

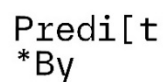


Digital Decade e-Health Indicators Development

CNECT/LUX/2022/MVP/0027
Final Report



A study prepared for the European Commission
DG Communications Networks, Content & Technology by



EUROPEAN COMMISSION

Directorate-General for Communications Networks, Content and Technology
Directorate H – Digital Society, Trust and Cybersecurity
Unit H.3 – eHealth, Wellbeing and Ageing

Contact: Renata Palen

Email: CNECT-H3@ec.europa.eu
Renata.Palen@ec.europa.eu

European Commission
B-1049 Brussels

INTERNAL IDENTIFICATION

Contract number: LC-01882415
SMART number: 2022/MVP/0027

Disclaimer

The information and views set out in this document are those of the author(s) and do not necessarily reflect the official opinion of the European Commission. The European Commission does not guarantee the accuracy of the data included in this document. Neither the European Commission nor any person acting on the Commission's behalf may be held responsible for the use which may be made of the Information contained therein.

© European Union, 2023. All rights reserved.

AUTHORS

Lucas Deimel (empirica Gesellschaft für Kommunikations- und Technologieforschung mbH)
Maike Hentges (empirica Gesellschaft für Kommunikations- und Technologieforschung mbH)
Valentina Latronico (PredictBy)
Rainer Thiel (empirica Gesellschaft für Kommunikations- und Technologieforschung mbH)
Francisco Lupiáñez-Villanueva (PredictBy)

with

Mouaz Hanafi, Sabah Firdous, Eriona Dashja (empirica Gesellschaft für Kommunikations- und Technologieforschung mbH), Federico Puppo and Karlijn Van Houten (PredictBy)

ACKNOWLEDGEMENTS

We would like to acknowledge the contribution of numerous representatives of EU Member States and other European countries, and experts on electronic health data and citizen access who have been involved in the study through interviews, workshops and a survey.

We are grateful to Renata Palen from the European Commission, Directorate General Communications Networks, Content and Technology (DG CONNECT), eHealth, Well-Being and Ageing Unit, and Konstantin Hyppönen, Directorate-General for Health and Food Safety (DG SANTE), Digital Health unit, for their guidance and continuous support.

EN PDF doi: 10.2759/530348 Catalogue number: KK-09-23-338-EN-N ISBN: 978-92-68-05709-4

Manuscript completed in June 2023, 1st edition

The European Commission is not liable for any consequence stemming from the reuse of this publication.

Luxembourg: Publications Office of the European Union, 2023

@ European Union, 2023



The reuse policy of European Commission documents is implemented by the Commission Decision 2011/833/EU of 12 December 2011 on the reuse of Commission documents (OJ L 330, 14.12.2011, p. 39). Except otherwise noted, the reuse of this document is authorised under a Creative Commons Attribution 4.0 International (CC-BY 4.0) licence (<https://creativecommons.org/licenses/by/4.0/>). This means that reuse is allowed provided appropriate credit is given and any changes are indicated.

For any use or reproduction of elements that are not owned by the European Union, permission may need to be sought directly from the respective rightholders.

Cover: cover image, source: istockphoto.com, element by Jackie Niam.

Contents

Abstract.....	1
Résumé.....	2
Executive summary.....	3
Synthèse.....	11
1 Introducing the new benchmark on citizen’s access to electronic health records	20
1.1 About this report.....	20
1.2 Recent policy developments.....	20
1.3 Monitoring framework to measure access to electronic health records in the EU.....	23
1.4 Synthesis of approach and methods.....	24
2 Europe’s state-of-play: access to electronic health records.....	26
2.1 ‘Citizens’ access’: a multi-dimensional concept.....	26
2.2 The EU picture: Citizens’ access to electronic health records data.....	27
2.2.1 Implementation of electronic access services for citizens.....	36
2.2.2 Categories of accessible health data.....	37
2.2.3 Access technology and coverage.....	41
2.2.4 Access opportunities for certain categories of people.....	45
2.3 Limitations and reflections on the framework.....	50
3 Key insights towards 100% citizens’ access to electronic health records in the EU.....	51

Figures

Figure 1. Citizens’ access to their electronic health records in the EU, 2022	4
Figure 2. Citizens’ access to their electronic health records in the EU (combined layer scores), 2022	5
Figure 3. Accès des citoyens à leur dossier médical électronique dans l'UE, 2022.....	12
Figure 4. Accès des citoyens à leurs dossiers médicaux électroniques dans l'UE (scores combinés), 2022	13
Figure 5. Digital Decade e-health composite indicator structure	23
Figure 6. Citizens’ access to their electronic health records in the EU (composite score), 2022.....	34
Figure 7. Citizens’ access to electronic health records in the EU (stacked layer scores), 2022.....	35
Figure 8. Implementation of electronic access services for citizens in the EU, 2022.....	36
Figure 9. Scores for categories of accessible health data in the EU, 2022.....	38
Figure 10. Available and timely updated electronic health records summary data in the EU, 2022	39
Figure 11. Available and timely updated ePrescription/eDispensation data in the EU, 2022.....	40
Figure 12. Available and timely updated electronic results and reports in the EU, 2022	40

Figure 13. Scores for access technology and coverage in the EU, 2022 42

Figure 14. Access to electronic health records data with an eID in the EU, 2022..... 43

Figure 15. Access via an online portal or mobile application in the EU, 2022..... 43

Figure 16. Percentage of national population able to access their electronic health records in the EU, 2022 44

Figure 17. Healthcare providers connected and supplying relevant health data in the EU, 2022 45

Figure 18. Scores for access opportunities for certain categories of people in the EU, 2022..... 46

Figure 19. Access for legal guardians in the EU, 2022..... 48

Figure 20. Access for authorised persons in the EU, 2022..... 48

Figure 21. Assistance measures supporting access for disadvantaged groups in the EU, 2022..... 49

Figure 22. Compliance with WCAG v2.1 guidelines and Web Accessibility Directive in the EU, 2022 50

Tables

Table 1. Overview of the sub-indicators 24

Table 2. EU performance on citizens' access to their electronic health records (composite scores), 2022 34

Table 3. EU performance on categories of accessible health data, 2022 38

Table 4. EU performance on access technology and coverage, 2022 42

Table 5. EU performance on providing citizens with additional access opportunities, 2022 47

Abstract

This report presents the results of the baseline assessment on EU27 countries' (plus Iceland and Norway) state-of-play (31.12.2022) towards delivering the Digital Decade Policy Programme 2030 e-health target of 100% EU citizens' access to electronic health records by 2030.

The study developed a comprehensive monitoring framework and survey tool to annually measure citizens' access, covering the implementation of electronic access services, categories of accessible health data, access technology (eID, access via portals or apps), coverage (by population and healthcare providers), and equitable access opportunities. An online survey was distributed to national competent authorities in 29 countries.

The results show that countries are progressing well in facilitating citizens' access to electronic health records with an EU27-average score of 72% out of 100%, but the picture is heterogeneous across the framework layers. Apart from Ireland, electronic access services exist in all responding countries, however secure and equitable access to a comprehensive set of updated health data provided from a range of healthcare providers has not been fully established yet in many countries.

The report presents key insights for future efforts to reach the Digital Decade e-health target of 100% EU citizens' access to electronic health records by 2030.

Résumé

Ce rapport présente les résultats de l'évaluation de référence sur l'état d'avancement (31.12.2022) des pays de l'UE27 (plus l'Islande et la Norvège) dans la réalisation de l'objectif de santé en ligne du programme politique 2030 de la décennie numérique, à savoir l'accès de 100 % des citoyens de l'UE aux dossiers médicaux électroniques d'ici à 2030.

L'étude a développé un cadre de suivi complet et un outil d'enquête pour mesurer annuellement l'accès des citoyens, couvrant la mise en œuvre des services d'accès électronique, les catégories de données de santé accessibles, la technologie d'accès (eID - moyen d'identification électronique, accès via des portails ou des applications), la couverture (par la population et les prestataires de soins de santé), et les opportunités d'accès équitable. Une enquête en ligne a été distribuée aux autorités nationales compétentes de 29 pays.

Les résultats montrent que les pays progressent bien dans la facilitation de l'accès des citoyens aux dossiers médicaux électroniques, avec un score moyen de 72 % sur 100 % pour l'UE27, mais la situation est hétérogène à travers les différentes couches du cadre de suivi. À l'exception de l'Irlande, des services d'accès électronique existent dans tous les pays ayant répondu à l'enquête, mais un accès sûr et équitable à un ensemble complet de données de santé actualisées fournies par une série de prestataires de soins de santé n'a pas encore été pleinement mis en place dans de nombreux pays.

Le rapport présente des informations essentielles pour les efforts futurs visant à atteindre l'objectif de la décennie numérique en matière de santé en ligne, à savoir l'accès de 100 % des citoyens de l'UE aux dossiers médicaux électroniques d'ici à 2030.

Executive summary

The new e-health benchmark: Citizens' access to electronic health records in Europe

As one of the targets in the Digital Decade Policy Programme 2030, facilitating **100% of EU citizens with access to their electronic health records by 2030** is a key priority and ambition for Europe's digital transformation. To deliver this target, enhanced cooperation and coordination between Member States and EU-level is needed with common criteria to guarantee the same level of access and quality of e-health services for citizens within and across borders. Especially over the past five years, EU Member States and institutions have increased their efforts to accelerate and advance secure and interoperable electronic health data infrastructures, among others, towards the proposed European Health Data Space. Nevertheless, citizens' access to health data still varies greatly in terms of regulation, security, user rights, and visible data sets leading to a fragmented EU picture.

Where is the EU situated on the path to facilitating 100% citizens' access to their electronic health records? Until now, a methodological approach with harmonised indicators to annually collect data for answering this question and tracking progress across Member States until 2030 has been lacking. Therefore, between July '22 and April '23, the study team of the 'Study for Digital Decade e-Health Indicators Development', commissioned by DG CNECT (CNECT/LUX/2022/MVP/0027), developed and executed a **new monitoring framework**. The concept of the framework addresses a methodological gap that stemmed from a lack of a clear definition of 'citizens' access' and from the use of the term 'access' to refer to constructs not associated with the possibility to access certain types of data but rather to measure usage frequency and ease. Thus, the proposed framework comprehensively describes how the target of 100% citizens' access to electronic health records by 2030 is to be defined and measured using data that Member State national competent authorities can collect and provide.

The **aim of the study** was to provide the baseline assessment of the state-of-play of EU27 Member States plus Iceland and Norway (EU27+2) in enabling citizens to access their electronic health records from a health policy perspective, and to identify areas with potential for improvement vis-à-vis EU policy objectives.

This report presents the results of the baseline data collection, representing Member States' state-of-play as of 31.12.2022, and recommends actionable steps towards delivering 100% citizens' access to electronic health records.

Measuring citizens' access to electronic health records in Europe

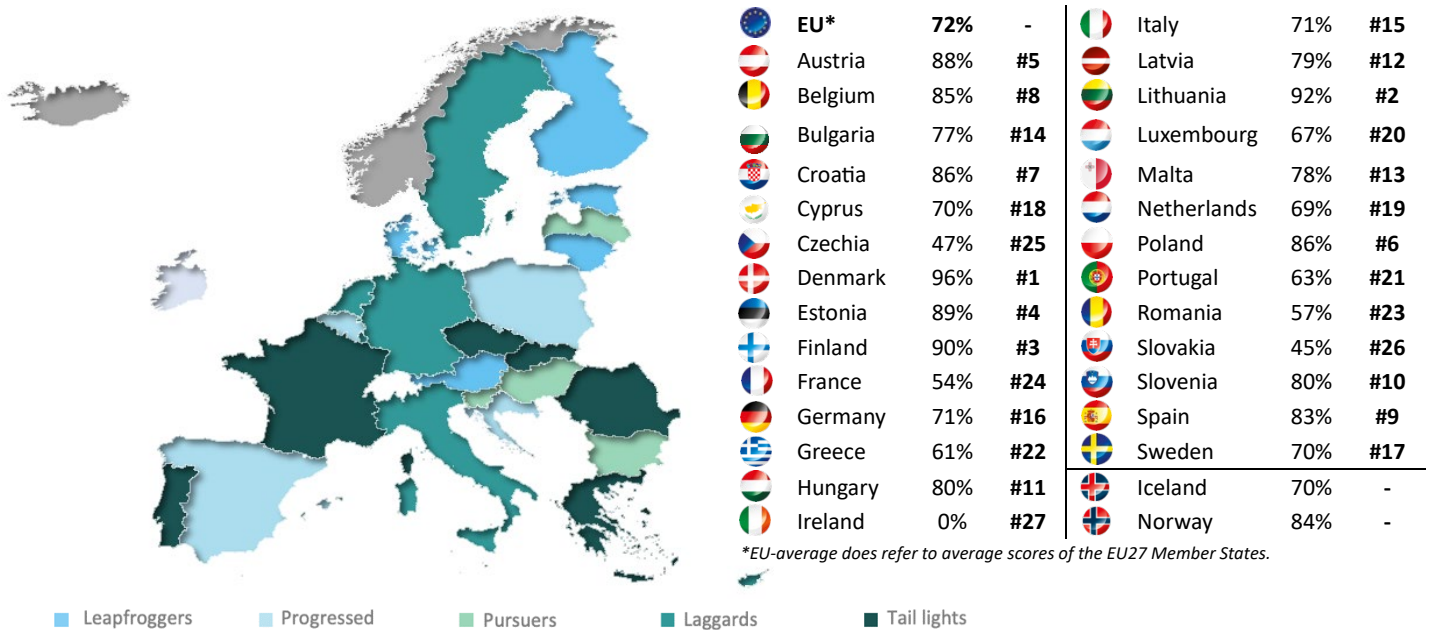
- The baseline data collection of this new benchmark assesses citizens' access to electronic health records in **EU27 Member States plus Iceland and Norway**.
- Competent authorities in **28 countries responded** to an online survey between 23 February and 30 March 2023. **Bulgaria submitted data in early June 2023**.
- This benchmarking study proposes a clear definition of 'citizens' access' as a multi-dimensional concept from which **four thematic layers** are derived, constituting one e-health composite indicator broken down into 12 sub-indicators. These consider 'citizens' access' from the following angles focused on a technical perspective:

1. **Implementation of electronic access services for citizens** - Citizens’ access to electronic health records is facilitated once the technical prerequisites are fulfilled, i.e., an electronic access service is available.
2. **Categories of accessible health data** - Health data categories that are accessible to citizens include electronic health records summary data, ePrescription/eDispensation, electronic results and reports (laboratory test results, medical images and imaging reports, hospital discharge reports).
3. **Access technology and coverage** - Access is enabled for the entire population and ensured by all care sectors independently of time and place (e.g., through mobile applications or online portals) with secure authentication mechanisms compliant with the eIDAS Regulation.
4. **Access opportunities for certain categories of people** - Mechanisms for legal guardians or other authorised persons to access electronic health records of those under their responsibility and opportunities for disadvantaged groups are in place (web accessibility).

Europe’s state-of-play: citizens’ access to electronic health records

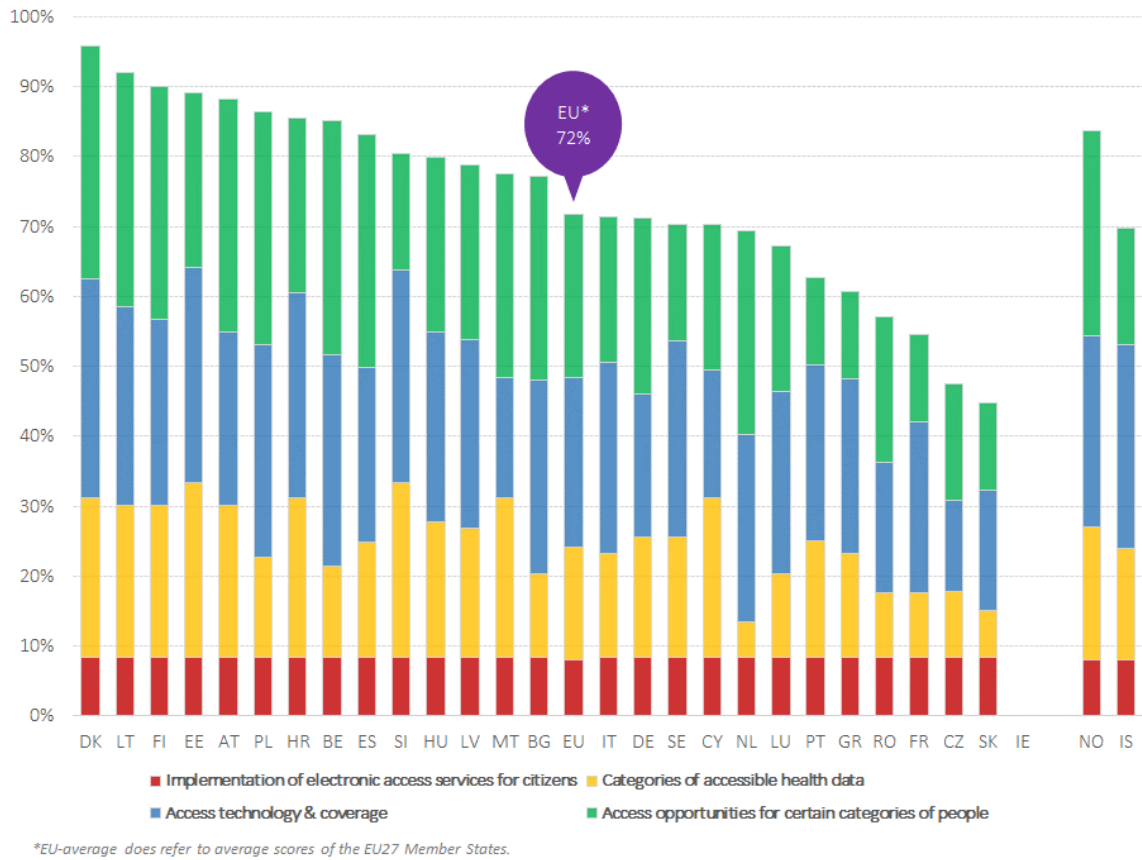
Combining the four layers with 12 sub-indicators to the overall **Digital Decade e-health composite indicator**, the composite is a measure of **genuine and effective access to electronic health records for citizens** in EU27 Member States plus Iceland and Norway. This composite indicator ranges from 0% to 100%.

Figure 1. Citizens’ access to their electronic health records in the EU, 2022
Overall performance of e-health composite scores by country groups



EU27 Member States can be divided into five groups based on the proximity of their composite scores to those of their immediate ‘ranking neighbour’. This results in a distribution into highly progressed *Leapfroppers* (Denmark, Lithuania, Finland, Estonia and Austria), *Progressed* Member States (Poland, Croatia, Belgium and Spain), a group of *Pursuers* (Slovenia, Hungary, Latvia, Malta and Bulgaria), *Laggards* (Italy, Germany, Sweden, Cyprus, Netherlands and Luxembourg) and the *Tail lights* (Portugal, Greece, Romania, France, Czechia, Slovakia and Ireland). Iceland and Norway are reported separately.

Figure 2. Citizens’ access to their electronic health records in the EU (combined layer scores), 2022



Each of the four framework layers contributes differently to the overall e-health composite indicator on citizens’ access to their electronic health records in each Member State (Figure 2). The data demonstrates that the combined layer scores vary substantially between Member States with the exception of the first layer where all but Ireland did implement an electronic access service(s) for its citizens available nationwide. Different stages of progress regarding the categories of electronic health data accessible by citizens as well as access opportunities ensuring equitable access are observed. Hence, Member States are generally advanced from a technical perspective, but other aspects that constitute full and equitable access to electronic health data require further attention.

Almost all EU27 Member States offer some sort of national or regional online access service, e.g., via an online portal or a mobile application. In terms of the health data categories citizens have access to, ePrescription and eDispensation data are most widely accessible and frequently updated. Most EU citizens are provided with online access to their identification and personal information, data on procedures and operations, and current and relevant past medicines or a medication plan equivalent. The least accessible category of electronic health records data are electronic results and reports.

About half of EU27 Member States (Belgium, Bulgaria, Cyprus, Denmark, Estonia, Spain, Finland, Greece, Croatia, Hungary, Lithuania, Latvia, Poland, Slovenia) have connected both public and private healthcare providers of the primary, secondary and tertiary care sector as well as pharmacies with a rate of >60% of total healthcare institutions. While 23 of EU27 Member States (Austria, Belgium, Bulgaria, Czechia, Germany, Denmark, Estonia, Spain, Finland, France, Croatia, Hungary, Italy, Lithuania, Luxembourg, Latvia, Netherlands, Poland, Portugal, Romania, Sweden, Slovenia, Slovakia) deploy authentication systems using a notified eID-scheme based on two-factor

authentication, 13 of those (Austria, Belgium, Bulgaria, Germany, Estonia, Spain, Croatia, Italy, Lithuania, Latvia, Netherlands, Poland, Sweden) have (pre-)notified their eID and are compliant with the eIDAS Regulation. Only four Member States (Cyprus, Greece, Malta, Ireland) report to require different means of authentication for citizens to gain access to their electronic health data. 12 Member States (Belgium, Bulgaria, Germany, Denmark, France, Greece, Italy, Luxembourg, Poland, Portugal, Sweden, Slovenia) provide access via both online portals and mobile applications, while 14 (Austria, Cyprus, Czechia, Estonia, Spain, Finland, Croatia, Hungary, Lithuania, Latvia, Malta, Netherlands, Romania, Slovakia) provide access with online portals only. The vast majority of citizens (>80%), including minors, in 18 Member States (Austria, Belgium, Denmark, Estonia, France, Greece, Croatia, Hungary, Italy, Lithuania, Luxembourg, Latvia, Malta, Netherlands, Poland, Portugal, Sweden, Slovenia) is able to access their health data online, mirroring the significant efforts and progress undertaken by the relevant authorities towards digital transformation of the health and care sector. In three Member States (Czechia, Germany, Slovakia), only less than 20% of citizens are facilitated with access as of end of 2022.

Legal guardians are able to access the health data on behalf of their assigned wards in 19 of EU27 Member States (Austria, Belgium, Bulgaria, Cyprus, Germany, Denmark, Estonia, Spain, Finland, Greece, Croatia, Hungary, Lithuania, Luxembourg, Latvia, Netherlands, Poland, Romania, Slovenia), while five (Czechia, France, Italy, Malta, Slovakia) have at least established the legal ground to implement such a functionality in the future. Given a proper authorisation is in place, informal carers in 15 Member States (Austria, Belgium, Germany, Denmark, Estonia, Spain, Finland, Hungary, Lithuania, Luxembourg, Latvia, Malta, Netherlands, Poland, Romania) can access the electronic health data of another individual. Eight out of EU27 Member States (Bulgaria, Cyprus, Czechia, Greece, Italy, Portugal, Slovenia) have not yet developed a technical solution that supports such a functionality, while another four (France, Croatia, Ireland, Sweden) did not report any efforts in this regard. Citizens in 20 Member States (Austria, Belgium, Bulgaria, Cyprus, Germany, Denmark, Estonia, Spain, Finland, France, Croatia, Hungary, Lithuania, Latvia, Malta, Poland, Portugal, Romania, Sweden, Slovakia) are offered with support measures and services to gain assistance with online health data access. The most common support mechanisms are online FAQs and guidelines and real-time remote assistance on the phone or online. In addition to these access mechanisms, 14 Member States (Austria, Belgium, Bulgaria, Czechia, Denmark, Spain, Finland, Croatia, Italy, Lithuania, Malta, Netherlands, Poland, Sweden) follow international guidelines on web accessibility to support an appropriate presentation of information and data online for everyone. The remaining half of the EU27 Member States (Cyprus, Germany, Estonia, France, Greece, Hungary, Ireland, Luxembourg, Latvia, Portugal, Romania, Slovenia, Slovakia) has not realised the stipulations of Directive (EU) 2016/2102 (Web Accessibility Directive) in the context of citizens' access to electronic health data.

The 2022 baseline assessment of EU citizens' access to electronic health records yields an EU27-average of 72%, demonstrating that most Member States are on track towards facilitating full access.

In summary, the **EU27** baseline assessment for this monitoring exercise shows:

1. In the EU27, all Member States but Ireland have **implemented electronic access services** for citizens to access their electronic health records. Of the EU27 Member States, 21 deployed at least one national access service. In Spain, Italy and Sweden, the regions are responsible for electronic access services. The Netherlands and Czechia are the only Member States where healthcare providers offer own access services to citizens.
2. For **categories of accessible health data**, EU27 Member States reached an average layer score of 64 out of 100, suggesting that this area has overall the greatest potential for improvement in the future. Estonia and Slovenia are two cases of best practice through making available all

considered categories with frequent updates following a care episode. Across Member States, data on medical devices and implants are the least available of the set of electronic health records summary data. Frequently updated ePrescription and eDispensation information is most widely available to citizens in about three quarters of EU27 Member States (Austria, Cyprus, Czechia, Germany, Denmark, Estonia, Spain, Finland, Greece, Croatia, Hungary, Italy, Lithuania, Latvia, Malta, Poland, Portugal, Sweden, Slovenia). Hospital discharge reports and laboratory test results are also widely available, whereas medical images are only available in one quarter of Member States (Belgium, Germany, Estonia, Spain, Luxembourg, Latvia, Slovenia).

3. Regarding **access technology and coverage**, EU27 Member States score on average 73 out of 100. When accessing their electronic health records, citizens in 13 Member States (Austria, Belgium, Bulgaria, Germany, Estonia, Spain, Croatia, Italy, Lithuania, Latvia, Netherlands, Poland, Sweden) use a (pre-)notified eID scheme compliant with the eIDAS Regulation for authentication. In 12 Member States (Belgium, Bulgaria, Germany, Denmark, France, Greece, Italy, Luxembourg, Poland, Portugal, Sweden, Slovenia), citizens can use both an online portal and mobile application to access their electronic health data. Between 80-100% of the national population in 18 Member States (Austria, Belgium, Denmark, Estonia, France, Greece, Croatia, Hungary, Italy, Lithuania, Luxembourg, Latvia, Malta, Netherlands, Poland, Portugal, Sweden, Slovenia) is technically able to access their electronic health records online. Denmark, Estonia, Finland and Greece are best practice cases concerning the connection of healthcare providers: all types of public and private healthcare providers considered in this study supply citizens with relevant electronic health data. Across the EU27, private and public geriatric nursing homes are overall connected the least to citizens' electronic health records infrastructures, followed by mental health facilities and rehabilitation centres. Primary care practices, community care centers as well as hospitals in the public and private sectors are found to be most widely connected across the EU27.
4. Combined, the indicators on **access opportunities for certain categories of people** (legal guardians, other authorised persons, disadvantaged groups) reach a EU27-average score of 70 out of 100. One quarter of EU27 Member States (Austria, Belgium, Denmark, Finland, Lithuania, Poland, Spain) are fully supporting disadvantaged citizens with additional access opportunities scoring 100 in this layer. Whilst legal provisions to ease access for the disadvantaged are enacted in most Member States, the implementation of technical functionalities is in some cases lacking. Half of EU27 Member States (Austria, Belgium, Bulgaria, Czechia, Denmark, Spain, Finland, Croatia, Italy, Lithuania, Malta, Netherlands, Poland, Sweden) ensure that their access service to electronic health records complies with the Web Content Accessibility Guidelines (WCAG) v2.1 as required in Directive (EU) 2016/2102 (Web Accessibility Directive). Consequently, more efforts could be made to facilitate equitable access to electronic health records for all citizens.

In summary, key results for **Iceland and Norway** are as below:

1. Both countries developed **national access services** to health data for their citizens.
2. Iceland and Norway reach a layer score for **categories of accessible health data** that is equal to and slightly above the EU27-average, respectively. Health records summary data and ePrescription/eDispensation data is fully available and, in most cases, frequently updated, while access to summary data is only partially enabled in Iceland (diagnoses, medical devices and implants as well as procedures data missing). In terms of electronic results and reports, laboratory test results and hospital discharge reports are accessible in both countries.
3. Iceland and Norway perform better than the EU27-average regarding **access technology and coverage**, providing 80-100% of citizens with secure access to health data from the majority of public healthcare providers and some providers in the private sector. While Iceland employs an

eIDAS-(pre-)notified eID for its national online portal, Norway requires its citizens to authenticate with a nationally notified eID scheme whenever access to electronic health records data is sought via online portal(s) or mobile app(s).

4. In comparison to the EU27, Iceland lags behind in ensuring **equal access opportunities**, whilst Norway is much more progressed. The main factors of influence here are the fact that Iceland's online portal does not comply with the Directive (EU) 2016/2102 (Web Accessibility Directive) and a lack of implemented support measures for disadvantaged groups and third-party access to data for authorised persons.

Gaps towards 100% citizens' access to electronic health records data by 2030

Citizens' access to health data still varies greatly between EU27 Member States in terms of regulation, security, user rights, and visible data sets, leading to a fragmented EU picture. Member States and institutions are increasing their efforts to accelerate and advance secure and interoperable electronic health data infrastructures that enable health data access and use. However, gaps remain where policy interventions could be opportune and deliver a boost towards the target of 100% citizens' access until 2030.

Electronic results and reports, in particular medical imaging reports, hospital discharge reports and laboratory test results to some extent, are the least accessible category of electronic health records data where citizens in most EU27 Member States are still facing '**data gaps**'. Despite the efforts of the eIDAS Regulation to harmonise authentication schemes across the EU27, half of all Member States are yet to notify their schemes on EU-level leaving a '**harmonisation gap**' for secure and mutually recognised access to electronic health. The share of private healthcare provider types that are connected to data infrastructures and supply relevant health data for citizens in the EU27, in particular outside the primary and secondary care sector, is low, creating a '**data supply gap**' and a need for cooperation between Member States and the private providers. Half of studied Member States do not guarantee equitable access opportunities through compliance with Directive (EU) 2016/2102 (Web Accessibility Directive) resulting in a '**digital equity gap**' for disadvantaged groups of citizens across the EU27.

In order to be able to achieve the Digital Decade e-health target, Member States will need to assure that access to electronic health records with a minimum set of health-related data stored in public and private EHR systems is technologically enabled and easily accessible to at least 80% of national population (via a patient portal or a patient mobile app), while providing secure means of authentication (using of an eIDAS (pre-)notified eID scheme), the measures to facilitate equitable access opportunities for all citizens (guardians for children, people with disabilities, elderly) and at least 60% of potential public and private providers being technically connected and consistently supplying health data.

Key insights towards 100% citizens' access to electronic health records in the EU

The analysis and further visualisation of the final data allows to go beyond a mere descriptive processing and reporting of the state-of-play on the study topic. Based on the overall performance of the 12 sub-indicators, key insights are presented with relevance to topics that potentially require closer examination through future studies (sub-indicators where EU27 Member States score low overall) compared with topics which are already well progressed (sub-indicators with an overall high score across EU27 Member States). With this perspective in mind, the study team performed an assessment of the results per each sub-indicator and identified six key insights:

- **Measuring access beyond technology towards a multi-channel approach.** Technological access to electronic health records by citizens is widespread across all Member States. Except for Ireland without an access service, all EU27 Member States, plus Norway and

Iceland, deployed an access service available nationwide. Therefore, additional metrics need to be assessed in the future for a more granular representation of citizens' access to electronic health records beyond the mere technical level.

- **Expanding and deepening the categories of accessible health data**, in particular electronic results and reports category, followed by health records summary data accessibility. In order to reach the target until 2030, Member States would need to extend the range of accessible electronic health data that is also timely updated and up to date. This minimum set of health data would not only need to include health records summary data, ePrescription and eDispensation data or electronic lab results, but also hospital discharge reports as well as imaging reports and medical imaging. The availability of more granular health data and the mutual recognition of their electronic health records could facilitate EU citizens with further relevant data for the continuity of care nationally and across borders, ultimately increasing the value of accessible data and closing current data gaps.
- **Ensuring harmonised and equally secure access to electronic health records across the EU**, in particular through EU-wide notification and eIDAS-compliant national eID schemes. The eIDAS Regulation is a crucial component of the EU's efforts to create a trusted and secure digital environment and boost the growth of the digital economy across Europe. In order to ensure equally secure access to online health data for all citizens in the EU, further assessments are needed to support Member States in the transition towards eIDAS-compliant eID schemes in all Member States and closing existing harmonisation gaps.
- **Collecting and exchanging best practices and incentives** that attract private sector providers in particular to connect to electronic access services. The experience with applying such measure across Member States may vary as to the constitutional frameworks of healthcare systems across the EU that determine which measure can be applied. Due to the sheer diversity of healthcare systems and their organization, a one-size-fits-all solution is hardly possible to formulate. However, the exchange of knowledge and experience in on-boarding private care providers to actively use electronic access services could prove as a valuable source for new approaches for some Member States who are currently showing less progress in this regard, ultimately closing data supply gaps. Member States could more closely collaborate with public, and private providers in particular, to assure that at least 60% of healthcare provider institutions in all care sectors are connected to electronic health records data infrastructures that allow citizens access to their data.
- **Ensuring equitable access to electronic health records in the EU**. There is a clear need to improve equal access opportunities to online electronic health records data for all citizens, as access services in 13 EU27 Member States are not compliant with the Directive (EU) 2016/2102 (Web Accessibility Directive). While this study is only able to highlight the issue and raise awareness for the relevance of the topic, efforts should be made to address this digital equity gap. To reach 100% of the target until 2030, all Member States would need to follow the Web Content Accessibility Guidelines and provide or improve additional support mechanisms for disadvantaged groups, such as access for legal guardians or authorised persons to facilitate equal access opportunities.
- **Lessons-learned and capacity building**. While the baseline assessment yields a respectable EU27-average score of 72% citizens' access, thirteen EU Member States (Italy, Germany, Sweden, Cyprus, Netherlands, Luxembourg, Portugal, Greece, Romania, France, Czechia, Slovakia, Ireland) rank slightly below the EU27-average with half of them by 10% below average or more. Citizens' access to their electronic health data could be considered as a driver for health systems digital transformation in general. In this regard, Member States could share good practices and 'tools' through capacity building activities, possibly supported by the European Commission and future studies or projects (e.g., policy twinings). This would be of particular interest as the herein measured citizens' access

should be interpreted not as an absolute benchmark to assess the overall digitisation of the healthcare system, but instead as an indication of the overall progress of the digital transformation in the health and care sector, of which citizen access is one aspect among many.

Synthèse

Le nouveau point de référence en santé en ligne : L'accès des citoyens aux dossiers médicaux électroniques en Europe

L'un des objectifs du programme politique 2030 de la décennie numérique est de permettre à **100 % des citoyens de l'UE d'accéder à leurs dossiers médicaux électroniques** d'ici à 2030, ce qui constitue une priorité et une ambition essentielles pour la transformation numérique de l'Europe. Pour atteindre cet objectif, il faut renforcer la coopération et la coordination entre les États membres et au niveau de l'UE, avec des critères communs pour garantir le même niveau d'accès et de qualité des services de santé en ligne pour les citoyens à l'intérieur et à l'extérieur des frontières. Au cours des cinq dernières années, les États membres et les institutions de l'UE ont redoublé d'efforts pour accélérer et faire progresser les infrastructures de données de santé électroniques sécurisées et interopérables, notamment en vue de la création de l'espace européen des données de santé. Néanmoins, l'accès des citoyens aux données de santé varie encore considérablement en termes de réglementation, de sécurité, de droits des utilisateurs et d'ensembles de données visibles, ce qui donne une image fragmentée de l'UE.

Où se situe l'UE sur la voie d'un accès à 100 % des citoyens à leurs dossiers médicaux électroniques ? Jusqu'à présent, il n'existait pas d'approche méthodologique assortie d'indicateurs harmonisés permettant de collecter chaque année des données pour répondre à cette question et suivre le progrès dans les États membres jusqu'en 2030. C'est pourquoi, entre juillet 22 et avril 23, l'équipe chargée de l'étude sur le développement d'indicateurs de santé en ligne pour la décennie numérique, mandatée par la DG CNECT (CNECT/LUX/2022/MVP/0027), a élaboré et mis en œuvre un **nouveau cadre de suivi**. Le concept du cadre répond à une lacune méthodologique résultant de l'absence d'une définition claire de "l'accès des citoyens" et de l'utilisation du terme "accès" pour se référer à des concepts non associés à la possibilité d'accéder à certains types de données, mais plutôt pour mesurer la fréquence et la facilité d'utilisation. Ainsi, le cadre proposé décrit de manière exhaustive la façon dont l'objectif d'un accès de 100 % des citoyens aux dossiers médicaux électroniques d'ici à 2030 doit être défini et mesuré à l'aide de données que les autorités nationales compétentes des États membres peuvent collecter et fournir.

L'**objectif de l'étude** était de fournir une évaluation de base de l'état d'avancement des États membres de l'UE27 plus l'Islande et la Norvège (UE27+2) en ce qui concerne l'accès des citoyens à leurs dossiers médicaux électroniques du point de vue de la politique de santé, et d'identifier les domaines susceptibles d'être améliorés par rapport aux objectifs de la politique de l'UE.

Ce rapport présente les résultats de la collecte des données de base, qui représentent l'état d'avancement des États membres au 31.12.2022, et recommande des mesures concrètes pour permettre aux citoyens d'accéder à 100 % à leurs dossiers médicaux électroniques.

Mesurer l'accès des citoyens aux dossiers médicaux électroniques en Europe

- La collecte de données de base de ce nouveau point de référence évalue l'accès des citoyens aux dossiers médicaux électroniques dans les États membres de **l'UE27 ainsi qu'en Islande et en Norvège**.
- Les autorités compétentes de **28 pays ont répondu** à une enquête en ligne entre le 23 février et le 30 mars 2023. **La Bulgarie a soumis ses données au début du mois de juin 2023.**
- Cette étude comparative propose une définition claire de "l'accès des citoyens" en tant que concept multidimensionnel à partir duquel quatre couches thématiques sont dérivées, constituant un indicateur composite de santé en ligne divisé en 12 sous-indicateurs. Ceux-ci examinent "l'accès des citoyens" sous les angles suivants, en se concentrant sur une

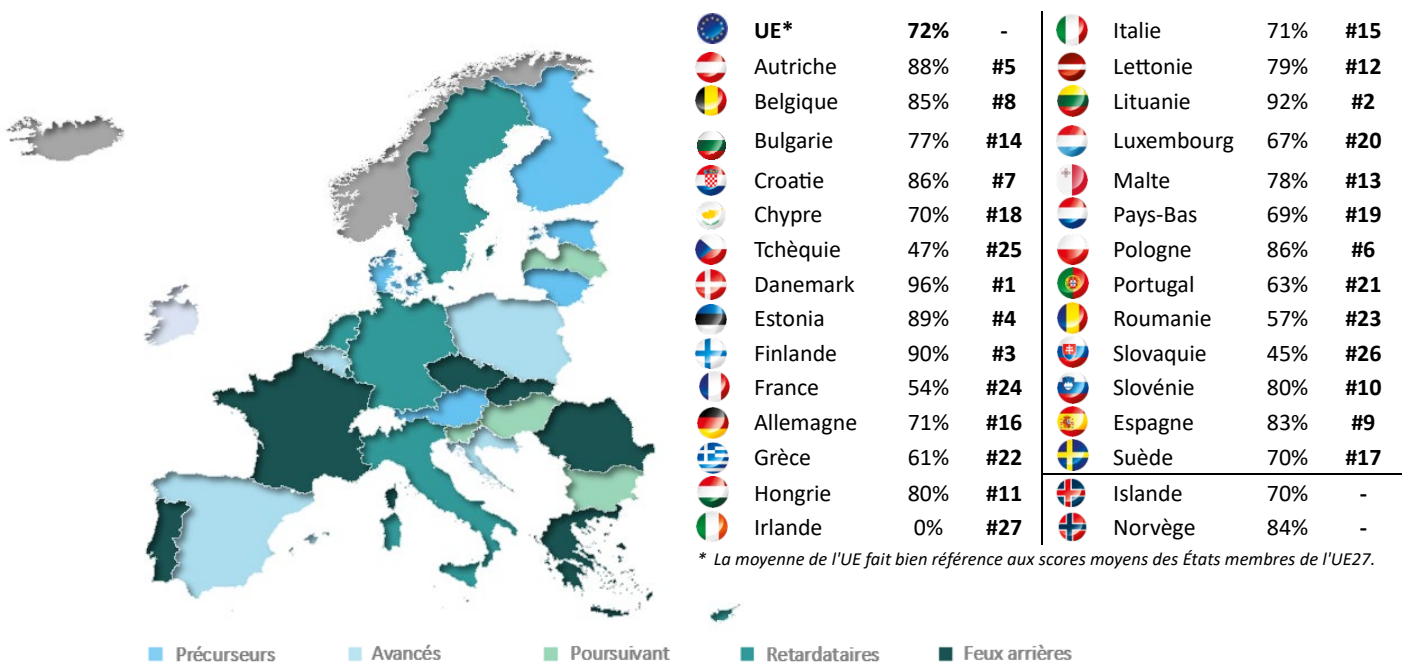
perspective technique:

- 1. Mise en œuvre de services d'accès électronique pour les citoyens** - L'accès des citoyens aux dossiers médicaux électroniques est facilité dès lors que les conditions techniques sont remplies, c'est-à-dire qu'un service d'accès électronique est disponible.
- 2. Catégories de données de santé accessibles** - Les catégories de données de santé accessibles aux citoyens comprennent les données sommaires des dossiers médicaux électroniques, la prescription/la délivrance en ligne, les résultats et les rapports électroniques (résultats d'analyses de laboratoire, images médicales et rapports d'imagerie, rapports de sortie d'hôpital).
- 3. Technologie d'accès et couverture** - L'accès est possible pour l'ensemble de la population et assuré par tous les secteurs de soins indépendamment du temps et du lieu (par exemple, au moyen d'applications mobiles ou de portails en ligne) avec des mécanismes d'authentification sécurisés conformes au règlement eIDAS.
- 4. Opportunités d'accès pour certaines catégories de personnes** - Des mécanismes permettant aux tuteurs légaux ou à d'autres personnes autorisées d'accéder aux dossiers médicaux électroniques des personnes placées sous leur responsabilité et des possibilités pour les groupes défavorisés sont en place (accessibilité du web).

L'état des lieux en Europe : l'accès des citoyens aux dossiers médicaux électroniques

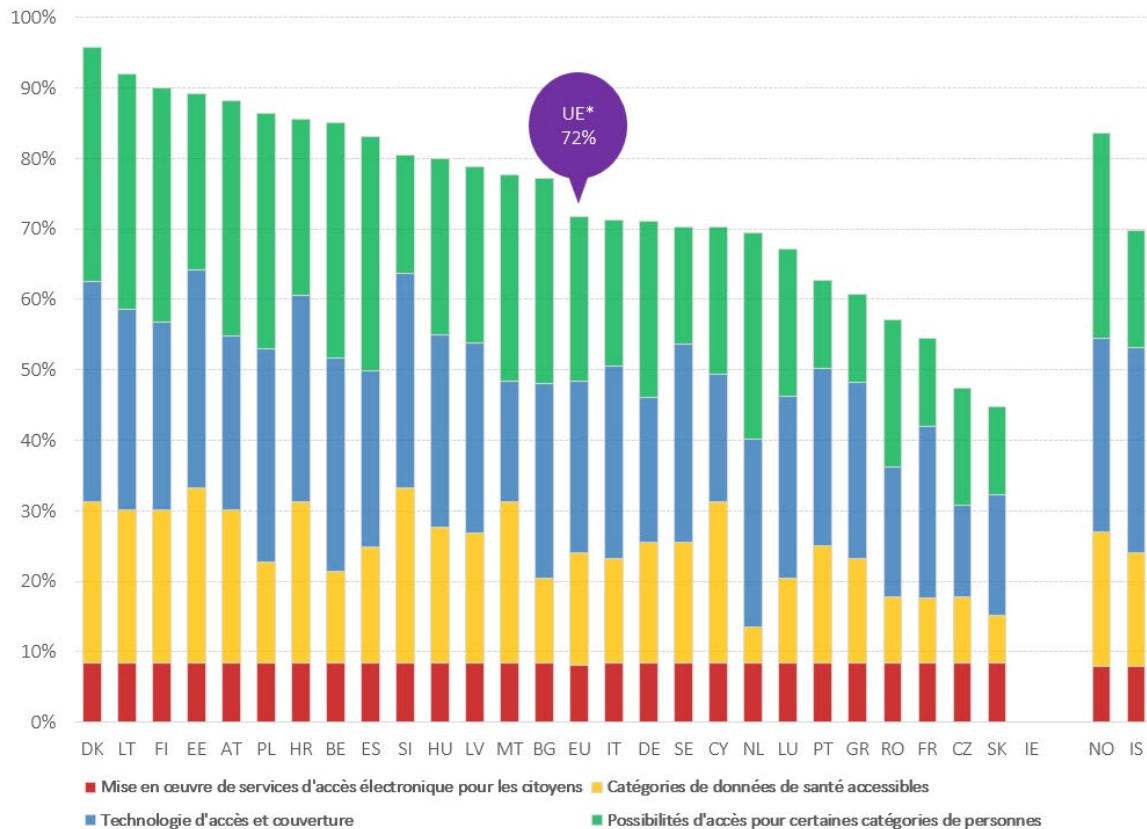
En combinant les quatre couches avec 12 sous-indicateurs pour **obtenir l'indicateur composite global de santé en ligne de la décennie numérique**, l'indicateur composite est une mesure de l'**accès réel et effectif aux dossiers médicaux électroniques pour les citoyens** des États membres de l'UE27 ainsi que de l'Islande et de la Norvège. Cet indicateur composite est compris entre 0 % et 100 %.

Figure 3. Accès des citoyens à leur dossier médical électronique dans l'UE, 2022
Performance globale des scores composites de santé en ligne par groupes de pays



Les États membres de l'UE27 peuvent être divisés en cinq groupes en fonction de la proximité de leurs scores composites avec ceux de leur "voisin de classement" immédiat. Il en résulte une répartition en États membres précurseurs très avancés, (Danemark, Lituanie, Finlande, Estonie et Autriche), États membres avancés (Pologne, Croatie, Belgique et Espagne), un groupe de poursuivants (Slovénie, Hongrie, Lettonie, Malte et Bulgarie), les retardataires (Italie, Allemagne, Suède, Chypre, Pays-Bas et Luxembourg) et les feux arrières (Portugal, Grèce, Roumanie, France, Tchéquie, Slovaquie et Irlande). L'Islande et la Norvège font l'objet d'un rapport distinct.

Figure 4. Accès des citoyens à leurs dossiers médicaux électroniques dans l'UE (scores combinés), 2022



*La moyenne de l'UE fait bien référence aux scores moyens des États membres de l'UE27.

Chacune des quatre couches du cadre contribue différemment à l'indicateur composite global de la santé en ligne concernant l'accès des citoyens à leurs dossiers médicaux électroniques dans chaque État membre (Figure 4). Les données montrent que les scores combinés des différentes couches varient considérablement d'un État membre à l'autre, à l'exception de la première couche, où tous, à l'exception de l'Irlande, ont effectivement mis en place un ou plusieurs services d'accès électronique pour ses citoyens disponibles à l'échelle nationale. On observe différents stades d'avancement en ce qui concerne les catégories de données électroniques de santé accessibles aux citoyens ainsi que les possibilités d'accès garantissant un accès équitable. Ainsi, les États membres sont généralement avancés d'un point de vue technique, mais d'autres aspects qui constituent un accès complet et équitable aux données électroniques sur la santé requièrent davantage d'attention.

Presque tous les États membres de l'UE27 proposent une sorte de service national ou régional d'accès en ligne, par exemple via un portail en ligne ou une application mobile. En ce qui concerne les catégories de données de santé auxquelles les citoyens ont accès, les données relatives à la

prescription et à la délivrance électroniques sont les plus largement accessibles et les plus fréquemment mises à jour. La plupart des citoyens de l'UE ont accès en ligne à leurs données d'identification et à leurs informations personnelles, à des données sur les procédures et les opérations, ainsi qu'aux médicaments actuels et aux médicaments antérieurs pertinents ou à un plan de médication équivalent. Les résultats et les rapports électroniques constituent la catégorie de données de dossiers médicaux électroniques la moins accessible.

Environ la moitié des États membres de l'UE27 (Belgique, Bulgarie, Chypre, Danemark, Estonie, Espagne, Finlande, Grèce, Croatie, Hongrie, Lituanie, Lettonie, Pologne, Slovaquie) ont connecté les prestataires de soins de santé publics et privés des secteurs des soins primaires, secondaires et tertiaires, ainsi que les pharmacies, avec un taux supérieur à 60 % du total des établissements de soins de santé. Alors que 23 des États membres de l'UE27 (Autriche, Belgique, Bulgarie, République Tchèque, Allemagne, Danemark, Estonie, Espagne, Finlande, France, Croatie, Hongrie, Italie, Lituanie, Luxembourg, Lettonie, Pays-Bas, Pologne, Portugal, Roumanie, Suède, Slovaquie) déploient des systèmes d'authentification utilisant un schéma d'eID (moyen d'identification électronique) notifié basé sur l'authentification à deux facteurs, 13 d'entre eux (Autriche, Belgique, Bulgarie, Allemagne, Estonie, Espagne, Croatie, Italie, Lituanie, Lettonie, Pays-Bas, Pologne, Suède) ont (pré)notifié leur eID et sont en conformité avec le règlement eIDAS. Seuls quatre États membres (Chypre, Grèce, Malte, Irlande) déclarent exiger différents moyens d'authentification pour que les citoyens puissent accéder à leurs données de santé électroniques. 12 États membres (Belgique, Bulgarie, Allemagne, Danemark, France, Grèce, Italie, Luxembourg, Pologne, Portugal, Suède, Slovaquie) fournissent un accès via des portails en ligne et des applications mobiles, tandis que 14 (Autriche, Chypre, Tchéquie, Estonie, Espagne, Finlande, Croatie, Hongrie, Lituanie, Lettonie, Malte, Pays-Bas, Roumanie, Slovaquie) fournissent un accès via des portails en ligne uniquement. La grande majorité des citoyens (>80%), y compris les mineurs, dans 18 États membres (Autriche, Belgique, Danemark, Estonie, France, Grèce, Croatie, Hongrie, Italie, Lituanie, Luxembourg, Lettonie, Malte, Pays-Bas, Pologne, Portugal, Suède, Slovaquie) est en mesure d'accéder à ses données de santé en ligne, ce qui reflète les efforts et les progrès significatifs entrepris par les autorités compétentes en vue de la transformation numérique du secteur de la santé et des soins. Dans trois États membres (République Tchèque, Allemagne, Slovaquie), seuls moins de 20 % des citoyens auront accès à leurs données à la fin de 2022.

Les tuteurs légaux sont en mesure d'accéder aux données de santé au nom de leurs pupilles désignés dans 19 des 27 États membres (Autriche, Belgique, Bulgarie, Chypre, Allemagne, Danemark, Estonie, Espagne, Finlande, Grèce, Croatie, Hongrie, Lituanie, Luxembourg, Lettonie, Pays-Bas, Pologne, Roumanie, Slovaquie), tandis que cinq (République Tchèque, France, Italie, Malte, Slovaquie) ont au moins établi le fondement juridique pour mettre en œuvre une telle fonctionnalité à l'avenir. Dans 15 États membres (Autriche, Belgique, Allemagne, Danemark, Estonie, Espagne, Finlande, Hongrie, Lituanie, Luxembourg, Lettonie, Malte, Pays-Bas, Pologne, Roumanie), les aidants informels peuvent accéder aux données de santé électroniques d'une autre personne, à condition de disposer d'une autorisation en bonne et due forme. Huit des 27 États membres de l'UE (Bulgarie, Chypre, République Tchèque, Grèce, Italie, Portugal, Slovaquie) n'ont pas encore mis au point une solution technique permettant une telle fonctionnalité, tandis que quatre autres (France, Croatie, Irlande, Suède) n'ont fait état d'aucun effort à cet égard. Les citoyens de 20 États membres (Autriche, Belgique, Bulgarie, Chypre, Allemagne, Danemark, Estonie, Espagne, Finlande, France, Croatie, Hongrie, Lituanie, Lettonie, Malte, Pologne, Portugal, Roumanie, Suède, Slovaquie) bénéficient de mesures et de services d'aide pour accéder aux données de santé en ligne. Les mécanismes d'assistance les plus courants sont les FAQ et les lignes directrices en ligne, ainsi que l'assistance à distance en temps réel par téléphone ou en ligne. Outre ces mécanismes d'accès, 14 États membres (Autriche, Belgique, Bulgarie, République Tchèque, Danemark, Espagne, Finlande, Croatie, Italie, Lituanie, Malte, Pays-Bas, Pologne, Suède) suivent des lignes directrices

internationales sur l'accessibilité du web afin de favoriser une présentation appropriée des informations et des données en ligne pour tous. La moitié restante des États membres de l'UE27 (Chypre, Allemagne, Estonie, France, Grèce, Hongrie, Irlande, Luxembourg, Lettonie, Portugal, Roumanie, Slovaquie) n'a pas réalisé les stipulations de la directive (UE) 2016/2102 (directive sur l'accessibilité du web) dans le contexte de l'accès des citoyens aux données de santé électroniques.

L'évaluation de base de l'accès des citoyens de l'UE aux dossiers médicaux électroniques réalisée en 2022 donne une moyenne de 72 % pour l'UE-27, ce qui montre que la plupart des États membres sont sur la bonne voie pour faciliter un accès total.

En résumé, l'évaluation de base de l'**UE27** pour cet exercice de suivi montre:

1. Dans l'UE27, tous les États membres sauf l'Irlande ont **mis en place des services d'accès électronique** permettant aux citoyens d'accéder à leurs dossiers médicaux électroniques. Parmi les États membres de l'UE27, 21 ont déployé au moins un service d'accès national. En Espagne, en Italie et en Suède, les régions sont responsables des services d'accès électronique. Les Pays-Bas et la République Tchèque sont les seuls États membres où les prestataires de soins de santé offrent leurs propres services d'accès aux citoyens.
2. Pour les **catégories de données de santé accessibles**, les États membres de l'UE27 ont atteint un score moyen de 64 sur 100, ce qui suggère que ce domaine présente globalement le plus grand potentiel d'amélioration à l'avenir. L'Estonie et la Slovaquie sont deux exemples de bonnes pratiques, puisqu'elles mettent à disposition toutes les catégories considérées, avec des mises à jour fréquentes à la suite d'un épisode de soins. Dans l'ensemble des États membres, les données sur les dispositifs médicaux et les implants sont les moins disponibles parmi les données récapitulatives des dossiers médicaux électroniques. Les informations fréquemment mises à jour sur la prescription et la délivrance électroniques sont le plus largement accessibles aux citoyens dans environ trois quarts des États membres de l'UE27 (Autriche, Chypre, République Tchèque, Allemagne, Danemark, Estonie, Espagne, Finlande, Grèce, Croatie, Hongrie, Italie, Lituanie, Lettonie, Malte, Pologne, Portugal, Suède, Slovaquie). Les rapports de sortie d'hôpital et les résultats de tests de laboratoire sont également largement disponibles, alors que les images médicales ne le sont que dans un quart des États membres (Belgique, Allemagne, Estonie, Espagne, Luxembourg, Lettonie, Slovaquie).
3. En ce qui concerne la **technologie d'accès et la couverture**, les États membres de l'UE27 obtiennent en moyenne un score de 73 sur 100. Pour accéder à leurs dossiers médicaux électroniques, les citoyens de 13 États membres (Autriche, Belgique, Bulgarie, Allemagne, Estonie, Espagne, Croatie, Italie, Lituanie, Lettonie, Pays-Bas, Pologne, Suède) utilisent un système d'identification électronique (pré)notifié conforme au règlement eIDAS pour l'authentification. Dans 12 États membres (Belgique, Bulgarie, Allemagne, Danemark, France, Grèce, Italie, Luxembourg, Pologne, Portugal, Suède, Slovaquie), les citoyens peuvent utiliser un portail en ligne et une application mobile pour accéder à leurs données de santé électroniques. Dans 18 États membres (Autriche, Belgique, Danemark, Estonie, France, Grèce, Croatie, Hongrie, Italie, Lituanie, Luxembourg, Lettonie, Malte, Pays-Bas, Pologne, Portugal, Suède, Slovaquie), entre 80 et 100 % de la population nationale est techniquement en mesure d'accéder à ses dossiers médicaux électroniques en ligne. Le Danemark, l'Estonie, la Finlande et la Grèce sont des exemples de bonnes pratiques en ce qui concerne la connexion des prestataires de soins de santé : tous les types de prestataires de soins de santé publics et privés considérés dans cette étude fournissent aux citoyens des données de santé électroniques pertinentes. Dans l'ensemble de l'UE27, ce sont les maisons de retraite privées et publiques qui sont le moins connectées aux infrastructures de dossiers médicaux électroniques des citoyens, suivies par les établissements de santé mentale et les centres de réadaptation. Les cabinets de soins primaires, les centres de soins de proximité ainsi que les hôpitaux des secteurs public et privé sont les plus

largement connectés dans l'UE27.

4. Combinés, les indicateurs sur les **opportunités d'accès pour certaines catégories de personnes** (tuteurs légaux, autres personnes autorisées, groupes défavorisés) atteignent un score moyen de 70 sur 100 dans l'UE27. Un quart des États membres de l'UE27 (Autriche, Belgique, Danemark, Finlande, Lituanie, Pologne, Espagne) soutiennent pleinement les citoyens défavorisés en leur offrant des possibilités d'accès supplémentaires, avec un score de 100 dans ce domaine. Alors que des dispositions légales visant à faciliter l'accès des personnes défavorisées ont été adoptées dans la plupart des États membres, la mise en œuvre des fonctionnalités techniques laisse parfois à désirer. La moitié des États membres de l'UE27 (Autriche, Belgique, Bulgarie, République Tchèque, Danemark, Espagne, Finlande, Croatie, Italie, Lituanie, Malte, Pays-Bas, Pologne, Suède) veillent à ce que leur service d'accès aux dossiers médicaux électroniques soit conforme aux lignes directrices pour l'accessibilité des contenus web (WCAG) v2.1, comme l'exige la directive (UE) 2016/2102 (directive sur l'accessibilité du web). Par conséquent, davantage d'efforts pourraient être déployés pour faciliter un accès équitable aux dossiers médicaux électroniques pour tous les citoyens.

En résumé, les principaux résultats pour **l'Islande et la Norvège** sont les suivants :

1. Les deux pays ont développé des **services nationaux d'accès** aux données de santé pour leurs citoyens.
2. L'Islande et la Norvège obtiennent, pour les **catégories de données de santé accessibles**, un score de couche égal et légèrement supérieur à la moyenne de l'UE27, respectivement. Les données récapitulatives des dossiers médicaux et les données relatives à la prescription et à la délivrance électroniques sont entièrement disponibles et, dans la plupart des cas, fréquemment mises à jour, tandis que l'accès aux données récapitulatives n'est que partiellement possible en Islande (les données relatives aux diagnostics, aux dispositifs médicaux et aux implants, ainsi qu'aux procédures, sont manquantes). En ce qui concerne les résultats et les rapports électroniques, les résultats des tests de laboratoire et les rapports de sortie d'hôpital sont accessibles dans les deux pays.
3. L'Islande et la Norvège obtiennent de meilleurs résultats que la moyenne de l'UE27 en ce qui concerne **la technologie d'accès et la couverture**, offrant à 80-100% des citoyens un accès sécurisé aux données de santé de la majorité des prestataires de soins de santé publics et de certains prestataires du secteur privé. Alors que l'Islande utilise un système d'identification électronique (pré)notifié eIDAS pour son portail national en ligne, la Norvège exige de ses citoyens qu'ils s'authentifient à l'aide d'un système d'identification électronique notifié au niveau national chaque fois qu'ils souhaitent accéder aux données des dossiers médicaux électroniques via un ou plusieurs portails en ligne ou une ou plusieurs applications mobiles.
4. Par rapport à l'UE27, l'Islande est à la traîne pour garantir **l'égalité des opportunités d'accès**, tandis que la Norvège est beaucoup plus avancée. Les principaux facteurs d'influence à cet égard sont le fait que le portail en ligne de l'Islande n'est pas conforme à la directive (UE) 2016/2102 (directive sur l'accessibilité du web) et l'absence de mesures de soutien mises en œuvre pour les groupes défavorisés et l'accès des tiers aux données pour les personnes autorisées.

Lacunes dans l'accès de 100 % des citoyens aux données des dossiers médicaux électroniques d'ici à 2030

L'accès des citoyens aux données de santé varie encore considérablement entre les États membres de l'UE27 en termes de réglementation, de sécurité, de droits des utilisateurs et d'ensembles de données visibles, ce qui donne une image fragmentée de l'UE. Les États membres et les institutions redoublent d'efforts pour accélérer et faire progresser les infrastructures électroniques de données de santé sécurisées et interopérables qui permettent l'accès aux données de santé et leur utilisation. Toutefois, il subsiste des lacunes pour lesquelles des interventions politiques pourraient être

opportunes et donner un coup de pouce à l'objectif d'un accès de 100 % des citoyens d'ici à 2030.

Les résultats et rapports électroniques, en particulier les rapports d'imagerie médicale, les rapports de sortie d'hôpital et, dans une certaine mesure, les résultats d'analyses de laboratoire, constituent la catégorie de données de dossiers médicaux électroniques la moins accessible, et les citoyens de la plupart des États membres de l'UE27 sont toujours confrontés à des **"lacunes de données"**. Malgré les efforts du règlement eIDAS pour harmoniser les systèmes d'authentification dans l'UE27, la moitié des États membres n'ont pas encore notifié leurs systèmes au niveau européen, ce qui laisse une **"lacune de d'harmonisation"** pour un accès sécurisé et mutuellement reconnu à la santé électronique. La part des types de prestataires de soins de santé privés qui sont connectés aux infrastructures de données et fournissent des données de santé pertinentes pour les citoyens de l'UE27, en particulier en dehors du secteur des soins primaires et secondaires, est faible, ce qui crée une **"lacune d'approvisionnement en données"** et un besoin de coopération entre les États membres et les prestataires privés. La moitié des États membres étudiés ne garantissent pas des possibilités d'accès équitables conforme la directive (UE) 2016/2102 (directive sur l'accessibilité du web), ce qui entraîne une **"lacune d'équité numérique"** pour les groupes de citoyens défavorisés dans l'ensemble de l'UE27.

Pour être en mesure d'atteindre l'objectif de la décennie numérique en matière de santé en ligne, les États membres devront s'assurer que l'accès aux dossiers médicaux électroniques avec un ensemble minimum de données liées à la santé stockées dans les systèmes de dossiers médicaux électroniques publics et privés est technologiquement possible et facilement accessible à au moins 80 % de la population nationale (via un portail patient ou une application mobile pour les patients), tout en fournissant des moyens d'authentification sécurisés (à l'aide d'un système d'identification électronique (pré)notifié), des mesures visant à faciliter des possibilités d'accès équitables pour tous les citoyens (tuteurs pour les enfants, les personnes handicapées, les personnes âgées) et au moins 60 % des fournisseurs publics et privés potentiels étant techniquement connectés et fournissant de manière cohérente des données sur la santé.

Aperçu général de l'accès à 100 % des citoyens aux dossiers médicaux électroniques dans l'UE

L'analyse et la visualisation des données finales permettent d'aller au-delà d'un simple traitement descriptif et d'un rapport sur l'état d'avancement du sujet de l'étude. Sur la base de la performance globale des 12 sous-indicateurs, des informations clés sont présentées concernant les sujets qui nécessitent potentiellement un examen plus approfondi dans le cadre d'études futures (sous-indicateurs pour lesquels les États membres de l'UE27 obtiennent un score global faible) par rapport aux sujets qui sont déjà bien avancés (sous-indicateurs pour lesquels les États membres de l'UE27 obtiennent un score global élevé). Dans cette perspective, l'équipe chargée de l'étude a procédé à une évaluation des résultats pour chaque sous-indicateur et a identifié six points clés:

- **Mesurer l'accès au-delà de la technologie, vers une approche multicanale.** L'accès technologique des citoyens aux dossiers médicaux électroniques est largement répandu dans tous les États membres. Tous les États membres de l'EU-27, ainsi que la Norvège et l'Islande, ont déployé un service d'accès disponible à l'échelle nationale et fourni soit au niveau central, soit à partir d'une région, soit par des prestataires de soins de santé. Par conséquent, d'autres paramètres devront être évalués à l'avenir pour obtenir une représentation plus granulaire de l'accès des citoyens aux dossiers médicaux électroniques, au-delà du simple niveau technique.
- **Élargir et approfondir les catégories de données de santé accessibles,** en particulier la catégorie des résultats et rapports électroniques, suivie de l'accessibilité des données de synthèse des dossiers médicaux. Afin d'atteindre l'objectif fixé pour 2030, les États membres devraient élargir l'éventail des données de santé électroniques accessibles qui

sont également mises à jour en temps utile. Cet ensemble minimal de données de santé ne devrait pas seulement inclure les données de synthèse des dossiers médicaux, les données de prescription et de délivrance électroniques ou les résultats de laboratoire électroniques, mais aussi les rapports de sortie d'hôpital ainsi que les rapports d'imagerie et l'imagerie médicale. La disponibilité de données de santé plus détaillées et la reconnaissance mutuelle de leurs dossiers médicaux électroniques pourraient permettre aux citoyens de l'UE de disposer de données plus pertinentes pour la continuité des soins au niveau national et transfrontalier, ce qui augmenterait la valeur des données accessibles et comblerait les lacunes actuelles en matière de données.

- **Garantir un accès harmonisé et également sécurisé aux dossiers médicaux électroniques dans toute l'UE**, notamment par le biais d'une notification à l'échelle de l'UE et de systèmes nationaux d'identification électronique conformes au règlement eIDAS. Le règlement eIDAS est un élément essentiel des efforts déployés par l'UE pour créer un environnement numérique sûr et fiable et stimuler la croissance de l'économie numérique en Europe. Afin de garantir à tous les citoyens de l'UE un accès sécurisé aux données de santé en ligne, de nouvelles évaluations sont nécessaires pour aider les États membres à passer à des systèmes d'identification électronique conformes au règlement eIDAS dans tous les États membres et à combler les lacunes existantes en matière d'harmonisation.
- **Recueillir et échanger les meilleures pratiques et les mesures d'incitation** qui attirent les prestataires du secteur privé, en particulier pour qu'ils se connectent aux services d'accès électronique. L'expérience de l'application de ces mesures dans les États membres peut varier en fonction des cadres constitutionnels des systèmes de soins de santé dans l'UE qui déterminent la mesure à appliquer. En raison de la grande diversité des systèmes de soins de santé et de leur organisation, il n'est guère possible de formuler une solution unique. Toutefois, l'échange de connaissances et d'expériences en matière de formation des prestataires de soins privés à l'utilisation active des services d'accès électronique pourrait constituer une source précieuse de nouvelles approches pour certains États membres qui font actuellement moins de progrès à cet égard, ce qui permettrait en fin de compte de combler les lacunes en matière de fourniture de données. Les États membres pourraient collaborer plus étroitement avec les prestataires publics, et privés en particulier, pour veiller à ce qu'au moins 60 % des établissements de soins de santé, tous secteurs confondus, soient connectés à des infrastructures de données de dossiers médicaux électroniques permettant aux citoyens d'accéder à leurs données.
- **Garantir un accès équitable aux dossiers médicaux électroniques dans l'UE**. Il est manifestement nécessaire d'améliorer les opportunités d'accès équitable aux données des dossiers médicaux électroniques en ligne pour tous les citoyens, car les services d'accès dans 13 États membres de l'UE27 ne sont pas conformes à la directive (UE) 2016/2102 (directive sur l'accessibilité du web). Bien que cette étude ne permette que de mettre en évidence le problème et de sensibiliser à la pertinence du sujet, des efforts doivent être déployés pour combler cette lacune d'équité numérique. Pour atteindre 100 % de l'objectif jusqu'en 2030, tous les États membres devraient suivre les lignes directrices sur l'accessibilité des contenus web et fournir ou améliorer des mécanismes de soutien supplémentaires pour les groupes défavorisés, tels que l'accès pour les tuteurs légaux ou les personnes autorisées à faciliter l'égalité des opportunités en matière d'accès.
- **Enseignements tirés et renforcement des capacités**. Alors que l'évaluation de base donne un résultat respectable de 72 % d'accès des citoyens en moyenne dans l'UE-27, treize États membres de l'UE (Italie, Allemagne, Suède, Chypre, Pays-Bas, Luxembourg, Portugal, Grèce, Roumanie, France, République Tchèque, Slovaquie, Irlande) se classent légèrement en dessous de la moyenne de l'UE-27, la moitié d'entre eux se situant à 10 % en dessous de la moyenne ou plus. L'accès des citoyens à leurs données de santé électroniques pourrait être

considéré comme un moteur de la transformation numérique des systèmes de santé en général. À cet égard, les États membres pourraient partager leurs bonnes pratiques et leurs "outils" dans le cadre d'activités de renforcement des capacités, éventuellement avec le soutien de la Commission européenne et d'études ou de projets futurs (par exemple, des « jumelages de politiques »). Cela serait particulièrement intéressant car l'accès des citoyens mesuré ici ne devrait pas être interprété comme une référence absolue pour évaluer la numérisation globale du système de soins de santé, mais plutôt comme une indication de la progression générale de la transformation numérique dans le secteur de la santé et des soins, dont l'accès des citoyens est un aspect parmi d'autres.

1 Introducing the new benchmark on citizen's access to electronic health records

1.1 About this report

This report concludes the work of the study team and presents the work carried out to develop and execute the bespoke monitoring framework to measure citizens' online access to electronic health records in the EU27+2 (Iceland and Norway). The 'Study for Digital Decade e-Health Indicators Development' was commissioned by DG CNECT (CNECT/LUX/2022/MVP/0027) from July '22 to April '23.

From its outset, the focus of development and conceptual work was focused on the 'technical availability' of electronic health records for citizens; the framework does not measure citizens' actual usage of online services that provide access to health data or related services.

The application of the framework as a monitoring instrument across the EU allows for a focused and politically highly relevant reporting mechanism to track Member States' progress in enabling individuals to access their electronic health records data and identify areas with potential for improvement vis-à-vis EU policy objectives. Until 2030, this monitoring activity shall be carried out to present Member States' progress towards the Digital Decade Policy Programme 2030 target of 100% citizen access to their electronic health records. Results on the 'State of the Digital Decade' will be reported together with an enhanced Digital Economy and Society Index (DESI) and as part of the European Semester.

This report addresses and fills a major gap in the literature on the topic of access to electronic health records by citizens in the EU27. While previous studies have touched on one or more individual aspects of the framework underlying this exercise, a comprehensive picture that brings together comparable data from national competent authorities in EU27 Member States has yet been missing.

1.2 Recent policy developments

Digital Health developments date back to the early 1990s, yet major breakthroughs and implementation successes of nationwide Electronic Health Record (EHR) systems occurred in the latter half of the previous decade across the EU. Developing and fully implementing systems, standards, terminologies, and a transition of human behaviour requires a significant amount of time. Thus, while citizen health may already be electronically available locally in the doctor's office, only a fraction of our entire medical history may in fact be standardised and ready to be represented or exchanged in systems outside healthcare providing organisations.

Digital transformation and the Digital Decade

The digital transformation in health was greatly facilitated by publishing the Directive on patients' rights in cross-border healthcare (2011/24/EU) which set out the conditions under which a patient may travel to another EU country to receive medical care and reimbursement. It also included a minimum list of elements to be included in a medical prescription taken from one EU country to another (cross-border prescription), enabled through a dedicated eHealth Digital Service

Infrastructure (eHDSI)¹. In 2019, the first eHDSI exchanges of patient summaries and ePrescriptions took place between Finland and Estonia².

To address the growing use of health data in the EU, several relevant milestones were implemented, including the adoption of the EU Cybersecurity Act³ in 2019 and the adoption of stronger rules on data protection through the General Data Protection Regulation (GDPR)⁴ in 2018.

In 2018, another milestone in the EU's digital health journey was the publication by the European Commission of a Communication on the digital transformation of health and care. To empower citizens and to build a healthier society, the Commission proposed to take action in three areas: (1) citizens' secure access to and sharing of health data across borders, (2) better data to advance research, disease prevention and personalised health and care, (3) digital tools for citizen empowerment and person-centred care.

The Path to the Digital Decade Policy Programme 2030 sets out a novel form of governance with Member States and EU institutions through a mechanism of annual cooperation to ensure they jointly pursue digital policies that empower people and businesses to seize a human-centred, inclusive, sustainable, and more prosperous digital future. As part of a broader set of ambitions for Europe's digitalisation in the domains of skills, infrastructures, business, and government, 100% of Union citizens having online access to electronic health records is one target of the Digital Decade to be reached by 2030.

To advance progress towards increasing secure access to health data for citizens, the Commission is taking a number of actions. A legislative proposal for a Regulation on the European Health Data Space (EHDS) was published on 3 May 2022. This is one of the nine data spaces announced in 2020 in the EU Data Strategy. The proposal aims to promote better exchange and access to different types of health data (including electronic health records), to empower citizens, support healthcare delivery (so-called primary use of data) and also improve the quality and accessibility of health data for research, innovation and health policy making purposes. In particular, it aims to enhance citizen access to their own health data, to support exchange of health data between healthcare providers, and to foster the re-use of health data for supporting research, policy-making and other related purposes.

To support citizen access to their health data, the European Commission is also bringing forward a number of technical enablers to facilitate secure and trustworthy health data sharing and access in the EU. These include interoperability recommendations for common technical specifications for exchange format of Electronic Health Records (EEHRxF) (Commission Recommendation (EU) 2019/243 of 6 February 2019 on a European Electronic Health Record exchange format) as well as legislative frameworks for data protection, privacy and security (including e-ID systems and cyber resilience). Additionally, the on-going creation of the European Health Data Space culminated in a legislative proposal on the 3rd of May 2022. The document further details projects supported by the Commission in this sense and operational infrastructures among Member States, as well as proposed actions that can be taken by Member States to achieve the target.

¹ European Commission (2023): *Electronic cross-border health services*. [online] Available at: [Link](#).

² European Commission (2019): *First EU citizens using ePrescriptions in other EU country*. [online] Available at: [Link](#).

³ European Commission (2023): *The EU Cybersecurity Act*. [online] Available at: [Link](#).

⁴ [General Data Protection Regulation, Regulation \(EU\) 2016/679](#).

Measuring access to electronic health records

The assessment of maturity of Member States concerning citizens' access to their electronic health records data was also informed by a recent study published in 2021 by the Commission: Interoperability of Electronic Health Records in the EU⁵. According to this report, 80% of Member States had national laws governing EHRs. While 26 Member States generally granted their citizens legal access to EHR data, only 20 Member States had enacted legislation stating that citizen access must be guaranteed regardless of location or technology. However, just five Member States reported to send or receive patient record summaries to other Member States despite the fact that 18 Member States already had laws allowing the exchange of EHR data across country borders.

In 2021, 16 Member States reported that specific mechanisms were in place, for e.g., online portals routinely used at national level to provide citizen access to their health data, and another six Member States reported on-going pilot projects. However, harmonised, and consistent statistical data for all Member States was not yet available, therefore, a methodological approach to ensure such indicators are measurable was identified as most important. With this, the monitoring of the Digital Decade targets will be assigned to the DESI. As a result, DESI indicators are now structured around the four cardinal points of the Digital Decade Compass instead of the former five. One of these cardinal points refers to 'digital public services', including the e-health target of all citizens having online access to electronic health records by 2030. The EU digitalisation targets further aim to ensure that all individuals can obtain an electronic identification (eID), an important enabler for individuals to securely access key digital public services, including electronic health records online access services.

e-Health indicators have been used for instance in the 2019 DESI, including the following:

- *eHealth services* (5b1, as % of individuals who used online health and care services without having to go to a hospital or doctors' surgery);
- *medical data exchange* (5b2, as % of general practitioners using electronic networks to exchange medical data with other healthcare providers and professionals);
- *e-Prescription* (5b3, as % of general practitioners using electronic networks to transfer prescriptions to pharmacists).

Indicator 5b1 was taken from the 2017 Eurobarometer Special 460 (Attitudes towards the impact of digitisation and automation on daily life), underlying data for 5b2 and 5b3 was provided by the 2018 Benchmarking Deployment of eHealth among General Practitioners study by RAND Europe, Open Evidence and BDI Research. While these indicators were certainly relevant for a policy area of interest, they were not collected on a yearly basis and dropped for the 2020 DESI, potentially proving the difficulty of primary data collection.

Eurostat⁶ has estimated that, in 2020, only about one in ten individuals in the EU accessed their electronic health records online. However, there is overall a lack of direct, updated and comparable data for measuring Member States' progress towards citizens' access to and accessibility of electronic health records, including eID mechanisms, as highlighted in a 2022 report by Deloitte⁷. Further, information such as the proportion of individuals seeking health information and making medical appointments online (56% and 21% in the EU in 2020, respectively⁸) only provide a rough indication. Available data does also not sufficiently reflect various aspects of accessibility such as

⁵ European Commission (2021): *Interoperability of Electronic Health Records in the EU*. [online] Available at: [Link](#).

⁶ Eurostat. (2023). *Individuals - internet activities*. [online] Available at: [Link](#).

⁷ Deloitte LLP. (2022). *The progress towards the EU's Digital Decade ambition*. [pdf] Available at: [Link](#).

⁸ Eurostat. (2023). *Individuals - internet activities*. [online] Available at: [Link](#).

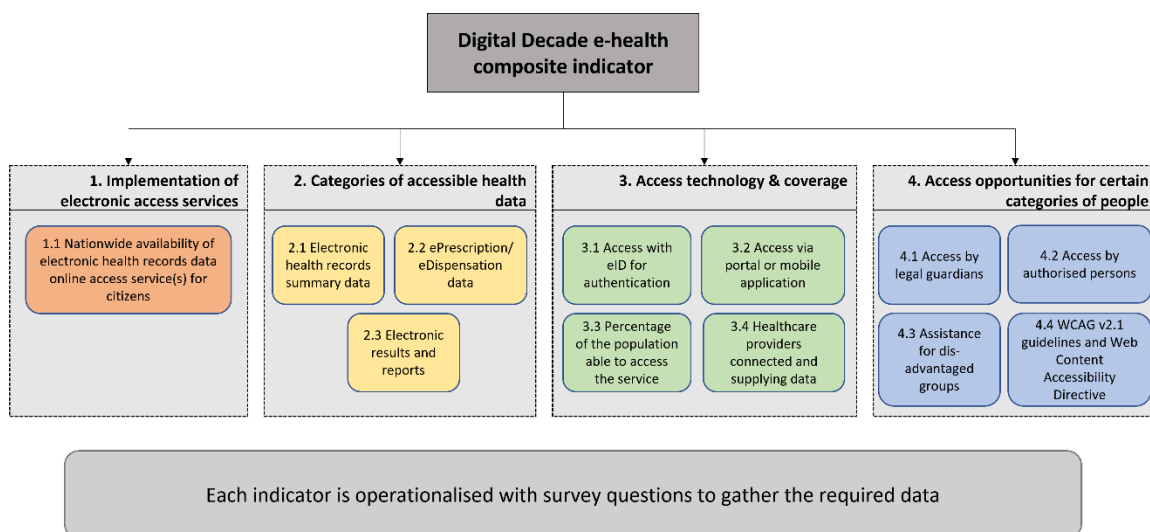
access opportunities for certain disadvantaged categories of people (e.g., elderly, people with disabilities or lower health or digital literacy). Information on what health-related data categories individuals can access is additionally lacking across Member States. Consequently, there is a clear need for the development and implementation of a common e-health indicators monitoring framework.

1.3 Monitoring framework to measure access to electronic health records in the EU

Taking stock of previous studies and incorporating relevant feedback of Member State representatives in the eHealth Network to refine the study’s methodology, the study team developed a Digital Decade e-health indicators monitoring framework. It is composed of four distinct thematic layers, each of which contains one or several sub-indicators, representing a key aspect of technical availability of citizens’ online access to electronic health records:

1. **Implementation of electronic access services for citizens:** Citizens’ access to electronic health information is facilitated once the technical prerequisites are fulfilled, i.e., an access service is available to them.
2. **Categories of accessible health data:** Health information categories that are accessible to citizens in each Member State, including electronic health records summary data, ePrescription/eDispensation, electronic results and reports (laboratory test results, medical images and imaging reports, hospital discharge reports).
3. **Access technology and coverage:** Access should be enabled independently of time and place (e.g., through mobile applications or online portals). Also, proper and secure authentication mechanisms should be in place compliant with the current eIDAS Regulation. The digital point of access should be available to the entire population in each Member State and data supply should be ensured by all sectors of care.
4. **Access opportunities for certain categories of people:** The mechanisms and opportunities for legal guardians or other authorized persons to access the health data of those under their responsibility and opportunities for groups with a low level of health and digital literacy such as elderly or disabled to access their electronic health records (web accessibility).

Figure 5. Digital Decade e-health composite indicator structure



In total, 12 sub-indicators form an overall **Digital Decade e-health composite indicator**, reflecting citizens' access to their electronic health records. The composite score is calculated by the weighted scores of the 12 sub-indicators.

Table 1. Overview of the sub-indicators

Sub-indicator	Details
1.1 Nationwide availability of electronic health records data online access service(s) for citizens	<ul style="list-style-type: none"> On National or regional level or by HCP Irrespective of time and place online
2.1. Electronic health records summary data	<ul style="list-style-type: none"> ID, personal information, allergies, current problems, medical devices, procedures, and medication As defined by applicable EU guidelines and specifications incl. eHealth Network guidelines
2.2. ePrescription/eDispensation data	<ul style="list-style-type: none"> ePrescription and eDispensation data As defined by applicable EU guidelines and specifications incl. eHealth Network guidelines
2.3. Electronic results and reports	<ul style="list-style-type: none"> Laboratory test results, medical images, imaging reports, and hospital discharge reports As defined by applicable EU guidelines and specifications incl. eHealth Network guidelines
3.1 Access to electronic health records with an eID	<ul style="list-style-type: none"> Use of an eIDAS (pre-)notified eID scheme, a two-factor authentication or other means
3.2 Access via an online portal or mobile application	<ul style="list-style-type: none"> Either via online portal, mobile application, or both
3.3 Percentage of national population able to access their electronic health records	<ul style="list-style-type: none"> Children count, if guardians have access on their behalf Estimated percentage brackets (0-20%, 20-40%, ..., 80-100%)
3.4 Healthcare provider types connected and supply relevant health data	<ul style="list-style-type: none"> 'Connected', if at least 60% of potential providers are technically connected Consistently supply health data
4.1 Access for legal guardians	<ul style="list-style-type: none"> Legislation and technical solution implemented
4.2 Access for authorised persons	<ul style="list-style-type: none"> Legislation and technical solution implemented
4.3 Assistance for disadvantaged groups	<ul style="list-style-type: none"> Legislation and technical solution implemented
4.4 WCAG v2.1 and Web Accessibility Directive compliance	<ul style="list-style-type: none"> Access service complies or not

More details on the monitoring framework are provided in the Annex A.

1.4 Synthesis of approach and methods

The e-health indicators monitoring activity to assess current Member State levels of citizens' access to their electronic health records in the context of the Digital Decade is centred around a benchmark approach covering the EU27 plus Iceland and Norway (EU27+2). The ultimate outcome is a single numerical value representing access. It is a percentage score composed of 12 individual values, henceforth referred to as composite score or composite indicator. The individual values represent to which level each Member State performs in a particular aspect that facilitates full access to electronic health records data for citizens. Each value belongs to one of 12 sub-indicators and are thematically structured according to the study's framework thematic layers (section 2.1). The framework is based on state-of-the-art scientific and policy insights and supported by extensive literature analysis on the topic of citizens' access to electronic health record data in all Member States.

An online survey among the EU27+2 competent Member State authorities for e-health was launched to gather the necessary data to calculate sub- and composite indicator scores by operationalising these with one survey question each. The set of questions and the methodology was evaluated and validated with the assistance of Member State representatives in the European eHealth Network to ensure high quality of the work done and that the survey is fit to yield the necessary data. eHealth Network representatives provided information on which competent authorities are most suitable to target. Where that was not possible, the survey was forwarded to the proper authority through the eHealth Network representatives. The nominal and categorial data submitted by the survey recipients reflects the state-of-affairs in Member States until 31.12.2022.

Through assigning point values to each answer item sub-indicator scores were calculated. EU27-average scores were calculated for each thematic layer, and layer scores multiplied with fixed weights. The weights were determined by the number of sub-indicators per layer, meaning that the more sub-indicators a certain layer is composed of, the more significant is its impact on the composite score. Details on the calculation formula, weights, and survey recipients are provided in Annex A. Note that all values presented in the report are rounded to the nearest whole digit.

The study team carefully scrutinised all received data and engaged with the respondents bilaterally where follow-ups were necessary to ensure correct and complete Member State data. Data from 28 countries has been collected between 23 February and 30 March. An in-time response to the online survey for Bulgaria has not been submitted due to changes in the administration of the Bulgarian Ministry of Health and national general elections. Contact was successfully established in early June resulting in the completion of the survey by the Ministry of Health.

2 Europe's state-of-play: access to electronic health records

This chapter presents the results of the European benchmark on citizens' access to their electronic health records. A description of concept of the framework on citizens' access to electronic health records is followed by the overall composite scores of citizens' access in Europe. Detailed results and scores on each of the 12 sub-indicators are structured around four sub-chapters – one per each framework layer. Lastly, limitations of the study framework are presented.

2.1 'Citizens' access': a multi-dimensional concept

The scientific literature on EHRs lacks a clear definition of 'access' for citizens. Although many studies focus on patient use of EHRs, few address the issue from a policy perspective. Recent studies have used 'access' as a link to measure constructs like usage frequency and ease, without operationalising or measuring the access construct itself. This creates a knowledge gap, as access to services varies greatly in terms of regulation, security, user rights, and visible data sets, leading to fragmented and uneven access across Member States. To address this methodological gap, this study explores citizens' access to their electronic health records from a health policy perspective.

The concept of access to electronic health data is complex and multi-dimensional. National readiness to enable citizen access to health data can be measured along three broad lines of progress: (1) nationwide availability of secure and easy to use data access service, (2) the scope of health data that is accessible to citizens (3) equity of access and availability of support.

These aspects provide a basis for a bespoke definition of 'citizens' access' that can be annually measured to monitor progress toward the Digital Decade target of 100% citizens' access to their electronic health records. The Proposal for a REGULATION OF THE EUROPEAN PARLIAMENT AND OF THE COUNCIL on the European Health Data Space⁹, published in May 2022, defines electronic health data as 'personal or non-personal electronic health data'.

Condensing the present information, the Digital Decade e-health composite indicator is defined, at high-level, as:

- i. the nationwide availability of electronic health records **data online access service(s) for citizens** (via a patient portal, or a patient mobile app) with **additional measures** in place that enable certain categories of people (guardians for children, people with disabilities, elderly) to also access their data, and
- ii. the **percentage of individuals** that have ability to obtain or make use of their own minimum set of health-related data currently stored in public and private electronic health record (EHR) systems.

The study team proposed a framework that comprehensively describes how the target of 100% *technical* access for citizens to their electronic health records by 2030 is to be measured. Four layers operationalise the composite indicator on a next level of detail:

1. Implementation of electronic access services for citizens;
2. Categories of accessible health data;
3. Access technology & coverage;
4. Access opportunities for certain categories of people.

Measuring citizens' actual use of the ability to access their health data through proper technical

⁹ https://eur-lex.europa.eu/resource.html?uri=cellar:dbfd8974-cb79-11ec-b6f4-01aa75ed71a1.0001.02/DOC_1&format=PDF

means is outside the scope of this study's objectives. A measurement of the number of citizens who have established online accounts that facilitate them with access to health data is not a meaningful representation to measure the Digital Decade target. 'Access' involves additional aspects which are measured with each of the four layers. As currently there is a lack of comparable data across Member States on the number of activated 'accounts', each account representing a citizen who has established online access to his or her electronic health records, the study team developed 12 indicators that can be measured with data and knowledge provided by Member State national competent authorities contacted for the study.

Therefore, the result of this study is an assessment of the level to which these dimensions and sub-indicators are fulfilled in each Member State. A combination of all layers into the Digital Decade e-health composite indicator results a measure of **genuine and effective access to electronic health records by citizens in each Member State**. This is expressed as a percentage value ranging from 0% to 100% to report in line with the Digital Decade target.

2.2 The EU picture: Citizens' access to electronic health records data

EU analysis

At a glance: The path towards realising the 2030 Digital Decade's e-health target is well underway

The 2022 baseline assessment of EU citizens' access to electronic health records data yields a result of 72% across EU27 Member States, demonstrating that most Member States are on track towards facilitating full citizen access. Almost all Member States offer some sort of national or regional online access service, e.g., via an online portal or a mobile application. Both non-EU countries included in the study (Iceland and Norway) developed national access services to health data for their citizens.

In terms of accessible health data categories, ePrescription and eDispensation data are the most widely accessible and frequently updated, being the case in about three quarters of EU27 Member States (Austria, Bulgaria, Cyprus, Czechia, Germany, Denmark, Estonia, Spain, Finland, Greece, Croatia, Hungary, Italy, Lithuania, Latvia, Malta, Poland, Portugal, Sweden, Slovenia). Most EU citizens are provided with online access to their identification and personal information, data on procedures and operations, and current and relevant past medicines or a medication plan equivalent. The least accessible health data categories are electronic results and reports. Iceland and Norway reached a layer score for categories of accessible health data that is equal to or slightly above the EU27-average, respectively.

While 23 of EU27 Member States (Austria, Belgium, Bulgaria, Czechia, Germany, Denmark, Estonia, Spain, Finland, France, Croatia, Hungary, Italy, Lithuania, Luxembourg, Latvia, Netherlands, Poland, Portugal, Romania, Sweden, Slovenia, Slovakia) deployed the authentication systems using a notified eID scheme based on two-factor authentication, 13 of those (Austria, Belgium, Bulgaria, Germany, Estonia, Spain, Croatia, Italy, Lithuania, Latvia, Netherlands, Poland, Sweden) have (pre-)notified their eID and are compliant with the eIDAS Regulation. Only four Member States (Cyprus, Greece, Malta, Ireland) report to require different means of authentication for citizens to gain access to their electronic health data. This creates an overall secure yet heterogeneous landscape of authentication mechanisms in the EU. Access security could be further enhanced by a larger share of eIDAS (pre-)notified eID schemes.

Twelve Member States (Belgium, Bulgaria, Germany, Denmark, France, Greece, Italy, Luxembourg, Poland, Portugal, Sweden, Slovenia) provide access via both online portals and mobile applications, while 14 (Austria, Cyprus, Czechia, Estonia, Spain, Finland, Croatia, Hungary,

Lithuania, Latvia, Malta, Netherlands, Romania, Slovakia) provide access with online portals only.

The vast majority of citizens (>80%), including minors and elderly, in 18 Member States (Austria, Belgium, Denmark, Estonia, France, Greece, Croatia, Hungary, Italy, Lithuania, Luxembourg, Latvia, Malta, Netherlands, Poland, Portugal, Sweden, Slovenia) is able to access their health data, mirroring the significant efforts and progress undertaken by the relevant authorities across the EU towards the digital transformation of the health and care sector. In three Member States (Czechia, Germany, Slovakia), only less than 20% of citizens are facilitated with access as of end of 2022.

About half of EU27 Member States (Belgium, Bulgaria, Cyprus, Denmark, Estonia, Spain, Finland, Greece, Croatia, Hungary, Lithuania, Latvia, Poland, Slovenia) have connected both public and private healthcare providers of the primary, secondary and tertiary care sector as well as pharmacies with a share of more than 60% of total healthcare institutions.

Overall, the technical component of ‘access’ are already quite advanced across the EU27 with the main differences being the amount of connected healthcare providers, especially in the private sector, and the notified eID schemes. Iceland and Norway perform better than the EU27-average regarding access technology and coverage, providing 80-100% of citizens with secure access to health data from the majority of public healthcare providers and some providers in the private sector. While Iceland employs an eIDAS-(pre-)notified eID for its national online portal, Norway requires its citizens to authenticate with a nationally notified eID scheme whenever access to electronic health records data is sought via online portal(s) or mobile app(s).

Legal guardians are able to access the health data on behalf of their assigned wards in 19 of EU27 Member States (Austria, Belgium, Bulgaria, Cyprus, Germany, Denmark, Estonia, Spain, Finland, Greece, Croatia, Hungary, Lithuania, Luxembourg, Latvia, Netherlands, Poland, Romania, Slovenia), while another five (Czechia, France, Italy, Malta, Slovakia) have at least established the legal ground to implement such a functionality in the future.

Given a proper authorisation is in place, informal carers in 15 Member States (Austria, Belgium, Germany, Denmark, Estonia, Spain, Finland, Hungary, Lithuania, Luxembourg, Latvia, Malta, Netherlands, Poland) can access the electronic health data of another individual. Eight Member States (Bulgaria, Cyprus, Czechia, Greece, Italy, Portugal, Slovenia) have not yet developed a technical solution that supports such a functionality, while another four (France, Croatia, Ireland, Sweden) do report to not have conducted any efforts on this topic. As a result, parents in most EU27 Member States can technically access their children’s electronic health data, yet an authorisation for other individuals is not facilitated as frequently, effectively limiting access for elderly citizens who may struggle to use the access opportunities themselves. 20 Member States (Austria, Belgium, Bulgaria, Cyprus, Germany, Denmark, Estonia, Spain, Finland, France, Croatia, Hungary, Lithuania, Latvia, Malta, Poland, Portugal, Romania, Sweden, Slovakia) report to have legally mandated additional support measures and offer these as services to their citizens. The most common support mechanisms are online FAQs and guidelines and real-time remote assistance in the phone or via online.

In addition to these access mechanisms, 14 Member States (Austria, Belgium, Bulgaria, Czechia, Denmark, Spain, Finland, Croatia, Italy, Lithuania, Malta, Netherlands, Poland, Sweden) follow international guidelines on web accessibility. Half of the EU27 (Cyprus, Germany, Estonia, France, Greece, Hungary, Ireland, Luxembourg, Latvia, Portugal, Romania, Slovenia, Slovakia) did not implement the stipulations of the Directive (EU) 2016/2102 (Web Accessibility Directive) in the context of citizens’ access to electronic health data. These findings reveal that while already a good amount of electronic health data is accessible to citizens and the technical conditions are

well advanced in most Member States, equity of ‘access’ is somewhat limited. In comparison to the EU27, Iceland lags behind in ensuring equal access opportunities, whilst Norway is much more progressed. The main factors of influence here are the fact that Iceland’s online portal does not comply with the Web Accessibility Directive and a lack of implemented support measures for disadvantaged groups and third-party access to data for authorised persons.

Citizens’ access to health data still varies greatly between EU Member States in terms of regulation, security, user rights, and visible data sets leading to a fragmented EU picture. Member States and institutions are increasing their efforts to accelerate and advance secure and interoperable electronic health data infrastructures that enable health data access and use. However, gaps remain where policy interventions could be opportune and deliver a boost towards the target of 100% citizens’ access until 2030.

Electronic results and reports, in particular medical imaging reports, hospital discharge reports and laboratory test results to some extent, are the least accessible category of electronic health records data where citizens in most EU27 Member States are still facing ‘data gaps’. Despite the efforts of the eIDAS Regulation to harmonise authentication schemes across the EU27, half of all Member States are yet to notify their schemes on EU-level leaving a ‘harmonisation gap’ for secure and mutually recognised access to electronic health. The share of private healthcare provider types that are connected to data infrastructures and supply relevant health data for citizens in the EU27, in particular outside the primary and secondary care sector, is low creating a ‘data supply gap’ and a need for cooperation between Member States and the private providers. Half of EU27 Member States do not guarantee equitable access opportunities through compliance with the Web Accessibility Directive resulting in a ‘digital equity gap’ for disadvantaged groups of citizens across the EU27. The first baseline data collection to create the foundation for future monitoring and policy-making decisions delivers an overall positive message both for policymakers and citizens alike. On a scale from 0% to 100%, EU27 citizens’ access to their electronic health records averages 72% already, demonstrating that most Member States are on track towards facilitating full citizen access as conceptualised in this benchmark. Notably, citizens in Ireland do not have access to their electronic health records as an online access service is not yet provided, leading to a score of 0%.

The average of 72% access to health data across the EU27 for the baseline monitoring clearly underlines that Member States are progressing well in facilitating citizens with the technical prerequisites to make effective use of their rights to health data. However, not all EU Member States, perform equally well in the composite score and across the four composite layers¹⁰. These layers serve as an additional level of analysis and group the sub-indicators into thematically linked dimensions, whose results are presented in the following.

Electronic access service for citizens

Almost all EU27 Member States offer some sort of national or regional online access service, e.g., via an online portal or a mobile application, to their citizens through which access to electronic health records is facilitated. Hence, this sub-indicator scores highest across the overall benchmark. Only in Ireland such a service does not exist at the moment. The constitution of the healthcare system in Czechia and the Netherlands has the healthcare providers offer their own services to citizens instead of national or regional services. Iceland and Norway developed national access services to health data for their citizens.

¹⁰ These are: 1. Implementation of electronic access services for citizens, 2. Categories of accessible health data, 3. Access technology and coverage, and 4. Access opportunities for certain categories of people. For more details, see the methodology in Annex A or the section 2.1.

Categories of accessible health data

In terms of health data categories citizens have access to the results present a clear pattern. ePrescription and eDispensation data are accessible and frequently updated in all but four Member States (France, Ireland, Luxembourg, Slovakia). One explanation for the wide prevalence of such data may be recent efforts to digitise prescription information for cross-border services which has been a major focus of EU and national policies in the past years. Also, as one of the most widely used healthcare services, ePrescribing is likely to yield the largest impacts in healthcare systems in terms of monetary savings, behavioral changes and facilitating acceptance for digital services overall. Following this, and part of a so-called ‘minimum set of accessible health data’, most EU27 citizens are provided with online access to their identification and personal information, data on procedures and operations, and current and relevant past medicines or a medication plan equivalent. Out of 27 Member States, 20 and 21 provide access to allergy data and current diagnoses, respectively, while information on medical devices and implants is electronically accessible in 16 Member States.

The least accessible category of electronic health records data are electronic results and reports. Within this category, the most widely accessible data are laboratory results and reports and hospital discharge reports. Citizens can access medical imaging reports online in 18 Member States (Austria, Belgium, Bulgaria, Cyprus, Germany, Denmark, Estonia, Finland, France, Croatia, Hungary, Italy, Lithuania, Luxembourg, Latvia, Malta, Poland, Slovenia), and seven Member States (Belgium, Germany, Estonia, Spain, Luxembourg, Latvia, Slovenia) provide them with a copy of the image in a suitable electronic format. That leaves the average EU citizen with a broad, but not yet complete range of accessible health data.

Iceland and Norway reached a layer score that is equal to or slightly above the EU27-average, respectively, for categories of accessible health data. Health records summary data and ePrescription/eDispensation data is fully available and, in most cases, frequently updated, while access to summary data is only partially enabled in Iceland (diagnoses, medical devices and implants as well as procedures data missing). In terms of electronic results and reports, laboratory test results and hospital discharge reports are accessible in both countries.

On the horizontal level of the various data categories, only little support will be required in the future towards full access to health data. A special focus of developments in the coming years could be on electronic report formats in general. Vertically, however, on the country level, some Member States have further progressed than others. Especially Ireland, but also France, Czechia, Hungary, Italy, Poland and Iceland show several ‘data gaps’ to be closed until 2030, particularly in the area of electronic health records summary data.

Access technology and coverage

Over two-thirds of Member States score above the EU27-average of 73 out of 100 in the ‘access technology and coverage’ layer, meaning that a small fraction of countries in the EU with a significantly lower layer score exert a strong negative influence on the EU27-average. While the performance in the sub-indicators of citizens’ access via online portals or mobile applications and the population share which can access their data contributes towards a higher score (overall Member States score well in these areas), the main negative driver is the indicator assessing which healthcare provider categories are connected to national data infrastructures and are supplying relevant health data for citizens.

About half of all Member States have connected both public and private healthcare providers of the primary, secondary and tertiary care sector as well as pharmacies with a rate of >60% of total healthcare institutions. Public primary, secondary and tertiary healthcare sector are connected in one-in-four Member States to supply citizens with relevant health data. About every third Member

State has managed to connect additional care provider types, such as rehabilitation centres, geriatric nursing homes and mental health facilities with varying success. In general, there appear to be significant barriers to connect private healthcare providers. This could be due to private entities acting outside the immediate control of the state in many Member States, thus limiting possibilities for the application of binding legal or policy measures as levers for boosting further progress. On average, citizens are able to access electronic health records data from half of all assessed healthcare provider types, leaving a large gap to be closed until 2030.

While 23 Member States deploy authentication systems using a notified eID scheme based on two-factor authentication, 13 of those have (pre-)notified their eID and are compliant with the eIDAS Regulation. Only four report that they require different means of authentication for citizens to access their electronic health data. The national notification and standardised procedure for the use and governance of eID schemes in 23 out of 27 Member States is already a promising resumé. However, to support harmonisation and acceptance of the various identification schemes deployed throughout the EU for the many digitised public services available and to be made available to citizens in the future, the gap towards eIDAS-compliant eID schemes has yet to be bridged for over half of the EU27.

A rather interesting finding is that none of the EU Member States report to provide access via mobile applications only. Most Member States started to develop online portals with secure authentication mechanisms and developed an app to support mobile access at a later point in time. 12 Member States have already done so, 14 provide access with an online portal only.

The sub-indicator on the percentage of the national population which is technically able to access electronic health records shows the second-best performance in this benchmark overall. The vast majority of citizens (>80%), including minors, in 18 Member States is able to access their health data, mirroring the significant efforts and progress undertaken by the relevant authorities across the EU towards the digital transformation of the health and care sector. In three Member States, only a minority of citizens (<20%) are facilitated with access as of 2022. This circumstance reinforces the need for a more complex monitoring framework that takes into account relevant indicators that go beyond the technical roll-out or availability of an access service for citizens, as full access also depends on what data can be accessed and whether all citizens, including disadvantaged people such as elderly and people with disabilities, have the opportunity to exercise their rights through additional support mechanisms.

Iceland and Norway perform better than the EU27-average regarding access technology and coverage, providing 80-100% of citizens with secure access to health data from the majority of public healthcare providers and some providers in the private sector. While Iceland employs an eIDAS-(pre-)notified eID for its national online portal, Norway requires its citizens to authenticate with a nationally notified eID scheme whenever access to electronic health records data is sought via online portal(s) or mobile app(s).

Access opportunities for certain categories of people

The study defines three key functionalities that should be available to all citizens in the EU if the Digital Decade target of 100% citizens' access to electronic health data is to be achieved in a meaningful way. Such functionalities require a legal ground to be implemented and technical development efforts to be realised.

Firstly, legal guardians should be able to access the health data on behalf of their assigned wards. This is both legally backed-up and technically possible in 19 Member States, while another five have at least established the legal ground to implement such a functionality in the future. Such efforts are yet to be undertaken in three Member States (Ireland, Portugal, Sweden).

Secondly, citizens, in particular the elderly, should be able to designate and authorise another person to access electronic health data on his or her behalf. In our ageing societies, informal care and nursing relationships tend to be the rule rather than the exception when demand surpasses supply. Given a proper authorisation is in place, informal carers in 14 Member States can access the electronic health data of another individual, whereas in Romania it is possible without a specific legal basis in place. Eight Member States (Cyprus, Bulgaria, Czechia, Greece, Italy, Portugal, Slovenia, Slovakia) have not yet developed a technical solution that supports such a functionality, while four (France, Croatia, Ireland, Sweden) did not report any efforts in this regard.

Lastly, there should be support measures in place for disadvantaged citizens or those who experience issues trying to make effective use of their access rights from public or private institutions. In total, 20 Member States report to have enshrined such support measures legally and offer these as services to their citizens, while such services are yet to be implemented legally and technically in three Member States (Czechia, Greece, Ireland). Luxembourg and the Netherlands report to offer such services without legal bases supporting or mandating such services. The most common support mechanisms are online FAQs and guidelines and real-time remote assistance via the phone or online.

In addition to these mechanisms, access to electronic health data follows international guidelines on web accessibility in only 14 EU27 Member States. Thus, about half of the EU27 has not realised the stipulations of the Directive (EU) 2016/2102 (Web Accessibility Directive) in the context of digital access services to health data for citizens. The study could not uncover specific reasons as to why the implementation of respective guidelines is lacking in those Member States. However, such a great degree of non-compliance with the Directive should be taken as a warning signal that equal access opportunities for all citizens in the web is not fully guaranteed across the EU.

In comparison to the EU27, Iceland lags behind in ensuring equal access opportunities, whilst Norway is much more progressed. The main factors of influence here are the fact that Iceland's online portal does not comply with the Web Accessibility Directive and a lack of implemented support measures for disadvantaged groups and third-party access to data for authorised persons.

Gaps towards 100% citizens' access to electronic health records data by 2030

An average measure of citizens' access of 72% across the EU27 already is a respectable result for the first baseline assessment. However, there remain certain gaps that need to be closed until 2030 in order to reach the Digital Decade e-health target. The study team identified these gaps from carefully analysing the monitoring data and taking into account current technical and political efforts on an EU-level. The 'Key insights towards 100% citizens' access to electronic health records in the EU' section 3 of this report translates the identified gaps into tangible study outputs to support policymakers and connects the findings from the data analysis with the wider policy field.

Citizens' access to health data still varies greatly between EU Member States in terms of regulation, security, user rights, and visible data sets leading to a fragmented EU picture. Member States and institutions are increasing their efforts to accelerate and advance secure and interoperable electronic health data infrastructures that enable health data access and use. All in all, the current diagnosis on the status of citizens' access to their electronic health records is at a satisfactory starting point, although gaps remain where policy interventions could be opportune and deliver a boost towards the target of 100% citizens' access until 2030 (see section 3 for insights into closing identified gaps):

- Electronic results and reports, in particular medical imaging reports, hospital discharge reports and laboratory test results to some extent, are the least accessible category of electronic health records data where citizens in most EU27 Member States are still facing

'data gaps'. Until 2030, Member States would need to extend the range of accessible electronic health data that is also up to date. This minimum set of health data shall not only include health records summary data, ePrescription and eDispensation data or electronic lab results, but also hospital discharge reports as well as imaging reports and medical imaging (Bulgaria, Cyprus, Czechia, Denmark, Spain, Finland, France, Greece, Croatia, Hungary, Ireland, Italy, Lithuania, Malta, Netherlands, Poland, Portugal, Romania, Sweden, Slovakia);

- Despite the efforts of the eIDAS Regulation to harmonise authentication schemes across the EU27, half of all Member States are yet to notify their schemes on EU-level leaving a **'harmonisation gap'** for secure and mutually recognised access to electronic health data (Cyprus, Czechia, Denmark, Finland, France, Greece, Hungary, Ireland, Luxembourg, Malta, Portugal, Romania, Slovenia, Slovakia);
- The share of private healthcare provider types that are connected to data infrastructures and supply relevant health data for citizens in the EU27, in particular outside the primary and secondary care sector, is low. This creates a **'data supply gap'** and a need for cooperation between Member States and the private providers (Austria, Czechia, Germany, France, Ireland, Italy, Luxembourg, Malta, Netherlands, Portugal, Romania, Sweden, Slovakia);
- Half of studied Member States do not guarantee equitable access opportunities through compliance with the Directive (EU) 2016/2102 (Web Accessibility Directive) resulting in a **'digital equity gap'** for disadvantaged groups of citizens across the EU27 (Cyprus, Estonia, Germany, France, Greece, Hungary, Ireland, Luxembourg, Latvia, Portugal, Romania, Slovenia, Slovakia).

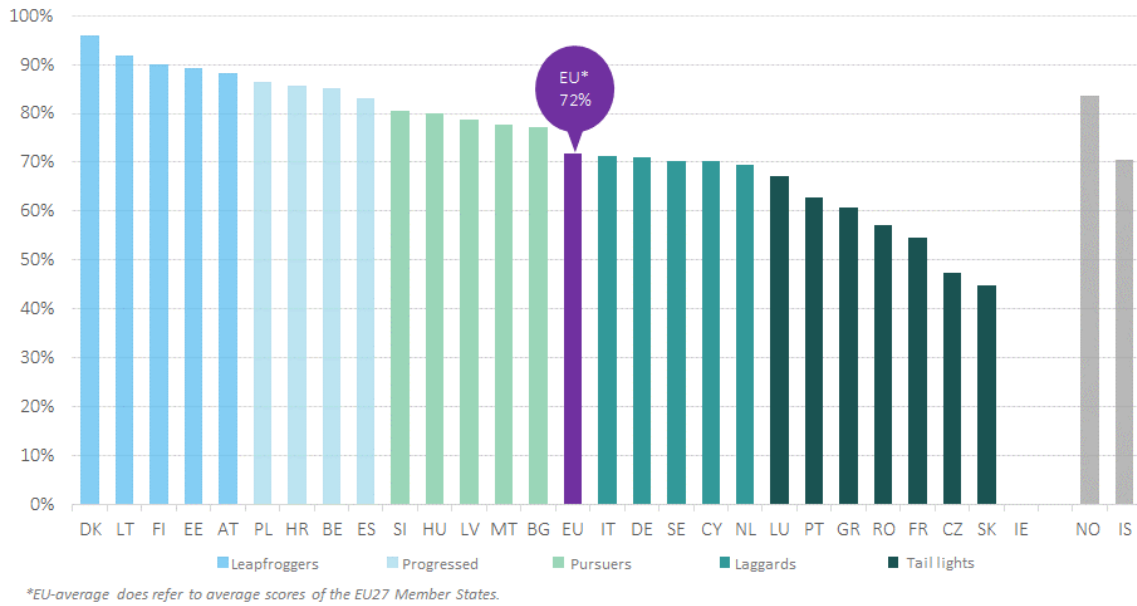
Citizens' access to their electronic health records (composite %-score) - country benchmark

Across the EU27, Member States with similar scores in the e-health composite indicator can be split into five groups (Figure 6). *'Leapfroggers'* are the European top five leaders: Denmark (96%), Lithuania (92%), Finland (90%), Estonia (89%) and Austria (88%). In these Member States, access to electronic health records is technologically enabled for a large proportion of the national population with mostly comprehensive access to health data, secure means of authentication and measures to facilitate equitable access opportunities for all citizens.

These frontrunners are closely followed by Poland (86%), Croatia (86%), Belgium (85%) and Spain (83%), labelled as *'Progressed'* Member States. Scoring just above the EU27-average is the group of *'Pursuers'*, which includes Slovenia (80%), Hungary (80%), Latvia (79%), Malta (78%) and Bulgaria (77%).

The largest group of Member States, the *'Laggards'*, reaches an e-health composite indicator score closely below the EU27-average. This group comprises Italy (71%), Germany (71%), Sweden (70%), Cyprus (70%), the Netherlands (69%) and Luxembourg (67%). Compared to the other EU Member States, six currently lag behind in their efforts of facilitating citizens' access to electronic health records. This group of *'Tail lights'* includes Portugal (63%), Greece (61%) Romania (57%), Czechia (47%), Slovakia (45%) and Ireland (0%), the latter currently not having an electronic access service for citizens in place. In addition to EU27 Member States, Norway and Iceland reach a composite score of 84% and 70%, respectively.

Figure 6. Citizens’ access to their electronic health records in the EU (composite score), 2022



The e-health composite scores and respective rankings of the EU27+2 is presented in Table 2 below.

Table 2. EU performance on citizens' access to their electronic health records (composite scores), 2022

Country name	Composite score (%)*	Country ranking #	Country name	Composite score (%)*	Country ranking #
EU27**	72	-	Italy	71	#15
Austria	88	#5	Latvia	79	#12
Belgium	85	#8	Lithuania	92	#2
Bulgaria	77	#14	Luxembourg	67	#20
Croatia	86	#7	Malta	78	#13
Cyprus	70	#18	Netherlands	69	#19
Czechia	47	#25	Poland	86	#6
Denmark	96	#1	Portugal	63	#21
Estonia	89	#4	Romania	57	#23
Finland	90	#3	Slovakia	45	#26
France	54	#24	Slovenia	80	#10
Germany	71	#16	Spain	83	#9
Greece	61	#22	Sweden	70	#17
Hungary	80	#11	Iceland	70	-
Ireland	0	#27	Norway	84	-

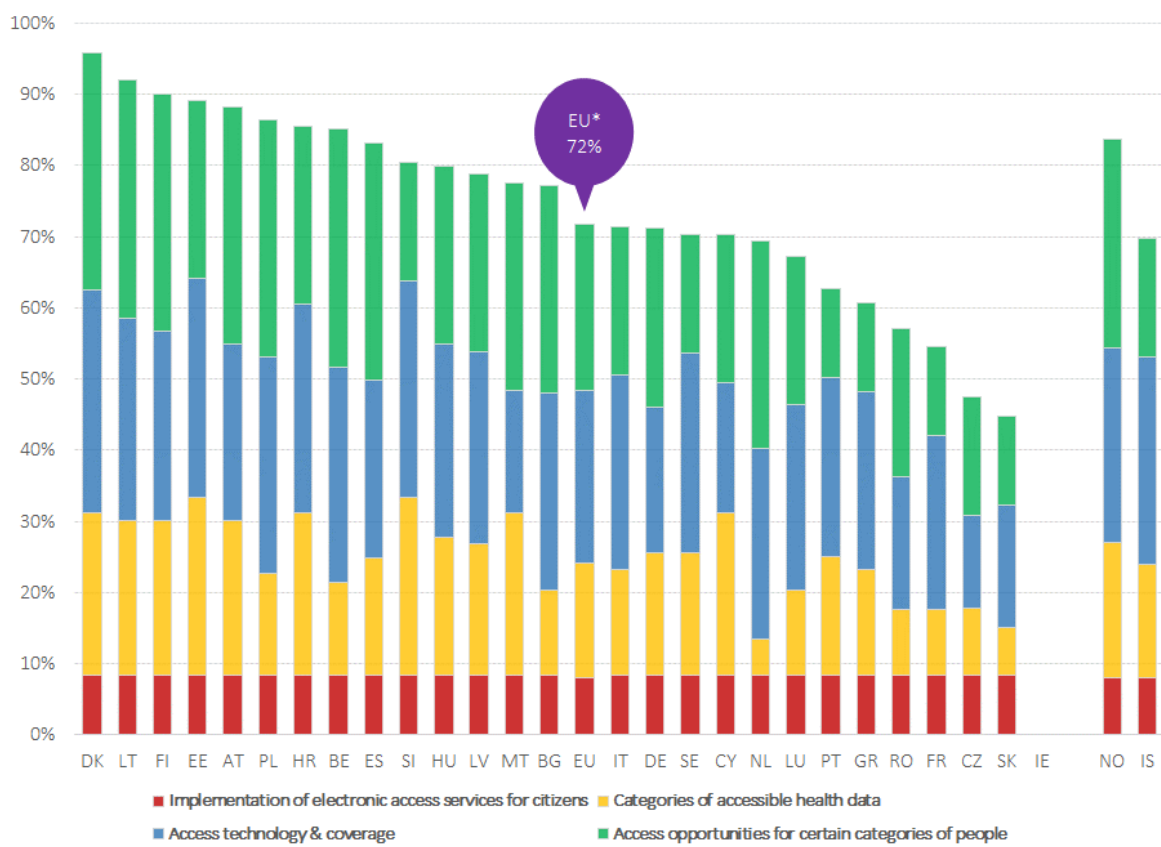
*Values are rounded to the nearest whole digit.
**EU-average does refer to average scores of the EU27 Member States.

Figure 7 below presents the e-health composite indicator as a summative composition of the four framework layers to depict how much each layer contributes to the overall composite per country.

While all Member States apart from Ireland have implemented an electronic access service, scores in the other framework layers range widely between Member States, particularly regarding categories of accessible health data and access opportunities. This way, the relative status of each layer can be identified per country and allows for comparison of progress with historical data in the future.

As a general observation, most Member States perform better in ‘Access technology and coverage’ (blue bars) and ‘Access opportunities for certain categories of people’ (green bars) compared to ‘Categories of accessible health data’ (yellow bars). Hence, technical prerequisites that facilitate access are well developed whereas the actual scope of accessible health data is rather moderate as of 2022. In the following four sections, the results for each framework layer are reported in further detail.

Figure 7. Citizens’ access to electronic health records in the EU (stacked layer scores), 2022



*EU-average does refer to average scores of the EU27 Member States.

2.2.1 Implementation of electronic access services for citizens

At a glance: Implementation of electronic access services for citizens in EU27 Member States

With the exception of Ireland, all EU27 Member States for which data are available have some sort of electronic access service for citizens in place to access their health data (EU27-average score: 96 out of 100). Three in four Member States with an access service have implemented at least one access service at national level. With decentralised healthcare systems, the regions in Spain, Italy and Sweden currently provide electronic access services, while the Netherlands and Czechia are the only studied Member State where such services are offered by healthcare providers. The scope and content of citizens’ electronic health records may vary between regions or healthcare providers, but such differences could not be captured in detail by respondents during the data collection.

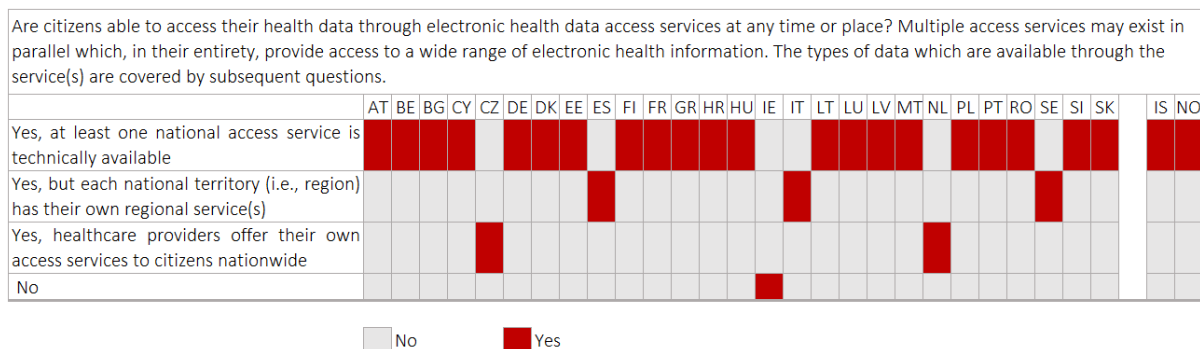
Both non-EU countries, Norway and Iceland, developed national access services to health data for their citizens.

The results for the first layer of the framework on the implementation of electronic access services for citizens are reported in the figure below. This layer is composed of one sub-indicator, reflecting the technical ability to access electronic health records through an online access service or a combination of multiple access services. Such services can have a national or regional scope or may also be offered to citizens nationwide by individual healthcare providers. The service itself may be offered through an online portal or mobile application (see section 2.2.3 for details). With only Ireland not having an electronic access service to electronic health records for citizens in place, the EU27-average score for this framework layer is the highest among the four layers, reaching 96 out of 100 points.

Individual country responses to the sub-indicator in this layer are presented in the heatmap below. Respondents in 21 EU27 Member States have stated that citizens can retrieve health data through at least one national access service. The type of electronic access service deployed may reflect the organisation of the healthcare system. This is the case for Sweden, Spain and Italy, where each national territory (i.e., region) has its own regional service for citizens to access their electronic health records. Potential regional differences in these services were not captured during the baseline data collection. In the Netherlands and Czechia, electronic health records are accessible to citizens through services offered directly by healthcare providers.

Iceland and Norway have both implemented a national access service for citizens.

Figure 8. Implementation of electronic access services for citizens in the EU, 2022



2.2.2 Categories of accessible health data

At a glance: Categories of accessible health data in EU27 Member States

Across the EU27 Member States, the categories of health data that citizens can access in their electronic health records varies. With an EU27-average score of 64 out of 100, this framework layer lags generally behind, indicating that there is room for further progress in many Member States. Estonia and Slovenia are leading the way, making accessible and frequently updating all considered health records summary data, ePrescription and eDispensation information, electronic laboratory test results, hospital discharge reports, medical imaging reports and medical images. Whilst other electronic data on administrative information, medicines, ePrescription/eDispensation are widely accessible across Member States, the most prevalent gaps concern updated information on medical devices and implants (available in eight Member States) and updated medical images (available in three Member States). Hospital discharge reports and laboratory test results are the most available types of electronic reports and results. However, five Member States do currently not make available any electronic results and reports, including Ireland where no access service for citizens is currently in place.

Iceland and Norway reach a layer score for categories of accessible health data slightly above the EU27-average. Apart from diagnoses, medical devices and implants as well as procedures data, citizens in both non-EU countries have access to a broad range of updated electronic health records data.

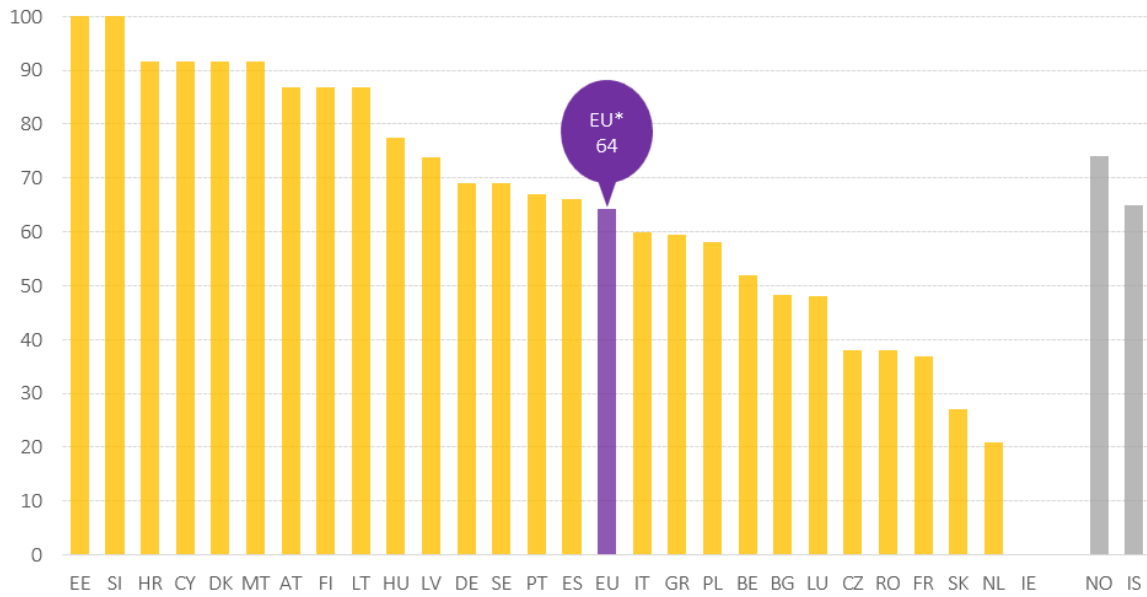
The layer on the types of accessible health data categories considers three broad categories: health records summary data, ePrescription and eDispensation information, as well as electronic results and reports. The data captured by the three sub-indicators are derived from the eHealth Network guidelines for Member States. Electronic health records data should be accessible for citizens through at least one nationwide electronic health records data online access service and can be made available in various formats as PDF files or as machine-readable data based on semantic interoperability standards. If such data is updated timely, i.e., within a few hours or days following each care episode or dispensation event, this makes the available data more valuable and meaningful.

Estonia and Slovenia have enabled citizens' access to all updated electronic health records data considered relevant for this study, positioning the Member States first in the ranking. On the other hand, the types of health data categories accessible to citizens via healthcare providers in the Netherlands are limited, positioning the country second-to-last, before Ireland without an electronic access service. With an EU27-average score of 64 out of 100, Member States score overall the lowest in this framework layer. This underlines that increased efforts are needed across many Member States to expand the scope of the types of data accessible by citizens as well as the granularity of such data.

Norway performs better than the EU27-average in this layer (74 out of 100), whilst Iceland's layer score (65 out of 100) is just above the EU27-average.

The country responses for each type of data category are presented in the following sub-sections.

Figure 9. Scores for categories of accessible health data in the EU, 2022



*EU-average does refer to average scores of the EU27 Member States.

Table 3. EU performance on categories of accessible health data, 2022

Country name	Layer score	Country ranking #	Country name	Layer score	Country ranking #
EU27**	64	-	Italy	60	#16
Austria	87	#7	Latvia	74	#11
Belgium	52	#19	Lithuania	87	#9
Bulgaria	48	#20	Luxembourg	48	#21
Croatia	92	#3	Malta	92	#6
Cyprus	92	#4	Netherlands	21	#26
Czechia	38	#22	Poland	58	#18
Denmark	92	#5	Portugal	67	#14
Estonia	100	#1	Romania	38	#23
Finland	87	#8	Slovakia	27	#25
France	37	#24	Slovenia	100	#2
Germany	69	#12	Spain	66	#15
Greece	60	#17	Sweden	69	#13
Hungary	77	#10	Iceland	65	-
Ireland	0	#27	Norway	74	-

*Values are rounded to the nearest whole digit.

**EU-average does refer to average scores of the EU27 Member States.

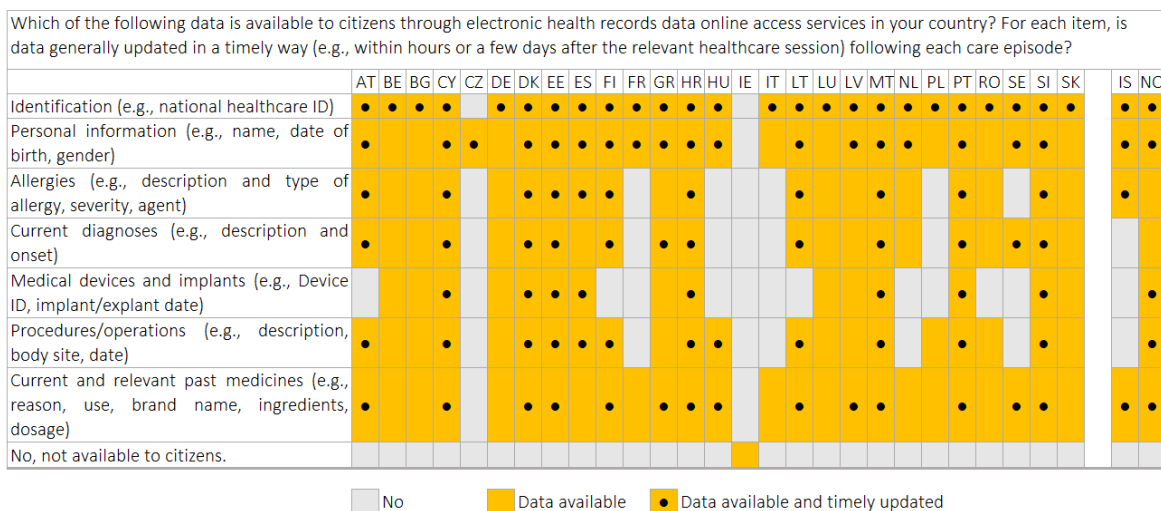
Electronic health records summary data

Overall, the majority of EU27 Member States make available most of the electronic health records summary data considered in this study, and such data is also usually updated within a few hours or days following a care episode.

Specifically, updated identification data (e.g., national healthcare ID) is accessible to citizens in all Member States with an electronic access service, apart from Czechia. Personal information (e.g., name, date of birth, gender) is accessible to citizens in all EU27 Member States with an access service, and, of those, 18 Member States update such information frequently. Data regarding allergies (e.g., description and type of allergy, severity, agent) is accessible to citizens in 20 Member States, of which eleven report that this information is timely updated. Data on current diagnoses (e.g., description and onset) is accessible to citizens in 21 Member States, of which, 12 report timely updates. Information on medical devices and implants (e.g., device ID, implant/explant date) is accessible to citizens in 15 EU27 Member States, with eight Member States providing timely updates on such information. Data on procedures and operations (e.g., description, body site, date) is accessible to citizens in 21 Member States, of which 12 report frequent updates of such data. Finally, information on current and relevant past medicines (e.g., reason, use, brand name, ingredients, dosage) is accessible to citizens in all EU27 Member States with an access service apart from Czechia. Such information is frequently updated in 14 Member States.

Norway makes available all electronic health records summary data for citizens. Only information on allergies and current diagnoses are not frequently updated. In Iceland, citizens have access to updated information for administrative purposes, allergies and medicines.

Figure 10. Available and timely updated electronic health records summary data in the EU, 2022



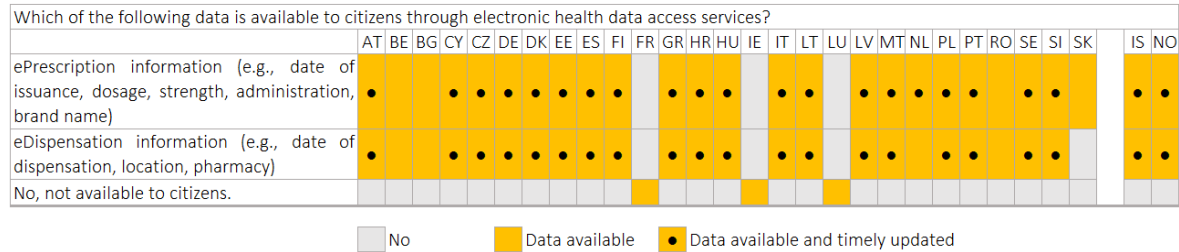
ePrescription/eDispensation data

Overall, ePrescription and eDispensation data is available to citizens with frequent updates in almost all EU27 Member States, reflecting the combined efforts at country and EU-level towards facilitating the cross-border exchange of electronic prescription information.

Specifically, ePrescription information (e.g., date of issuance, dosage, strength, administration, brand name) is accessible to citizens in 24 Member States, and out of those 20 Member States report timely updating the data. In parallel, eDispensation information (e.g., date of dispensation, location, pharmacy) is accessible to citizens in 23 Member States, of which a timely update of the data is possible in 19 Member States. Apart from Ireland where no access service has been implemented thus far, only France and Luxembourg have neither made available ePrescription nor eDispensation information to citizens nationwide. Further, Slovakia does currently not make available eDispensation information to citizens in their electronic health records, although ePrescription data is accessible.

Both ePrescription and eDispensation information is available and timely updated for citizens in Iceland and Norway.

Figure 11. Available and timely updated ePrescription/eDispensation data in the EU, 2022



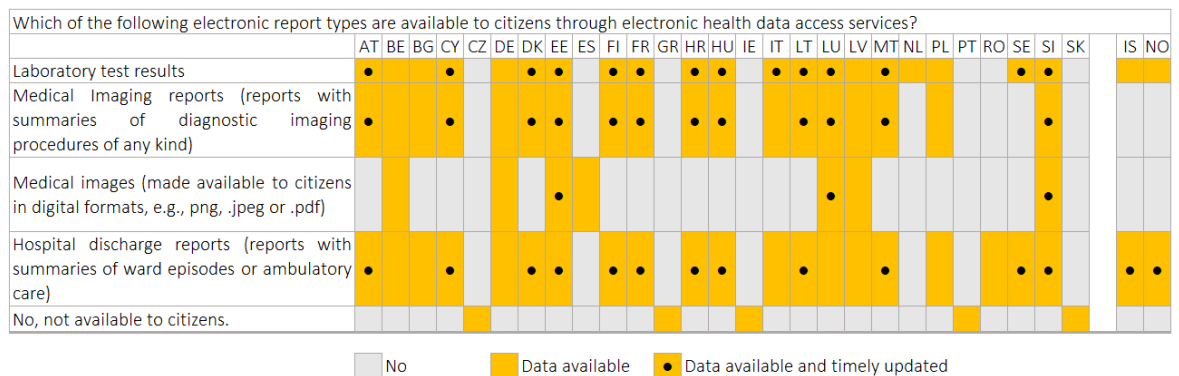
Electronic results and reports

The category of electronic results and reports shows the largest gaps among all considered categories across EU27 Member States, underlining that many Member States could benefit from prioritising measures to support electronic report formats for citizens. Gaps have especially been identified for medical images, which are only accessible to citizens in digital formats (e.g., png, .jpeg, or .pdf) in seven EU27 Member States, out of which three (Estonia, Luxembourg, Slovenia) report timely updating this information. In contrast, electronic laboratory test results and hospitals discharge reports are the most frequently accessible types of electronic results and reports. Laboratory test results are accessible to citizens in 20 EU27 Member States, and 14 note timely updating such results.

Hospital discharge reports (i.e., reports with summaries of ward episodes or ambulatory care) are also accessible to citizens in 20 Member States, of which 12 report timely updating such reports. Medical imaging reports (i.e., reports with summaries of diagnostic imaging procedures of any kind) are accessible to citizens in 18 Member States, of which 12 report timely updating the data. Five Member States (Czechia, Greece, Portugal, Ireland, Slovakia) note that no electronic results or reports have been made available to citizens in their electronic health records yet.

Citizens in Norway and Iceland have access to laboratory test results and updated hospital discharge reports.

Figure 12. Available and timely updated electronic results and reports in the EU, 2022



2.2.3 Access technology and coverage

At a glance: Access technology and coverage in EU27 Member States

With an EU27-average score of 73 out of 100 in this framework layer, **Member States** are overall progressing well concerning access means and functionalities, population coverage and the care sectors that supply health data to citizens' electronic health records. Denmark, Estonia, Slovenia, Belgium and Poland are the top five European frontrunners in this regard, scoring above 90 out of 100.

Almost half of the EU27 Member States require citizens to use a secure eID scheme (pre-)notified under the eIDAS Regulation (48%) and facilitate ease of access through both mobile app(s) and online portal(s) (44%). Around 67% of EU27 Member States cover 80-100% of the national population with electronic health records. Thus, the nationwide roll-out is to be expanded in nine Member States.

In Denmark, Estonia, Finland and Greece all types of the considered public and private healthcare providers are supplying relevant health data to citizens' electronic health records. Pharmacies supply information in almost all EU27 Member States (85%). Whilst public primary and secondary care providers are generally well connected, there are clear gaps for private and public geriatric nursing homes, mental health and rehabilitation facilities.

Iceland and Norway perform better than the EU27-average regarding access technology and coverage, providing 80-100% of citizens with secure access to health data from the majority of public healthcare providers and some providers in the private sector. While Iceland employs an eIDAS-(pre-)notified eID for its national online portal, Norway requires its citizens to authenticate with a nationally notified eID scheme whenever access to electronic health records data is sought via online portal(s) or mobile app(s).

This layer is composed of four sub-indicators, assessing whether citizens are required to log in to online portal(s) and/or mobile app(s) to access their electronic health records using a secure mean of authentication, what proportion of the national population, including the elderly and minors, can technically access their electronic health records (i.e., not actual use), and which healthcare providers are connected to the data infrastructure and contribute relevant health data for citizens' electronic health records.

On average, EU27 Member States reach a layer score of 73 out of 100, suggesting favourable progress of Member States with regard to access technologies, eID schemes, and roll-out among the national population and healthcare providers. Denmark performs best with a layer score of 94, closely followed by four other Member States with scores >90 (Estonia, Slovenia, Belgium, Poland). In total, more than two-thirds of Member States score above the EU27-average, implying the negative impact on the average score from a few Member States who lag behind. Specifically, excluding Ireland where no access service is currently available, seven EU Member States score below the EU27-average, the last being Czechia with a layer score of 39 out of 100.

Norway and Iceland score both above the EU27-average layer score, reaching 82 and 88 out of 100, respectively. Details on the sub-indicators in this layer are provided in the following sections.

Figure 13. Scores for access technology and coverage in the EU, 2022

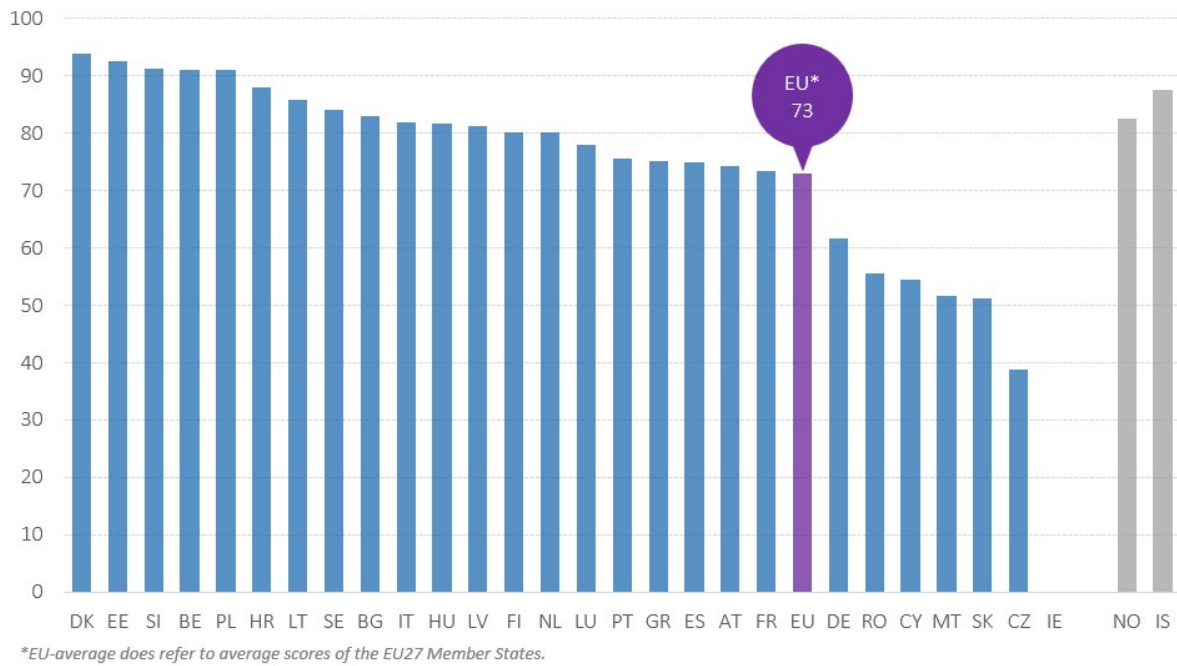


Table 4. EU performance on access technology and coverage, 2022

Country name	Layer score	Country ranking #	Country name	Layer score	Country ranking #
EU27**	73	-	Italy	82	#10
Austria	74	#19	Latvia	81	#12
Belgium	91	#4	Lithuania	86	#7
Bulgaria	83	#9	Luxembourg	78	#15
Croatia	88	#6	Malta	52	#24
Cyprus	54	#23	Netherlands	80	#14
Czechia	39	#26	Poland	91	#5
Denmark	94	#1	Portugal	76	#16
Estonia	93	#2	Romania	56	#22
Finland	80	#13	Slovakia	51	#25
France	73	#20	Slovenia	91	#3
Germany	62	#21	Spain	75	#18
Greece	75	#17	Sweden	84	#8
Hungary	82	#11	Iceland	88	-
Ireland	0	#27	Norway	82	-

*Values are rounded to the nearest whole digit.

**EU-average does refer to average scores of the EU27 Member States.

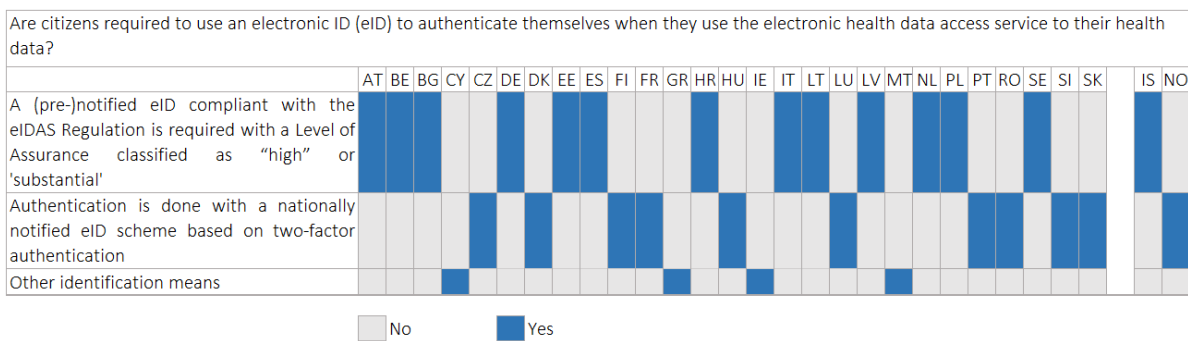
Access to electronic health records with an eID

Of all responding EU27 Member States, 13 Member States require citizens to use a (pre-)notified eID compliant with the eIDAS Regulation with the Level of Assurance classified as ‘high’ or ‘substantial’.

Ten EU27 Member States report that authentication is currently done with a nationally notified eID scheme based on two-factor authentication. Apart from Ireland without an access service, Cyprus, Greece and Malta note that other authentication means have been implemented in order to grant citizens access to their electronic health records via mobile apps and/or online portals. These results suggest that ensuring citizens’ secure access to electronic health records is generally well facilitated across the EU27 as part of overall digitisation of public services. Nevertheless, efforts towards harmonised identification and authentication schemes following the eIDAS Regulation could be further supported.

Whilst Iceland requires citizens to use a (pre-)notified eID compliant with the eIDAS Regulation with a Level of Assurance classified as ‘high’ or ‘substantial’, Norway has implemented a nationally notified eID scheme based on two-factor authentication.

Figure 14. Access to electronic health records data with an eID in the EU, 2022

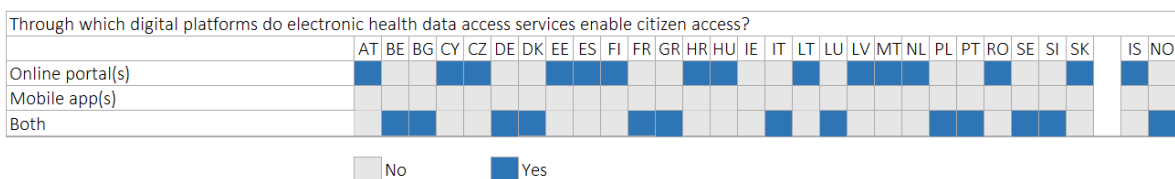


Access via an online portal or mobile application

Online portals are the most frequent type of digital platform in the EU27, being provided by 14 Member States. Citizens in 12 Member States can use both online portals and mobile apps to make use of their electronic health records. Accordingly, no Member State solely relies on dedicated mobile apps suggesting that these are mostly developed as an addition to ease mobile access after an online portal has been successfully implemented.

Citizens in Iceland can access their electronic health data via an online portal, and Norwegian citizens can additionally use mobile applications to access their electronic health data.

Figure 15. Access via an online portal or mobile application in the EU, 2022

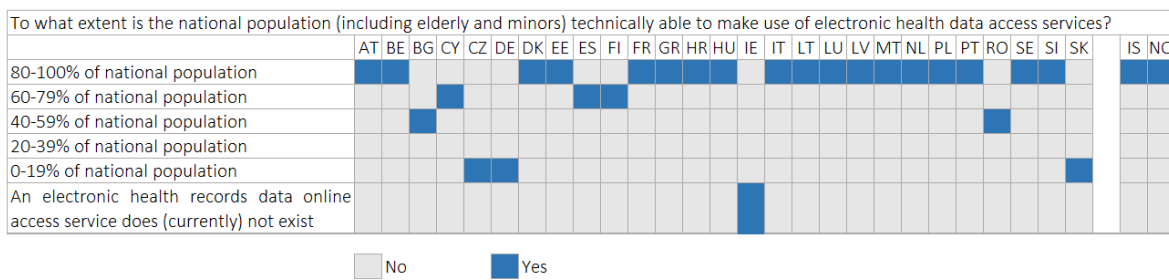


Percentage of national population able to access their electronic health records

This sub-indicator reports on the proportion of the national population, including the elderly and minors, that is technically able to access and make use of their electronic health records (i.e., not actual use). In more than two-thirds of EU27 Member States (18), 80-100% of the national population are technically able to access their electronic health records through the provided access service. Three Member States (Cyprus, Spain, Finland) report a coverage of 60-79% of the national population, Romania and Bulgaria state 40-59% of the national population. In addition to Ireland without an access service, the roll-out of the access service is in early stages and ongoing in Czechia, Germany and Slovakia, where only 0-19% of the national population is technically able to make use of their electronic health records. Hence, the technical basis for facilitating citizens’ nationwide access to electronic health records at any time and place is overall established across the EU, and further country activities can focus on addressing other aspects of citizens’ access, such as tackling potential access barriers and gaps in available health data.

Iceland and Norway have rolled-out their access services nationwide, covering 80-100% of the national population.

Figure 16. Percentage of national population able to access their electronic health records in the EU, 2022



Healthcare providers connected and supplying relevant health data

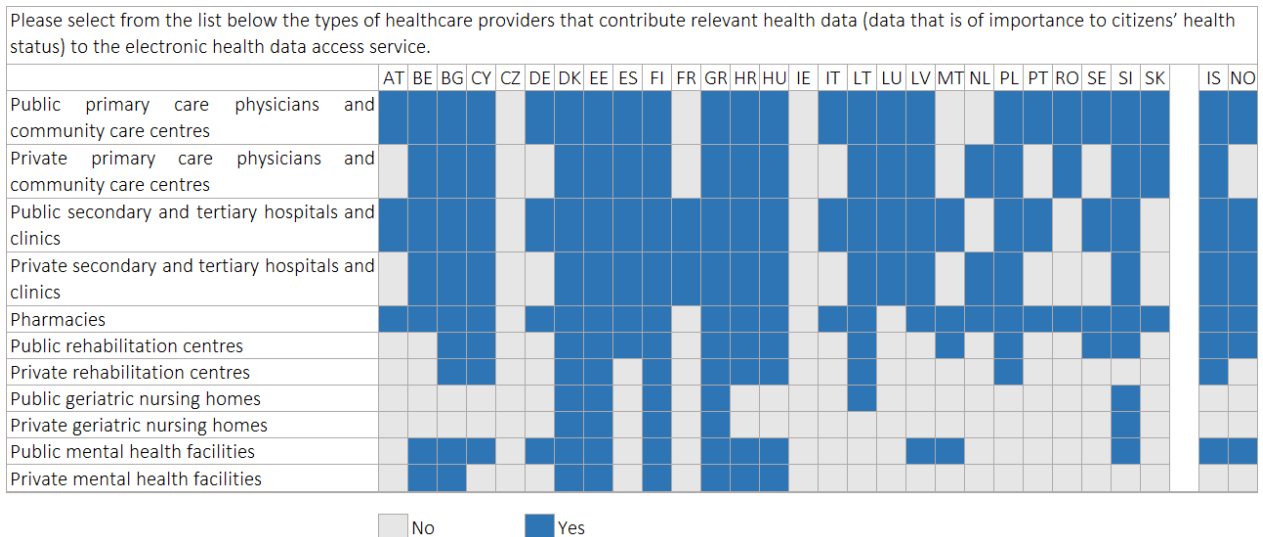
The types of healthcare providers that are connected to the digital infrastructure and contribute relevant health data to the electronic health records accessible by citizens are captured with this sub-indicator. Of all sub-indicators in this framework layer, results for this sub-indicator show generally a rather fragmented picture across EU27 Member States, implying the biggest potential for improvement in this layer. Nevertheless, Denmark, Estonia, Finland and Greece serve as best practice examples, having successfully realised the connection among all healthcare provider types considered in this study.

With most EU27 Member States being advanced in making available ePrescription and eDispensation information, pharmacies are in parallel the healthcare providers most frequently connected across the EU, being the case in 23 Member States. This is followed by public primary care physicians and community care centres, as well as public hospitals and clinics for secondary and tertiary care, all supplying relevant health data to the access service in 22 Member States. Private primary care physicians and community care centres as well as private hospitals or clinics supply relevant health data to citizens in their electronic health records in 18 and 17 Member States, respectively. Public rehabilitation centres contribute data in 14 Member States, and private rehabilitation centres in another ten Member States. In 13 Member States, public mental health facilities are connected to electronic health records infrastructures and make available relevant health data, while private mental health facilities do so in eight Member States. Public and private geriatric nursing homes are the least connected across EU27 Member States, contributing data in

six and in five Member States, respectively. None of the healthcare provider types considered have been connected to the infrastructure in Czechia and Ireland as of December 2022.

In Iceland, only public and private geriatric nursing homes as well as private mental health facilities are not contributing relevant health data to the national access service. In Norway, this is the case for private primary care providers, rehabilitation centres, public and private geriatric nursing homes, and private mental health facilities.

Figure 17. Healthcare providers connected and supplying relevant health data in the EU, 2022



2.2.4 Access opportunities for certain categories of people

At a glance: Access opportunities for certain categories of people in EU27 Member States

Seven EU27 Member States (Austria, Belgium, Denmark, Finland, Lithuania, Poland, Spain) reach full scores for legally and technically implementing measures to ensure citizens' equitable access to electronic health records. In contrast, eight Member States, including Ireland without an access service, score half or less than half of the points in this layer, far below the EU27-average (70 out of 100), underlining that efforts towards equitable access could be prioritised in these Member States. Legal provisions for legal guardians and other authorised individuals to access electronic health records on another person's behalf, as well as provisions for citizens to seek assistance in gaining access, are implemented in the vast majority of Member States. However, the technical implementation thereof is still lacking in some cases. Especially web content accessibility should be improved in half of Member States that do currently not follow the Web Content Accessibility Guidelines (WCAG v2.1) as per Directive (EU) 2016/2102 (Web Accessibility Directive).

In comparison to the EU27, Iceland lags behind in ensuring equal access opportunities, whilst Norway is much more progressed. The main factors of influence here are the fact that Iceland's online portal does not comply with the Web Accessibility Directive and a lack of implemented support measures for disadvantaged groups and third-party access to data for authorised persons.

The overall results for the fourth layer of the framework concerns access opportunities for certain categories of people. Composed of four sub-indicators, this layer assesses whether and what

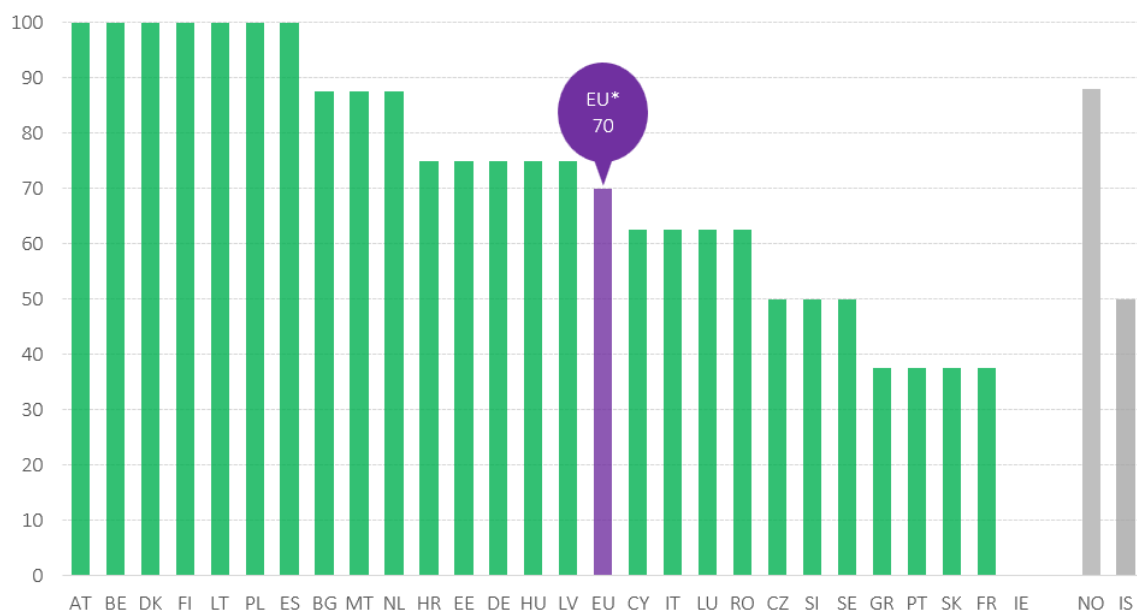
additional measures are provided to ensure that certain categories of people, such as children, elderly or citizens with disabilities, can access their electronic health records. A particular focus is on the provision of a legal basis to provide such measures and the implementation of technical functionalities to make use of the enacted legal rights and principles of equitable access. How can access for children or disabled citizens be guaranteed? In all cases, either legal guardians or authorized persons other than legal guardians (such as informal caregivers) should have the possibility to access the electronic health records on the behalf of the data subject. Especially the elderly or disabled citizens may need assistance when trying to make use of their access opportunities. From an inclusive perspective, this is highly relevant and captured by a third sub-indicator. The sub-indicator is open towards the form of assistance provided. Online access to health data should also be designed in a way that is easily understandable for everyone. Therefore, the last sub-indicator includes compliance of the health data access service(s) with the WCAG v2.1 guidelines following the Directive (EU) 2016/2102 (Web Accessibility Directive).

EU27 Member States score on average 70 out of 100 in this layer, suggesting that more efforts are needed in some Member States to ensure equitable access opportunities to electronic health records for all citizens. Nevertheless, seven EU27 Member States (Austria, Belgium, Denmark, Finland, Lithuania, Poland and Spain) reach full scores in this dimension and thus are considered best practice examples in this aspect of ‘citizen access’. In contrast, eight EU27 Member States reach only half or less than half the full layer score. Apart from Ireland without an access service, especially citizens in Greece, Slovakia, France, and Portugal would benefit from enhanced measures to support equitable access opportunities.

Norway performs well above the EU27-average in facilitating equal access opportunities to electronic health data with a score of 88 out of 100 in this framework layer. In contrast, more measures are needed in Iceland, reaching half of the points in this layer and thus well below the EU27-average.

Details on the sub-indicators in this layer are provided in the following sections.

Figure 18. Scores for access opportunities for certain categories of people in the EU, 2022



*EU-average does refer to average scores of the EU27 Member States.

Table 5. EU performance on providing citizens with additional access opportunities, 2022

Country name	Layer score	Country ranking #	Country name	Layer score	Country ranking #
EU27**	70	-	Italy	63	#17
Austria	100	#1	Latvia	75	#15
Belgium	100	#2	Lithuania	100	#5
Bulgaria	88	#8	Luxembourg	63	#18
Croatia	75	#11	Malta	88	#9
Cyprus	63	#16	Netherlands	88	#10
Czechia	50	#20	Poland	100	#6
Denmark	100	#3	Portugal	38	#24
Estonia	75	#12	Romania	63	#19
Finland	100	#4	Slovakia	38	#25
France	38	#26	Slovenia	50	#21
Germany	75	#13	Spain	100	#7
Greece	38	#23	Sweden	50	#22
Hungary	75	#14	Iceland	50	-
Ireland	0	#27	Norway	88	-

*Values are rounded to the nearest whole digit.

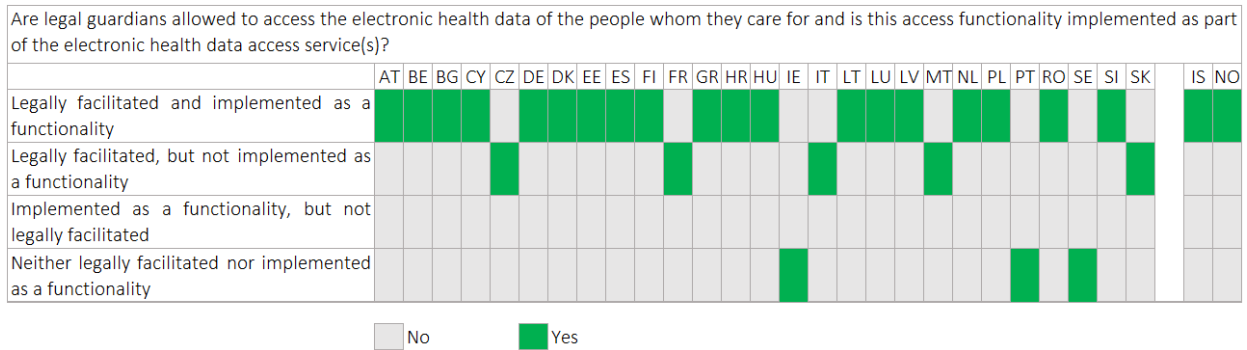
**EU-average does refer to average scores of the EU27 Member States.

Access for legal guardians

The figure below reports whether legal guardians are allowed to access the electronic health records of the people whom they care for, and whether this access functionality is technically implemented. The results show that most of the EU27 Member States are quite advanced in this aspect from a legal and technical point of view: in 19 Member States legal guardians are legally allowed to access the electronic health record of the person they care for, and this is implemented as a functionality. In five Member States (Czechia, France, Italy, Malta, Slovakia) access is legally facilitated, but technical features are not yet implemented. All Member States respondents noted that access for legal guardians is backed by appropriate legal stipulations and under no circumstances possible without a legal ground. Only in Ireland, Portugal and Sweden access to electronic health records for legal guardians is neither legally facilitated nor implemented as a functionality.

Iceland and Norway legally and technically enable legal guardians to access the electronic health data of the people whom they care for.

Figure 19. Access for legal guardians in the EU, 2022

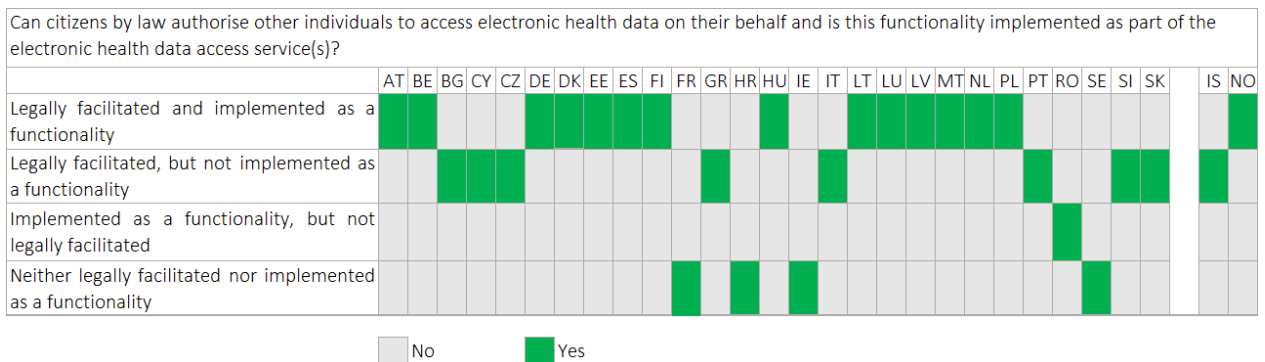


Access for authorised persons

Citizens’ right to authorise other individuals to access their electronic health records on their behalf, and whether this access functionality is technically implemented, is captured with this sub-indicator. The results are rather similar to the previous sub-indicator on access for legal guardians, but some Member States are slightly less advanced in facilitating access to authorised persons. In the majority of EU27 Member States (14), citizens can legally authorise other persons to access their electronic health records, and can also rely on technical functionalities for authorised persons to do so. In eight EU27 Member States, access is legally facilitated but not implemented as a functionality. As an exception in this regard, Romania has not implemented legal provisions but technical features granting access for authorised persons. In four Member States (France, Croatia, Ireland and Sweden), access for authorised persons is neither legally facilitated nor implemented as a functionality.

As was the case for legal guardians, authorised persons in Norway are legally and technically facilitated with access to electronic health data on behalf of the person they care for. In Iceland, only the legal provisions for authorised persons are in place.

Figure 20. Access for authorised persons in the EU, 2022



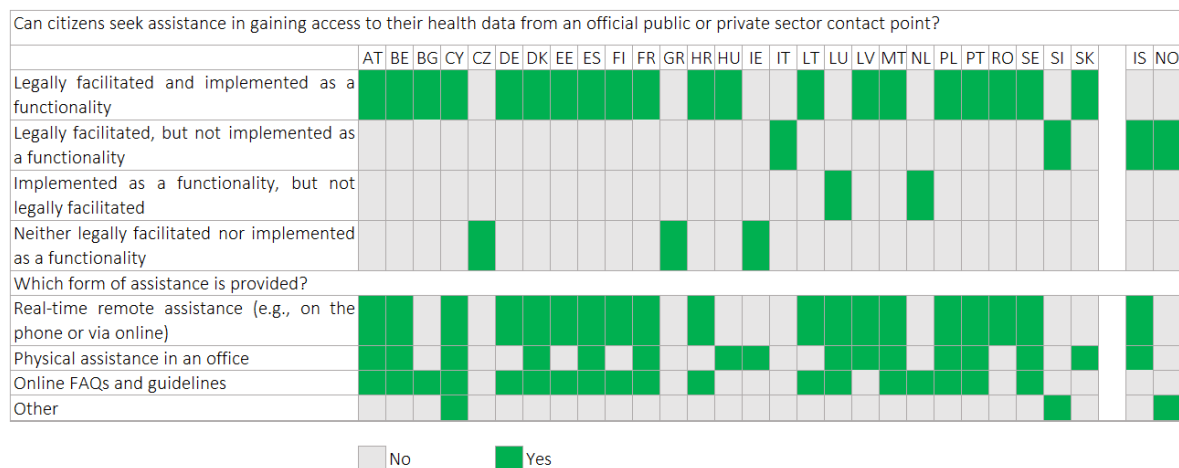
Assistance for disadvantaged groups

The below graph shows in which Member States citizens can seek assistance in gaining access to their electronic health records from an official public or private sector contact point, whether this is implemented as a functionality, and what forms of assistance are provided. Across the EU27, citizens in 20 Member States have the right to seek assistance in gaining access to their electronic health

records, and functionalities for such assistance are technically available. In two Member States, Italy and Slovenia, citizens have the right to seek assistance, but there are no functionalities yet in place for them to do so. In Luxembourg and the Netherlands, seeking assistance is not legally facilitated, but technical features are available. Citizens in Czechia, Greece and Ireland can neither seek assistance on legal grounds, nor have technical features available to do so. Concerning the forms of assistance provided, real-time remote assistance (e.g., via the phone or online) is the most frequently provided across EU27, being available to citizens in 18 Member States. Online FAQs and guidelines as well as physical assistance in an office are also prevalent in 18 and 15 Member States, respectively. Cyprus and Slovenia reported assistance being available by means other than those listed.

Both Iceland and Norway legally enable citizens to seek assistance in gaining access to their electronic health data from official public or private sector contact points. However, the countries have not implemented functionalities in their national access services. In contrast to Norway where other forms of assistance are available, citizens in Iceland can seek remote assistance and physical assistance.

Figure 21. Assistance measures supporting access for disadvantaged groups in the EU, 2022

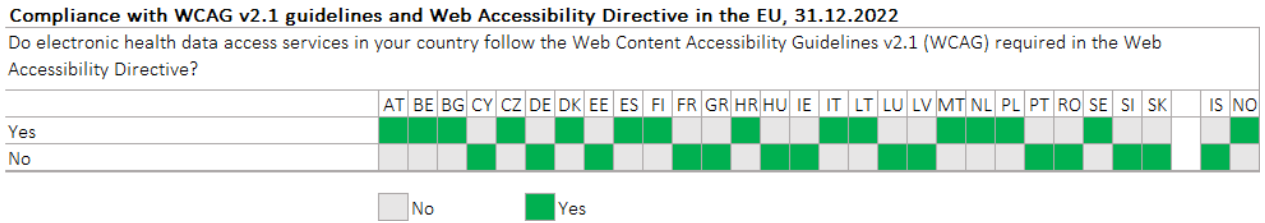


WCAG v2.1 and Web Accessibility Directive compliance

Member States’ compliance with the Web Content Accessibility Guidelines v2.1 (WCAG), as required in the Directive (EU) 2016/2102 (Web Accessibility Directive), is reported below. Only about half of the responding EU27 Member States (14) state that their access service to electronic health records is compliant with WCAG v2.1 guidelines. This underlines that Member States could pay increased attention to ensuring web content accessibility for disadvantaged groups, such as people with disabilities or elderly, as one of the pre-requisites for ensuring principles of equitable access.

This also counts for Iceland whose national access service to electronic health data does not follow the WCAG v2.1 guidelines. In contrast, Norway provides for web content accessibility as required in the Web Accessibility Directive.

Figure 22. Compliance with WCAG v2.1 guidelines and Web Accessibility Directive in the EU, 2022



2.3 Limitations and reflections on the framework

As mentioned in the previous section, a measurement of citizens’ actual use of access services to electronic health records is outside the study’s scope. This is primarily because the total number of accessed records in a given period of time or the number of citizens who accessed their electronic health records online does not allow for meaningful conclusions on the topic of the Digital Decade target on citizens’ access. The reasons for actually using the service should, ideally, be driven by demand, i.e., in the case of illness or the need to check own electronic health records. Therefore, metrics reflecting on the actual usage of such services allow for conclusions on the frequency of said demand and events for a subset of the population (i.e., those being sick or in temporary demand to consult their electronic health records), but not for the population as a whole. Citizens in good health have less reasons to frequently access their data or may object to this concept entirely. As a result, the study team opted to operationalise and measure the supply side of the concept of ‘citizen access to electronic health records’ and avoided any measurement of the actual use of online access services.

3 Key insights towards 100% citizens' access to electronic health records in the EU

This report concludes a study with the objective to develop and execute a monitoring framework to collect data on the Digital Decade target of 100% citizens' access to their electronic health records by 2030 in all EU27 Member States plus Iceland and Norway. It has developed a relevant and efficient survey tool for this purpose and operationalised the concept of 'citizens' access' with four distinct layers, each representing a crucial aspect to describe the situation of citizens' online access to their electronic health records data.

The study has successfully conducted an online survey among Member State representatives of national competent authorities in 29 countries. The report has presented an overview of the baseline data obtained for 12 sub-indicators, four layers and the Digital Decade e-health composite indicator. It has presented the final framework and methodology, and the results of the first baseline data collection to inform developments in the context of the Digital Decade and the DESI. While the country factsheets (see Annex) explore Member State-specific performances and present detailed data, overarching insights for future EU policies are derived from and based on EU-level survey data.

The analysis and further visualisation of the final data allows to go beyond a mere descriptive processing and reporting of the state-of-play on the study topic. As such, descriptive outputs have been the main goal of the study and given the fact that scientific literature on the topic rather scarce, few additional qualitative information could be uncovered to yield sound insights that allow a profound interpretation of the findings. However, based on the overall performance of the 12 sub-indicators, early indications and assumptions can be drawn with regards to topics that may require a more dedicated policy support (sub-indicators where EU Member States score low overall) compared with topics which are already well progressed (sub-indicators with an overall high score across EU Member States). With this perspective in mind, the study team performed an assessment of the results per each sub-indicator and identified six topics which require a closer examination:

- Measuring access beyond technology towards a multi-channel approach;
- Expanding and deepening the categories of accessible health data, in particular electronic results and report documents followed by health records summary data;
- Ensuring harmonised and equally secure access to electronic health records across the EU, in particular through EU-wide notification and eIDAS-compliant national eID schemes;
- Collecting and exchanging best practices and incentives that attract private sector providers in particular to connect to electronic access services;
- Ensuring equitable access to electronic health records in the EU;
- Lessons-learned and capacity building.

Measuring access beyond technology towards a multi-channel approach

Technological access to electronic health data by citizens is widespread across all Member States, being facilitated in all responding EU27 Member States apart from Ireland. The vast majority deploys at least one access service at national level. This is also the case in Norway and Iceland. Nevertheless, there is potential to incorporate additional types of access services facilitating citizens with a multi-channel experience. This expansion might need to be balanced with expanding the type of services available through the available access points. In this regard, the current benchmark provides EU Member States with a four-layered approach (Implementation of electronic access services for citizens; Categories of accessible health data; Access technology and coverage; Access opportunities for certain categories of people) to identify areas to further make progress.

Expanding and deepening the categories of accessible health data

Decades of previous work conducted by the eHealth Network around health records summary data, ePrescription and eDispensation data, electronic results and report data are reflected in the scores of most of the Member States, two reporting a score of 100 (Estonia and Slovenia). Therefore, it is time to advocate for a more granular health data approach on a more detailed level. The European Commission together with Member States already successfully developed and launched the EU COVID passport that allows citizens to travel across Europe in the midst of a pandemic. The availability of more granular health data and the mutual recognition of their electronic health records could facilitate EU citizens with further relevant data for the continuity of care nationally and across borders, ultimately increasing the value of accessible data.

Until 2030, Member States need to extend the range of accessible electronic health data that is also timely updated and up to date. This minimum set of health data shall not only include health records summary data, ePrescription and eDispensation data or electronic lab results but also hospital discharge reports as well as imaging reports and medical imaging.

Ensuring harmonised and equally secure access to electronic health records across the EU

Out of EU27 Member States, 13 have reported to require a (pre-)notified eID compliant with the eIDAS Regulation with a Level of Assurance classified as 'high' or 'substantial' for citizen authentication to access electronic health records. Another ten Member States have at least a nationally notified eID scheme in place. However, Cyprus, Greece, Ireland and Malta either do not require proper eID for authentication or currently employ less secure authentication means. Iceland and Norway deploy secure eID schemes, although only the scheme in Iceland is (pre-)notified under eIDAS. The eIDAS Regulation aims to create a common legal framework for electronic transactions and ensure that they are secure, reliable, and legally binding across all EU Member States. Among others, it sets out rules for electronic identification services. Overall, the eIDAS Regulation is a crucial component of the EU's efforts to create a trusted and secure digital environment and boost the growth of the digital economy across Europe. This clearly entails that Member State authorities facilitate access to the citizens to their health data using recognised eID schemes based on harmonised and secure standards across the EU.

In order to ensure equally secure access to online health data for all citizens in the EU, further assessments are needed to support the transition towards eIDAS-compliant eID schemes in all Member States. Topics to be addressed include current technical or policy barriers that potentially hinder or slow down the notification process, financial issues and on-going plans to initiate the notification process.

Collecting and exchanging best practices and incentives

With a few exceptions, the majority of EU27 Member States have not connected all relevant healthcare provider types to supply relevant health data accessible for citizens. This is especially true for private care providers. A similar situation is observed in Iceland and Norway. While most publicly owned or financed providers can be more or less mandated to use or connect to a new solution, it is difficult to exercise legal force upon private care providers, self-employed or freelancers. A promising approach to ensure a high connection or participation rate are incentives or sanctions coupled to the use or non-use of the respective solutions. The experience with applying such measures across Member States may vary as to the constitutional frameworks of healthcare systems across the EU that determine which measures yield optimal results.

Due to the sheer diversity of healthcare systems and their organization, a one-size-fits-all solution is hardly possible to formulate. However, the exchange of knowledge and experience in on-boarding

private care providers to actively use electronic access services could prove as a valuable source for new approaches for some Member States who are currently showing less progress in this regard. Member States could collaborate with public, and private providers in particular, to assure that at least 60% of healthcare provider institutions in all care sectors are connected to electronic health records data infrastructures that allow citizens access to their data.

Ensuring equitable access to electronic health records in the EU

Currently, citizens in 13 out of EU27 Member States and citizens in Iceland access their health data via an online service that is not compliant with the Directive (EU) 2016/2102 (Web Accessibility Directive). This may result in access barriers that could easily be mitigated. The Directive aims to ensure that websites and mobile applications of public sector bodies are accessible to everyone, including people with disabilities. It requires EU Member States to ensure that public sector bodies' websites and mobile applications comply with the Web Content Accessibility Guidelines (WCAG) 2.1 at level AA. WCAG 2.1 is an internationally recognized set of guidelines for making web content more accessible to people with disabilities, including those who are blind or visually impaired, have mobility impairments, or have cognitive or learning disabilities. The Directive is part of the EU's efforts to create a more inclusive society and ensure that everyone has equal access to information and services, regardless of their abilities or disabilities.

There is a clear need to ensure equal access opportunities to online electronic health records data for all citizens. While this study is only able to highlight the issue and raise awareness for the relevance of the topic, efforts should be made to address this shortcoming on an EU-level in conjunction with the European Commission. Until 2030, all Member States should follow the Web Content Accessibility Guidelines and provide or improve additional support mechanisms for disadvantaged groups, such as access for legal guardians or authorised persons to facilitate equal access opportunities.

Lessons learned and capacity building

While the baseline assessment already yields a respectable EU27-average score of 72% citizens' access, 13 EU Member States rank below the EU27-average with half of them by 10% below average or more. Citizens' access to their electronic health data could be considered as a driver for the overall digital transformation of health systems. In this regard, lessons learned and good practices should be shared through capacity building activities supported by the European Commission and future studies and projects (e.g., policy twinnings). This is of particular interest, as the herein measured citizens' access should be interpreted not as an absolute benchmark to assess the overall digitisation of the healthcare system, but instead as an indication of the overall progress of the digital transformation in the health and care sector, of which citizen access is one aspect among many.

Apart from gaining a better understanding of Member State needs in terms of reaching the Digital Decade target, it is equally important to understand the broader impact of increased citizen access to electronic health data for the health system in general (efficiency, efficacy, sustainability). The identification of benefits of increased digitisation and communication of these to all stakeholders results in a transformation from benefits into actual drivers for further deployment. It is these drivers that will eventually guarantee a wider onboarding and acceptance of transformation among all stakeholders.

This work constitutes a firm steppingstone towards regular gathering and analysis of the information and data which is fundamental for the further development of European as well as national policy and programmes on citizens' access to electronic health records and their empowerment. The collected data and insights can deliver the input needed by further evidence-based policy making,

and for developing and implementing measures to promote enabling and facilitating factors towards the Digital Decade target of 100% citizens' access to their electronic health records in the EU.

