Synopsis Report

Consultation: Transformation Health and Care in the Digital Single Market
Prepared by the European Commission
DG Communications Networks, Content & Technology and DG Health with support from:

College of Europe
Collège d’Europe
This report was drafted by the European Commission with support from

The College of Europe

Experts’ Team
Prof Adam Cygan
Dr Roxana Nedelescu
Ms Martina Francesca Ferracane

Project Management
Ms Cristina Macovei
Ms Alissa Albrechts

Internal identification
SMART 2017/0093
30-CE-0890629/00-41

Legal notice
Neither the European Commission nor any person acting on its behalf is responsible for the use which might be made of the information contained in the present publication. The European Commission is not responsible for the external web sites referred to in the present publication.

The views expressed in this publication are those of the authors and do not necessarily reflect the official European Commission’s view on the subject.

The Publications Office of the European Union.

Catalogue number: KK-04-18-135-EN-N
doi: 10.2759/18589

© European Union, 2018
Reproduction is authorised provided the source is acknowledged.
# Table of Contents

1. **Executive summary** ........................................................................................................... 2
2. **Introduction** ......................................................................................................................... 2
3. **Events and other elements of consultation** ........................................................................... 3
   3.1 Workshop on the General Data Protection Regulation (GDPR) implementation and health data...................................................................................................................... 3
   3.2 eHealth Stakeholder Group .................................................................................................... 3
   3.3 eHealth Network ................................................................................................................... 3
   3.4 Roadmap comments and Roadmap website ........................................................................... 3
   3.5 eHealth Conference Tallinn ................................................................................................... 4
   3.6 Council Conclusions on Health in the Digital Society ............................................................ 4
4. **Online public consultation: overview of respondents** ........................................................... 4
   4.1 Online public consultation: access to and use of personal data concerning health ................................................................................................................................. 6
   4.1.1 Propensity for health data sharing ...................................................................................... 6
   4.1.2 Major barriers to electronic access and sharing of health data ........................................ 8
   4.2 Online public consultation: making use of personal data to advance health research, disease prevention, treatment and personalised medicine ........................................ 11
   4.2.1 Support for sharing health data for research purposes ..................................................... 11
   4.2.2 Use of data and digital tools to advance research in the EU .............................................. 12
   4.3 Online public consultation: promoting uptake of digital innovation to support interaction between citizens and health care providers ....................................................... 15
   4.3.1 Limited access to existing digital health and care services ............................................ 15
   4.3.2 Improving health care services through digital innovation ............................................ 15
5. **Overall Conclusions** ............................................................................................................. 16
6. **Annex: Figures from the public consultation questionnaire** .................................................. 18
1 Executive summary

The present report provides an analysis of the results of consultation activities carried out by the European Commission in preparation of a Communication on the Transformation of Health and Care in the Digital Single Market.

The main findings show that over 93% of over 1400 respondents to an online questionnaire believe that “Citizens should be able to manage their own health data”. Furthermore, 83% of all respondents either agree or strongly agree with the statement that “Sharing of health data could be beneficial to improve treatment, diagnosis and prevention of diseases across the EU”. The overwhelming majority of all respondents (73.6%) identify improved possibilities for medical research as a reason for supporting cross border transfer of medical data, which was higher than for their purpose of their own treatment (67.8%).

Risks of privacy breaches and of cybersecurity are on the top of the lists among the major barriers identified to the cross-border transfer of medical data. Other than these, the current lack of infrastructure (51%) and the heterogeneity of electronic health records (58.2%) also scored high on the lists. To overcome these barriers, the following activities for the EU were strongly supported: developing standards for data quality and reliability (59.6%), standardizing electronic health records (56.8%), proposing health-related cybersecurity standards (54.4%) and supporting interoperability with open exchange formats (53.4%). To propose legislation setting the technical standards enabling citizen access and exchange of Electronic Health Records across the EU was supported by nearly 40% of respondents.

Thus, there is strong support among respondents for European Union action on privacy, security and interoperability of healthcare data, as well as for training of a skilled workforce with the necessary IT skills and competences to deliver improved patient-centred care.

2 Introduction

In May 2017, the European Commission presented the mid-term review of the Digital Single Market Strategy. The Communication identifies three main pillars in the area of digital health and care, which are the following:

- citizens' secure access to electronic health records and the possibility to share it across borders and the use of e-prescriptions;
- supporting data infrastructure, to advance research, disease prevention and personalised health and care in key areas including rare, infectious and complex diseases;
- facilitating feedback and interaction between patients and healthcare providers, to support prevention and citizen empowerment as well as quality and patient-centred care, focussing on chronic diseases and on a better understanding of the outcomes of healthcare systems.

1http://eur-lex.europa.eu/resource.html?uri=cellar:a4215207-362b-11e7-a08e-01aa75ed71a1.0001.02/DOC_1&format=PDF
To address the issues raised within the Communication, the European Commission launched an open public consultation on Transformation of Health and Care in the Digital Single Market with an online questionnaire which ran from 20 July 2017 to 12 October 2017, available in all official EU languages. Responses were submitted online to the survey questionnaire. It was complemented by various other consultation activities, including the targeted ones set out in the section below.

3 Events and other elements of consultation

3.1 Workshop on the General Data Protection Regulation (GDPR) implementation and health data

This workshop took place on 23 October 2017, it was co-organised by DG CNECT, DG SANTE, DG JUST and DG RTD and it attracted more than 190 participants from Member States, industry, research and associations. The purpose of the event was to exchange on the practical implementation of the EU GDPR with respect to health-relevant data, sharing of experiences and good practices, and to identify drivers and challenges regarding the processing of personal data concerning health. The meeting concluded with an invitation to participate in the consultation on guidelines and to liaise with national Data Protection Authorities as they are the first points of contact on GDPR implementation and compliance. The workshop was followed by a joint meeting between the GDPR experts and experts from the Health ministries on 6 December 2017.

3.2 eHealth Stakeholder Group

First results from the online questionnaire publication were discussed at the meeting of the eHealth Stakeholder Group on 24 October 2017.

3.3 eHealth Network

First results from the online questionnaire publication were discussed at the meeting of the eHealth Network on 28 November 2017.

3.4 Roadmap comments and Roadmap website

A Roadmap for the initiative on Transformation of Health and Care in the Digital Single Market was published on 19 July 2017. Four responses were received in the feedback period until 16 August 2017: The App Association’s Connected Health Initiative welcomed the initiative to define future policy goals and actions in the area of digital health and care, stressing the potential and necessity of connected health tools, remote monitoring and mobile health apps. The European Federation of Pharmaceutical Industries and Associations also welcomed the initiative with an emphasis on clarification of legislative and regulatory issues and funds for investment in patient-centred healthcare. EuroHealthNet gave positive feedback on the Roadmap with caveats calling for more action on trust, inequalities and access for all. The fourth response came from an individual who gave detailed recommendations on federated information systems and the use of standards and identifiers in the EU.
3.5 eHealth Conference Tallinn

The 'Health in the digital society. Digital society for health' conference took place from 16 to 18 October 2017 in Tallinn, where over 600 digital health experts from Europe and across the globe gathered to exchange knowledge and share best practices. The event focused on the impact that a digital transformation of healthcare systems could have on society as a whole.

The European Connected Health Alliance (ECHA) gave a presentation of the Digital Health Society Declaration launched under the high-level eHealth conference. The Digital Health Society, initiated by the Estonian Presidency of the Council of the European Union and ECHA have assembled an eHealth Declaration that includes more than 100 European organizations' proposals for developing eHealth in Europe. The Declaration has been launched in July 2017. The Declaration describes the bottlenecks that hamper the development of e-health, such as the lack of people's trust in e-services in Europe, the lack of interoperability between different information systems, the lack of a clear legal framework, and the inadequate training of healthcare professionals. Proposing solutions for overcoming these obstacles, the document emphasizes the need for unified approaches to the development of data exchange infrastructure, raising people's awareness of the use of e-health solutions and implementing the European Union Data Protection Regulation in a way that it does not create unnecessary obstacles to the free flow of data between member states.

The Declaration and the conference discussions will support the conclusions of the Council of the European Union, which are due to be adopted by the health ministers at the December health ministers' Council.

3.6 Council Conclusions on Health in the Digital Society

In December 2017, the Council adopted Conclusions\(^2\), inviting Member States and the Commission to work together on a range of aspects in order to seize the potential of digital technologies in health and care.

These include interoperable health information systems, data security and privacy-enhancing technologies, implementation of the eHealth Digital Service Infrastructure, cross-border exchange of health data, common disease registries and platforms, tools for rare diseases research, prevention and control of serious cross-border health threats, better use of European funding, transfer of good practices and development of common indicators. Member States have also called for the Commission's support in the development and deployment of interoperable national infrastructures for sharing and exchanging health data, especially for primary and integrated care. The Conclusions also call specifically for the implementation of existing EU legislation on data protection, electronic identification and information security in the health sector.

4 Online public consultation: overview of respondents

The public consultation differentiates across individuals answering in their personal capacity (hereafter referred to as Individuals) and individuals answering in their

professional capacity or on behalf of an organisation (hereafter referred to as Organisations).

Out of 1464 responses, 1004 respondents (69%) answered in their personal capacity, while 460 respondents answered in their professional capacity or on behalf of an organisation (31%). The majority of respondents answering in their personal capacity are citizens (45% of total respondents) while 14% of total respondents identified themselves as health and care professionals (e.g. doctors, nurses, social care professionals) who nevertheless responded to the survey in their personal capacity.

Figure 1 – Share of Respondents by Type

The geographical distribution of respondents is heterogeneous across the 28 EU Member States with a majority of respondents from Germany (52% of individuals and 17% of organisations). It is important to note that several responses of German individuals and organisations were nearly identical, pointing to the possibility of campaigning in the country. For individual respondents, the second country in terms of number of responses is Italy, followed by Belgium, Spain (around 6%) and Austria (5%).

Figure 2 – Number of Respondents by Country and Respondent Type

As a consultation instrument, the questionnaire is not statistically representative but with the large response it received it gives strong indications of the preferences and concerns of various types of stakeholders.
4.1 Online public consultation: access to and use of personal data concerning health

4.1.1 Propensity for health data sharing

As much as 93% of respondents overall either agree (28%) or strongly agree (64%) with the statement that "Citizens should be able to manage their own health data". For individuals, as consumers of healthcare questions of data management and security are of particular concern, whereas for organisations questions of standardization and interoperability of data transfer systems would appear to be priorities alongside data security.

In fact, while individuals show in their responses a clear preference for being always able to manage their data, certain organisations point out that a full control of the health by the individual can create problems especially in two cases: Firstly, when individuals have complete control over editing the information contained in their file and deleting information created by the doctor and, secondly, when there is an emergency which requires immediate access to the information and the patient is unable to give consent to access his/her health record. Certain stakeholders emphasize that individual health data management should be optional, and should go hand in hand both with the interoperability of data and the necessary protections in place.

**Figure 3 - Question 29.** Regarding the statement “Citizens should be able to manage their own health data”, do you...

![Survey Results](image)

Overall the respondents agree that individuals’ management of their data has positive implications when it comes to:

1. Individual critical value (the access and understanding of one’s own personal health data which could lead to better self-management of people in both acute care situations

---

3 Figures for the overall sample are provided in the Annex.
and when facing chronic conditions, hence, leading to improved patient outcomes and overall quality of life);

2. Value for the healthcare system (Better-managed care through increased self-management by patients and through connecting different healthcare professionals and providers could contribute to better clinical outcomes, more efficient care pathways, and a decrease in healthcare costs);

3. Economic and societal value (Due to improved patient outcomes, citizens would be able to actively participate in society and the economic system, while having continued income and facing less individual health costs).

In their responses, individuals have raised concerns over access to their health data by commercial organisations and by government authorities without consent. Individuals have also expressed a preference that only data necessary for a particular treatment is shared with the doctor and only after explicit consent, which the patient should be able to revoke. Individuals have also pointed out the need to be able to opt out if they are not able or unwilling to manage their data. Both individuals and organisations consider it to be critical for the individuals to receive appropriate information and education on how to manage their data as well as on how to interpret the contents.

Respondents are divided on whether data should be centrally stored (with individuals having the right to provide access to their doctors) or if data should be stored in a decentralized way (i.e. with the individual or with health care services providers), and be always accessible to the individual through one easy-to-use interface.

Nevertheless, 83% of respondents either agree (30%) or strongly agree (53%) with the statement "Sharing of health data could be beneficial to improve treatment, diagnosis and prevention of diseases across the EU".

Figure 4 - Question 31. Regarding the statement "Sharing of health data could be beneficial to improve treatment, diagnosis and prevention of diseases across the EU", do you...
Organisations point out that health data sharing across the EU is very useful for public health, research and prevention, especially for new big data applications and genomics.

4.1.2 Major barriers to electronic access and sharing of health data

The term ‘access’ has been interpreted in different ways by respondents. Some respondents refer to ‘access’ to data by doctors and therefore connect it to the willingness or capability of patients to provide their data. Restrictions identified in this case are mainly related to: technical barriers (lack of interoperability, data quality and reliability; lack of standardization of access and extraction mechanisms); legal barriers (different regimes among member states); ethical barriers (trust of patients in the system and difficulty to perceive the benefit of making data available); economic barriers (lack of resources to have a proper infrastructure to access data); lack of skills (IT skills and health literacy both of patients and practitioners).

Figure 5 - Question 33. What are the major barriers to electronic access to health data?

Other respondents considered that the term ‘access’ could refer to a patient’s own access to their personal health data. Restrictions identified in this case are mainly related to IT and health literacy; lack of proper infrastructure of institutions to make data easily available for the patient; and lack of awareness by citizens on how to access data.
Figure 6 - Question 35. What are the major barriers to electronic sharing of health data?

As in the case of access to data, privacy breaches (66%), heterogeneity of electronic health records (58.3%) and cybersecurity concerns (54.4%) are identified as the main restrictions to health data sharing in the overall sample. However, priorities across the range of respondents do differ. Individuals are more concerned with risks of privacy breaches and cybersecurity risks, while organisations are more concerned with heterogeneity of electronic health records and lack of technical interoperability.

Respondents have also referred to the need to explain properly to patients the advantages of safe sharing of data to public and population health and digital health engagement - while putting the challenges of privacy and cybersecurity into an appropriate perspective. Moreover, this is connected to the question of ‘trust‘ which is often mentioned by respondents as one of their concerns, as respondents are concerned with illicit access to information especially by insurance companies and the private sector more generally. Reference has also been made to widespread uncertainty about what is permissible under different legal frameworks, not only at European and national level, but also at local level where practices may differ. Several respondents have also pointed out the need to adopt standard technical specifications for cross-border access to health data, address the heterogeneity of technical specifications supporting EHR systems, and encourage best-practices around data quality which could facilitate technical and semantic interoperability. Finally, digital illiteracy in hospitals is identified as a barrier that needs to be addressed.

Most respondents confirmed they did not have access to digital health and care services. Of those who don’t, two out of three respondents would like to have access to these digital services and 83.6% recognise that digital innovation, particularly enabling citizen feedback can improve health care services.

The main options proposed by all respondents in order to overcome barriers to access and sharing of data in the EU are to develop harmonised standards for data quality and reliability (59.6%), to standardise electronic health records (56.8%), to propose health-related cybersecurity standards (54.4%) as well as to include to support interoperability with open exchange formats (53.5%). Other than these, increasing awareness of rights on data access under European law (46.9%), providing the necessary infrastructure for
Europe-wide access to health data (43.9%) and to propose legislation setting the technical standards enabling citizen access and exchange of Electronic Health Records across the EU (39.6%) were also favored by a higher number of respondents. Individuals and organisations showed similar preferences, with organisations assigning higher importance to the need to support interoperability with open exchange format and support healthcare professionals with common (EU-level) data aggregations.

As "other options", the main proposals from organisations are related to training health care professionals with the necessary digital and non-digital skills in order to be able to handle personal data and provide appropriate digital solutions.

Individual respondents have referred to the need to have the option to opt-out from sharing their data, to always request consent from the patient, the need for strict enforcement of privacy rules and stronger punishment in case of data breach, and the need to encrypt the data at all times. Several responses cautioned against sharing any health data electronically.

**Figure 7 - Question 37.** What should the EU do overcome barriers to access and sharing of data?
4.2 Online public consultation: making use of personal data to advance health research, disease prevention, treatment and personalised medicine

4.2.1 Support for sharing health data for research purposes

**Figure 8 - Question 39.** Would you agree with the principle that personal health data should be made available for further research, on a case-by-case basis, in a secure way, and in compliance with data protection legislation?

The main purposes for which respondents consider that their health data could be made available are: progressing research and innovation (73.4%), for their own treatment (67.8%), to improve clinical practice (66.4%). More than 50% of respondents also selected improvement of healthcare organisation and increase in efficiency of health and social care. Several respondents voiced concern with the possibility that the data could be used to develop discriminatory health insurance schemes, even in circumstances when these may be managed by the public sector. Several respondents suggested that citizens should have the choice to select to make their data available on a case-by-case basis, and that data should be anonymized or pseudonymised.

73.2% of respondents consider that, in order to share their data for research, data has to be secure and only accessible to authorised parties, while 62% of individuals would consider sharing their data subject to the condition that it is encrypted and cannot be traced back to the individual. 162 respondents consider other preconditions to be necessary, such as the need to be informed and to give consent on a case-by-case basis. It has also been pointed out that encryption may not guarantee privacy, and only anonymization would be able to achieve this. Yet, in the era of big data, certain respondents are also concerned with the fact that any data can be traced back to a certain individual irrespective of safeguards.
Figure 10 - Question 42: If you share your health and/or lifestyle data for research, the following preconditions have to be ensured.

<table>
<thead>
<tr>
<th>Condition</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>My data is secure and only accessible to authorised parties</td>
<td>73.2%</td>
</tr>
<tr>
<td>My data is encrypted and cannot be traced back to me</td>
<td>62.0%</td>
</tr>
<tr>
<td>My data is only used in 'not for profit' activities</td>
<td>47.3%</td>
</tr>
<tr>
<td>My data is only shared between societies and institutes</td>
<td>21.6%</td>
</tr>
<tr>
<td>Researching my disease area</td>
<td>11.2%</td>
</tr>
<tr>
<td>Not answered</td>
<td>11.2%</td>
</tr>
<tr>
<td>Other</td>
<td>11.1%</td>
</tr>
</tbody>
</table>

4.2.2 Use of data and digital tools to advance research in the EU

Figure 11 - Question 44. Should high-performance computing, big data analysis and cloud computing for health data research and personalised medicine be advanced?

Overall, 64% of respondents indicate that high-performance computing, big data analysis and cloud computing for health research should be advanced, while 18% of the respondents specify that such research should not be advanced.

Respondents have highlighted a wide range of application areas. These include applications related to: 1. Prevention (with risk stratification, genomics, analysis of healthy behaviours, disease outbreak detection, early warnings); 2. Early diagnosis (analysis on rare diseases, -omics data, imaging and in-vitro diagnostics); 3. Cure (treatment of chronic diseases, personalised medicine); 4. Follow-up of treatment (telemedicine, m-health and other tools for remote patient care).
In relation to research areas, high emphasis is given to oncology (cancer research), rare diseases, brain diseases, epidemiology, and active and healthy ageing.

**Figure 12 - Question 46.** Would it be useful to further develop digital infrastructure to pool health data and resources securely across the EU (linking and/or adding to existing infrastructure capacity)?

64% either agree (30%) or strongly agree (34%) that it would be useful to further develop digital infrastructure to pool health data and resources securely across the EU. Organisations tend to agree more with this statement (79% of the case) than individuals (58% of the cases). In addition, 22% of individuals strongly disagree with the statement, compared with only 2% of organisations.

Based on responses received, the European Commission’s role can be considered to facilitate greater cross border cooperation and where appropriate, to pursue harmonising legislation. It is also suggested that the European Commission should support initiatives aimed at improving the data collection process and the overall data quality (e.g. development of IT tools enhancing collection of complete, comparable and harmonised data and compression technology for genomic data) as well as research on encryptions and anonymization.

Respondents also highlighted the need for the European Commission to clarify privacy rules and the framework that applies to processing of health data, while also making sure that current restrictions on flow of data at national and regional level are removed.
**Figure 13 - Question 48:** Do you / Does your organisation encounter barriers to using big data analytics for personalized medicine?

23% of individuals state that they encounter barriers compared with 47% of the organisations. Overall, among those who responded with a Yes or No answer, 58% state that they or their organisation do encounter barriers.

The main barriers highlighted by respondents include both the lack of adequate data and (when available) barriers to process such data. Lack of adequate data is attributed to the fact that access to most databases and/or biobanks is restricted, that providers are unwilling to share data, that there is an absence of the correct infrastructure to share the data, and that there is no harmonized framework to make the data interoperable. Even when adequate data is available, barriers still arise from fragmented, unclear and burdensome legal frameworks on the legitimacy of sharing and processing data (not only at national but also at regional or local level), a lack of digital literacy and/or technical capacity to process the data, and a lack of understanding of the potential benefits arising from the application of big data analytics.

It has also been mentioned that it can be costly for hospitals and practitioners to make the data available both because it is time-consuming to access all information in electronic format, and because anonymising data is often complex and time-consuming (especially medical images like MRI and CT scans).
4.3 Online public consultation: promoting uptake of digital innovation to support interaction between citizens and health care providers

4.3.1 Limited access to existing digital health and care services

Figure 14 - Question 50. Do you currently have access to digital health services (e.g. remote monitoring, consultation with doctors or any kind of service provided through digital means)?

It appears that a disproportionate share of respondents does not have access to such services in: Germany, Austria, and the Czech Republic. On the other hand, in Belgium, Italy, Netherlands and Sweden there is a higher share of respondents that have access to digital health services than respondents who do not. Nevertheless, 50% of total respondents are not able to provide feedback on digital health services.

4.3.2 Improving health care services through digital innovation

A large majority agree with improving health care services through digital innovation. Overall, 84% of respondents agree (34%) or strongly agree (50%) with the statement "Citizen/patient feedback to health and care providers and professionals on the quality of treatment is essential to improve health and care services".

Factors considered essential or more important than citizen feedback in order to improve health and care services include, among others: the availability of statistics and other evidence collected by public authorities, including data on hospitals; research on and publication of standardized, meaningful and comprehensive outcome indicators; publication of the number of treated cases for complex treatments and sharing of best practices; promotion of patient-centred care and active patient involvement; cooperation

---

4 See Annex Table 1 for complete list.
and communication between stakeholders involved in healthcare processes to ensure effective and appropriate delivery of care; quality improvement initiatives (e.g. training of healthcare professionals; implementation of evidence-based practices; implementation of ad hoc platforms for exchange between practitioners); the need to increase e-health literacy of both patients and professionals; the rigorous analysis of the cost-efficiency of results obtained from new projects; an increase in investment and development of health practices; and, better access to statistics on the quality of care provided by hospitals.

The majority of respondents consider that the EU should support further research in the area, support regions and municipalities in rolling out new services and provide support for knowledge transfer between Member States and regions (67.1%). Respondents also pointed out the need for the EU to promote common approaches for feedback mechanisms about quality of treatment (56.5%) and support EU associations of patients and clinicians to improve clinical practices (49.5%). In addition, 145 respondents have pointed out additional areas of support by the EU and, in particular, greater emphasis is given to the necessity to promote (digital) health literacy among patients and digital literacy of health practitioners.

Other important suggestions include: the creation of partnerships to test implementation of new digital solutions; specify and implement common health care standards, common reporting and common patient rights across the entire EU; the promotion of research on patient-centric approach through digital solutions; forming a health data cooperation network of interested Member States as a basis to start collaboration between countries in the EU; define and implement new co-financing models for digital health to support large scale deployment; adopting innovative financing mechanisms that recognise the value created in terms of outcomes and create the adequate financial incentives for health and care providers to deliver integrated care, prioritise prevention and encourage patient engagement; develop policies for and drive adoption of new payment and reimbursement models for digital health solutions based on outcomes and long-term health of patients.

5 Overall Conclusions

Taking into account the priorities and opinions expressed by the eHealth Network, the Council Conclusions on Health in the Digital Society, eHealth Stakeholder Group, the Workshop on GDPR implementation and health data, via the Roadmap website, and at the eHealth Conference in Tallinn, the following main conclusions can be drawn from responses to the online questionnaire:

1. The outcome of the consultation activities demonstrates strong support for enabling citizens to have access to and use data concerning health across borders. Over 93% of respondents online believe that "Citizens should be able to manage their own health data" and 81% of respondents believe that "sharing of health data could be beneficial to improve treatment, diagnosis and prevention of diseases across the EU".

2. Data security and privacy are the key concerns which have been expressed by citizens. In particular, individuals as consumers of healthcare must have confidence that personal data concerning health will not be misused, will be stored correctly and high cybersecurity standards are applied for personal data concerning health. Individual respondents also expressed that there should be an opportunity to opt-out from sharing their data. Multiple stakeholders and citizens including some 64% of respondents to the online questionnaire supported the development of a cross-border infrastructure to pool access to health data and scientific expertise more securely across the EU.
3. Barriers that prevent the realization of the benefits associated to a digital single market for citizens, professionals and health care organisations were identified. Notably the heterogeneity of electronic health record (EHR) systems and lack of technical interoperability were mentioned frequently as "major barriers to cross-border access and use of health data". Further barriers include the need for improved digital literacy amongst healthcare practitioners in order to realise the full benefits of cross border data transfer.

4. The question "What should the EU do to overcome barriers to access and sharing of data?" was met with strong support for EU action to ensure cross-border access to and use of data concerning health. This activity could include inter alia, measures to establish cross-border interoperability of electronic health record (EHR) systems through open exchange formats and robust EU standards for health data quality, reliability, privacy and cybersecurity as well as to propose legislation setting the technical standards enabling citizen access and exchange of Electronic Health Records across the EU.

5. Most respondents confirmed they did not currently have access to digital health and care services. Of those who don't, two out of three respondents would like to have the opportunity to access these digital services and 83.6% recognise that digital innovation, particularly enabling citizen feedback may improve health care services. In order to address the low level of adoption of digital health solutions in health care, the respondents favoured sustained EU investment in research and innovation, transfer of knowledge and practices between Member States and regions, and common approaches for feedback mechanisms about quality of treatment.
6 Annex: Figures from the public consultation questionnaire

Type of organisation

- Churches and religious communities (1)
- Health and care organisation (e.g. hospitals, clinics, social and community care) (80)
- International or national public authority (19)
- Non-governmental organisation, platform or network (67)
- Other (38)
- Private enterprise (other) (35)
- Professional consultancy, law firm, self-employed consultant (18)
- Regional or local authority (public or mixed) (22)
- Research and academia (60)
- Service provider (e.g. digital health services, data and technology services,...) (64)
- Trade, business or professional association (55)

Regarding the statement "Citizens should be able to manage their own health data", do you...

- No Answer (7)
- Agree (418)
- Disagree (22)
- Neither agree nor disagree (60)
- Strongly agree (943)
- Strongly disagree (13)
Would you agree with the principle that personal health data should be made available for further research, on a case-by-case basis, in a secure way, and in compliance with data protection legislation?

- No Answer (18)
- Agree (476)
- Disagree (72)
- Neither agree nor disagree (86)
- Strongly agree (655)
- Strongly disagree (156)

Should high-performance computing, big data analytics and cloud computing for health research and personalised medicine be advanced?

- No Answer (26)
- Do not know (236)
- No (259)
- Yes (942)
Would it be useful to further develop digital infrastructure to pool health data and resources securely across the EU (linking and/or adding to existing infrastructure capacity)?

- No Answer (28)
- Agree (444)
- Disagree (101)
- Neither agree nor disagree (161)
- Strongly agree (504)
- Strongly disagree (225)

Do you / Does your organisation encounter barriers to using big data analytics for personalised medicine?

- No Answer (59)
- Do not know (638)
- No (318)
- Yes (448)
Do you currently have access to digital health services (e.g. remote monitoring, consultation with doctors or any other kind of service provided through digital means)?

- No Answer (49)
- Do not know (76)
- No (779)
- Yes (559)

Would you like to have access to digital health services (e.g. remote monitoring, consultation with doctors or any other kind of service provided through digital means)?

- No Answer (9)
- Do not know (44)
- No (214)
- Yes (512)
As a citizen, are you able to provide feedback to your health care provider on your treatment through electronic communication channels?

- Yes (509) - 50.4%
- No (738) - 34.8%
- Do not know (163) - 11.1%
- No Answer (53) - 3.6%
Table 1 - **Question 50** Do you currently have access to digital health services (e.g. remote monitoring, consultation with doctors or any other kind of service provided through digital means)?

<table>
<thead>
<tr>
<th>Country</th>
<th>Do not know</th>
<th>Not Answered</th>
<th>No</th>
<th>Yes</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Austria</td>
<td>1</td>
<td>1</td>
<td>44</td>
<td>18</td>
<td>64</td>
</tr>
<tr>
<td>Belgium</td>
<td>9</td>
<td>14</td>
<td>42</td>
<td>55</td>
<td>120</td>
</tr>
<tr>
<td>Bulgaria</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Croatia</td>
<td>0</td>
<td>1</td>
<td>5</td>
<td>8</td>
<td>14</td>
</tr>
<tr>
<td>Cyprus</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Czech Republic</td>
<td>1</td>
<td>0</td>
<td>11</td>
<td>2</td>
<td>14</td>
</tr>
<tr>
<td>Denmark</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>7</td>
<td>9</td>
</tr>
<tr>
<td>Estonia</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Finland</td>
<td>0</td>
<td>1</td>
<td>4</td>
<td>17</td>
<td>22</td>
</tr>
<tr>
<td>France</td>
<td>1</td>
<td>4</td>
<td>40</td>
<td>35</td>
<td>80</td>
</tr>
<tr>
<td>Germany</td>
<td>29</td>
<td>11</td>
<td>420</td>
<td>145</td>
<td>605</td>
</tr>
<tr>
<td>Greece</td>
<td>0</td>
<td>0</td>
<td>11</td>
<td>12</td>
<td>23</td>
</tr>
<tr>
<td>Hungary</td>
<td>1</td>
<td>0</td>
<td>5</td>
<td>2</td>
<td>8</td>
</tr>
<tr>
<td>Ireland</td>
<td>0</td>
<td>0</td>
<td>3</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Italy</td>
<td>5</td>
<td>2</td>
<td>35</td>
<td>53</td>
<td>95</td>
</tr>
<tr>
<td>Latvia</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Lithuania</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Luxembourg</td>
<td>0</td>
<td>0</td>
<td>3</td>
<td>4</td>
<td>7</td>
</tr>
<tr>
<td>Malta</td>
<td>0</td>
<td>0</td>
<td>6</td>
<td>6</td>
<td>12</td>
</tr>
<tr>
<td>Netherlands</td>
<td>5</td>
<td>1</td>
<td>13</td>
<td>33</td>
<td>52</td>
</tr>
<tr>
<td>Other</td>
<td>5</td>
<td>7</td>
<td>16</td>
<td>18</td>
<td>46</td>
</tr>
<tr>
<td>Poland</td>
<td>4</td>
<td>0</td>
<td>21</td>
<td>15</td>
<td>40</td>
</tr>
<tr>
<td>Portugal</td>
<td>2</td>
<td>0</td>
<td>3</td>
<td>14</td>
<td>19</td>
</tr>
<tr>
<td>Romania</td>
<td>1</td>
<td>0</td>
<td>14</td>
<td>4</td>
<td>19</td>
</tr>
<tr>
<td>Slovak Republic</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Slovenia</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Spain</td>
<td>4</td>
<td>2</td>
<td>46</td>
<td>44</td>
<td>96</td>
</tr>
<tr>
<td>Sweden</td>
<td>0</td>
<td>1</td>
<td>3</td>
<td>29</td>
<td>33</td>
</tr>
<tr>
<td>United Kingdom</td>
<td>6</td>
<td>3</td>
<td>26</td>
<td>26</td>
<td>61</td>
</tr>
<tr>
<td>Total</td>
<td>76</td>
<td>49</td>
<td>779</td>
<td>560</td>
<td>1,464</td>
</tr>
</tbody>
</table>