citizen odds for sharing of health data in association to age and education.

Type of data	Age	With healthcare providers		For research	
		OR	95% CI	OR	95% CI
≥4 Clinical Health Data**	18-29***	1		1	
	30-39	0,99	[0,81-1,21]	0,92	[0,77-1,11]
	40-49	0,87	[0,72-1,07]	0,77*	[0,64-0,93]
	50-59	0,80*	[0,65-0,97]	0,90	[0,75-1,09]
	60-69	0,71*	[0,58-0,86]	0,77*	[0,64-0,93]
	≥70	0,53*	[0,44-0,65]	0,77*	[0,64-0,93]
Collected/generated health data	18-29***	1		1	
	30-39	0,85	[0,69-1,04]	0,77*	[0,62-0,95]
	40-49	0,61*	[0,49-0,75]	0,57*	[0,45-0,71]
	50-59	0,42*	[0,34-0,54]	0,46*	[0,36-0,58]
	60-69	0,31*	[0,24-0,40]	0,29*	[0,22-0,38]
	≥70	0,24*	[0,18-0,32]	0,24*	[0,18-0,32]
Education					
≥4 Clinical Health Data	Primary***	1		1	
	Secondary	1,14	[0,91-1,43]	1,09	[0,87-1,37]
	University	1,63*	[1,3-2,04]	1,42*	[1,14-1,77]
Collected/generated health data	Primary***	1		1	
	Secondary	1,08	[0,81-1,47]	1	[0,73-1,38]
	University	1,40*	[1,05-1,87]	1,30	[0,96-1,79]

*p<0,05, **The category “≥4 Clinical Health Data” is a variable constructed to reflect cases where citizens are willing to share 4 to 6 types of health data based on the response options: “Medical history”, “Diagnoses” “Medication/prescriptions”, “Test results/laboratory data”, “Immunization” and “Allergies”. ***Citizens “18-29” years of age and citizens with a “Primary” education are used as reference groups.

Table 2 displays Nordic citizens' odds of sharing health data in association with age and education.

The numbers indicate that the odds of sharing “Clinical Health Data” and “Collected/generated health data” decreases with age. The exception is the sharing of “Clinical Health Data” for research, where the odds are consistent across age groups based on the statistically significant values but still a decrease in the odds ratio (OR=0,77) compared to the “18-29” age group.

Moreover, citizens with a university education have greater odds of sharing “Clinical Health Data” and “Collected/generated health data” compared to citizens who have “Primary” as their longest-completed education.

4. Discussion and Conclusions

This study discloses, firstly, that a majority of Nordic citizens are willing to share their health data with healthcare providers and for research purposes; especially, the types of data that are useful in clinical practice. Secondly, the Nordic citizens' odds of sharing health data with healthcare providers and for research decreases with age and increases with the level of education.

Robust and sustainable digital healthcare systems are built on principles of trust, citizen control and transparency, meaning that citizens need to know how their data are being stored and used, to ensure ethically acceptable applications of data. Therefore, continuous improvements in the technical infrastructure and implementation of security systems are required to make log data accessible; subsequently, protecting citizens' privacy, and preventing malign or inappropriate use of the citizens' health data [1-3,11].

A genuine digital transformation of current healthcare systems rests on the improved collection and better use of health data, making the mentioned requirements central in current digital health strategies [3-7], and when implementing interventions to promote equity in digital healthcare [12].

References

- [1] The World Health Organization (WHO), Global strategy on digital health 2020-2025, (2021). <https://www.who.int/docs/default-source/documents/gsdhdaa2a9f352b0445bafbc79ca799dce4d.pdf> (accessed March 8, 2024).
- [2] The European Commission, https, COMMUNICATION FROM THE COMMISSION TO THE EUROPEAN PARLIAMENT AND THE COUNCIL - A European Health Data Space: harnessing the power of health data for people, patients and innovation, (2022). https://health.ec.europa.eu/document/download/17c7065c-c432-445f-9b27-8ccf283581bc_en?filename=com_2022-196_en.pdf (accessed March 8, 2024).
- [3] The Danish Government, The Local Government Denmark (KL) Danish Regions, A Coherent and Trustworthy Health Network for All – Digital Health Strategy 2018-2022/(2024), (2018). https://sundhedsdatastyrelsen.dk/-/media/sds/filer/strategi-og-projekter/strategi-digital-sundhed/strategi-for-digital-sundhed-2018_2022.pdf (accessed March 8, 2024).
- [4] The Government, The Ministry of Health and Social Affairs and The Swedish Association for Local Authorities and Regions (SALAR), eHälsa 2025 – A strategy for implementing Vision for eHealth 2025 – The next step, (2020). <https://ehalsa2025.se/wp-content/uploads/2021/02/vision-e-halsa-2025-overenskommelse.pdf> (accessed March 8, 2024).
- [5] Direktoratet for e-helse, National eHealth strategy, (2023). https://www.ehelse.no/strategi/nasjonal-e-helsestrategi-for-helse-og-omsorgssektoren/_attachment/inline/69d58858-d324-48fe-8d2f-998cda199367:9a2712f7606599c7909bb182a00f1925ba3544e1/National%20eHealth%20strategy%20EN%20MASTER%20v%201.0.pdf (accessed March 8, 2024).
- [6] The Government of Iceland, Ministry of Health, Digital healthcare policy, (2021). <https://www.government.is/library/01-Ministries/Ministry-of-Health/PDF-skjöl/Digital%20healthcare%20policy.pdf> (accessed March 8, 2024)
- [7] The Ministry of Social Affairs and Health, Strategy for digitalisation and information management in healthcare and social welfare, (2024). <https://julkaisut.valtioneuvosto.fi/handle/10024/165362> (accessed March 8, 2024)
- [8] Eriksen J. Purpose, Functionality and Reconceptualisation of Patient-Reported Outcome: a patient participation perspective on pro in clinical practice post its digitalisation. Aalborg Universitetsforlag; 2021. 266 p. doi: <https://doi.org/10.54337/aau461776857>
- [9] The Ministry of Social Affairs and Health (Finland), The Nordic eHealth Network (NeRN), (2012). <https://thl.fi/en/research-and-development/research-and-projects/nordic-ehealth-research-network-nern> (accessed March 8, 2024)
- [10] Eriksen J, Bidstrup Hjermitslev C, Tuulikki V, Harðardóttir GA, Koch S, Faxvaag A, et al. A Nordic survey to monitor citizens use and experience with eHealth. Copenhagen: Nordic Council of Ministers; 2023. 328 p. doi: [10.6027/temanord2023-541](https://doi.org/10.6027/temanord2023-541)
- [11] Kickbusch I, Piselli D, Agrawal A, Balicer R, Banner O, Adelhardt M, et al. The Lancet and Financial Times Commission on governing health futures 2030: growing up in a digital world. Lancet. 2021 Oct; 398 p. 1727–76, doi:[https://doi.org/10.1016/S0140-6736\(21\)01824-9](https://doi.org/10.1016/S0140-6736(21)01824-9)
- [12] Eriksen J, Ebbesen M, Eriksen KT, Hjermitslev CK, Knudsen C, Bertelsen PS et al. Equity in digital healthcare – the case of Denmark. Frontiers in Public Health. 2023 Sep:1225222. doi: <https://doi.org/10.3389/fpubh.2023.1225222> Eriksen J, Ebbesen M, Eriksen KT, Hjermitslev CK, Knudsen C, Bertelsen PS et al. Equity in digital healthcare – the case of Denmark. Frontiers in Public Health. 2023 Sep:1225222. doi: <https://doi.org/10.3389/fpubh.2023.1225222>