Health Information and Quality Authority
An tÚdarás Um Fhaisnéis agus Cáilíocht Sláinte

An Roinn Sláinte
Department of Health

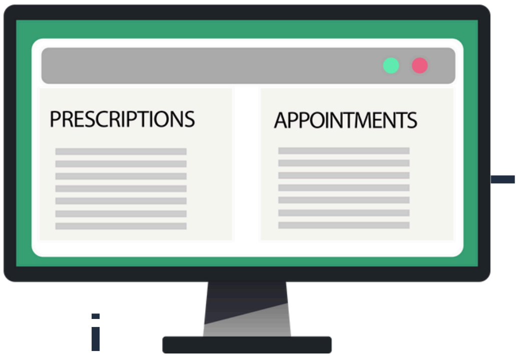
FINDINGS:

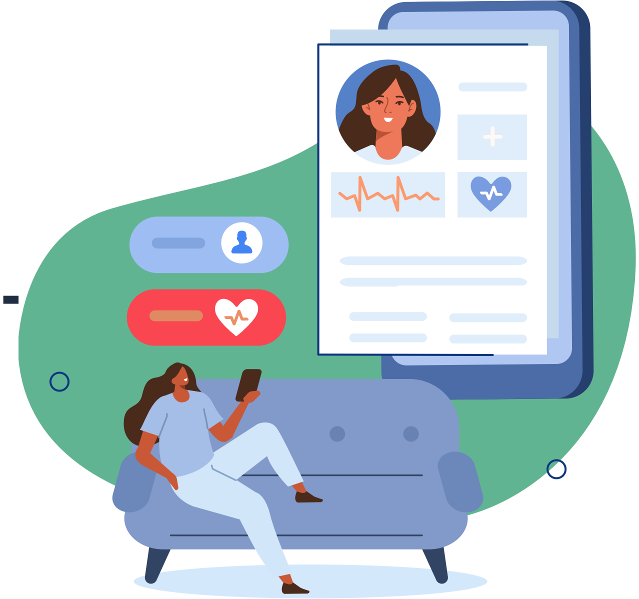
NATIONAL ENGAGEMENT ON Digital Health & Social Care

2024

Health Information and Quality Authority
An tÚdarás Um Fhaisnéis agus Cáilíocht Sláinte

An Roinn Sláinte
Department of Health





NATIONAL ENGAGEMENT ON Digital Health & Social Care

What did the public tell us?

2,009 **People surveyed**

41 **Focus group participants**

Members of the public told us their views about accessing and sharing information in an online health record and accessing services digitally.

The public feel ready to engage digitally with health and social care services.

74% said that they would access their online health record when it is made available online.

95% of people said they are comfortable getting text and email reminders about appointments.

55% said that they would access digital health services if available.

The public want their online health record for practical tasks to manage their health.

90% want to use it to contact professionals about mistakes or missing information.

90% want to use it to renew prescriptions for regular medications.

89% want to use it to track progress of tests.

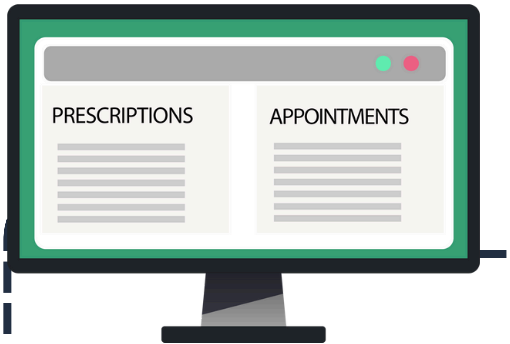
The public need an online record to have more autonomy and to actively participate in decisions around their care.

91% think it will help them understand their health.

90% think it will help them manage their health between visits.

88% think it will help them talk to a professional about their health.

> “Everybody would have the same view that the more information you can get about your own care and your own records the more it puts things in your own control to a certain extent. And that you are effectively managing your own health.”



NATIONAL ENGAGEMENT ON Digital Health & Social Care

What did the professionals tell us?

1,020 **People surveyed**

27 **Focus group participants**

Professionals working in health and social care services told us their views about the public having access to their online health record and providing services to the public digitally.

Professionals think that online records will empower people to be more in control of their health.

88% think the public will be better informed about their health.

88% think the public will be better prepared to ask questions.

Professionals feel that the public may not be ready to interact with them digitally.

54% think IT skills of people they treat or care for will be a challenge.

32% of professionals feel that the public may not be ready to interact digitally.

36% of professionals reported concerns that when care is provided digitally relationships with people they treat or care for may disimprove.

Professionals need technical support and training in place prior to feeling comfortable interacting digitally with the public.

92% want clarity on who to contact for technical support.

83% want training in digital tools.

79% want protocols in place on providing services or information digitally.

Professionals need policy direction and guidance on clinical note taking prior to feeling comfortable sharing their clinical notes.

66% of professionals are comfortable sharing clinical notes but professionals need policy direction and guidance on clinical note taking.

> I do think that going forward there would have to be some kind of formal mandatory training for healthcare professionals on how to conduct themselves on note taking....

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Executive summary

Background

Digital technology is an integral part of day-to-day life. Integrating technology into healthcare has the potential to improve the efficiency, safety and quality of service delivery. Progressing the digital transformation of health and social care services is a key focus both nationally and internationally.

The World Health Organization (WHO) promotes digital developments that are person centred, address identified health needs and are appropriate to a local context.(1) The European Commission has set goals to support Europe's digital transformation, one of which is to provide access to electronic health records for all European Union (EU) citizens by 2030.(2) To harness the power of this digital transformation, the Commission has also committed to delivering a number of common data spaces in key areas, the first of which will be in health. The Commission plans to publish the European Health Data Space (EHDS) Regulation in autumn 2024. The EHDS will enable people to access their electronic health record nationally and also across borders.

In Ireland, the Health Information Bill 2024 provides a comprehensive legislative framework to ensure that Ireland has a fit-for-purpose national health information system that enhances patient care and treatment and supports better planning and delivery of health services into the future.(3) The Bill aims to achieve several important goals, including the development of digital health records and enhancing people's right to access their own health information. The Digital Health Framework for Ireland 2024-2030 was published by the Department of Health in June 2024.(4) It sets out a clear vision to digitally transform health services, focused on harnessing the power of new technologies, digital and data to transform how health and social care services are delivered in Ireland. Patients as empowered partners and an enabled workforce are recognised as key pillars in the Framework. The Health Service Executive (HSE) has developed a corresponding Digital Health Strategic Implementation Roadmap which sets out the digital initiatives which will deliver the vision and mission of the Framework.(5)

Digital improvements will lead to greater availability of health information, improvements in decision-making, and ultimately safer care and better outcomes for patients. International experience highlights that engagement is crucial in order to learn what is acceptable to people and to help develop person centred digital systems. In this context, the Health Information and Quality Authority (HIQA), in partnership with the Department of Health and the HSE, has conducted a National Engagement on Digital Health and Social Care.

What is the National Engagement on Digital Health and Social Care?

The aim of the National Engagement on Digital Health and Social Care was to understand the opinions and attitudes of the Irish public and professionals in relation to the digitalisation of health and social care services. The key objective was to listen to the voice of the public and professionals working in health and social care and to use the findings to inform how digital health information and services are developed and provided so they are people-centred and built for the Irish context. To achieve this objective HIQA, the Department of Health and the HSE conducted a National Engagement on Digital Health and Social Care. This engagement involved:

- A national telephone survey with 2,009 members of the public. Focus groups and interviews were undertaken with 41 participants, including representatives of minority groups.
- A separate online survey with 1,020 professionals working in health and social care services. Focus groups were held with 27 professionals, including doctors, nurses and health and social care professionals.

Main findings of the National Engagement on Digital Health and Social Care

The surveys and focus groups with the public and professionals explored attitudes and opinions in relation to the digitalisation of health and social care services.

Main findings public survey and focus groups

The public overall are positive about the move to digital health and social care services, and want to be consulted on the format and delivery of digital care. The public see an online health record as having a number of practical uses for managing their health. The public did voice concerns about the security of their information in their online health record and want there to be equal access for all. The findings demonstrate the importance of upholding people's rights regarding the collection, use and sharing of their information. Key findings that emerged from the public survey and focus groups are discussed further below:

1. Overall, the public feel ready to engage digitally with health and social care services.

The majority of the public (74%) say that they would access their online health record when it is made available online. A lower proportion of the public indicated that they would access digital health services such as video consultations if available (55%). The public reported high levels of comfort receiving text message reminders about upcoming appointments (95%) and a text message to say the results of medical tests are available (93%). The public are less comfortable with chat features on websites (41%).

2. The public want their online health record to help manage their health.

The public rate renewing prescriptions for regular medications (90%), tracking progress of blood tests or other tests (89%) and tracking progress of referrals (87%) as very important functions of an online health record for managing their health. During the focus group discussions, participants indicated they would like an additional function within their record that would remind and prompt them to book any outstanding tests required, for example, if they are due a blood test or breast screening.

3. The public want to use their online record for practical tasks related to their healthcare journey.

The public rate contacting healthcare professionals about mistakes or information missing in their record (90%), updating contacting details like phone number or address (89%) and booking, rescheduling and cancelling appointments (88%) as very important administrative functions to have in an online health record. Focus group participants also said they would like the option to add notes to their online health record to flag information with professionals that might be relevant to their care, including family history, health information that has not been diagnosed by a professional and details of over-the-counter medication regularly used.

4. The public are happy to share personal information, including their name and date of birth or mobile number to identify them when accessing services.

The ability to correctly identify an individual using a unique identifier is essential for patient safety and the delivery of high quality services. The Health Information Bill makes provisions for information to be collected within the digital health record in order to identify a patient correctly(3) which include unique identifiers such as the their Personal Public Service Number (PPSN) and individual health identifier (IHI). Overall, the public are comfortable providing information to correctly identify them and 62% of people were comfortable providing their PPSN to correctly identify them when accessing services. Further and ongoing education and support is required to increase the public’s comfort providing their PPSN for identification purposes.

5. The public want their needs and preferences to be considered in any decisions regarding the format and delivery of their care.

The public noted that there is no 'one size fits all' in relation to digital care and it is important to ensure that people are given choice around the format and delivery of their care. The public are happy to have an online consultation for routine appointments but the public's preference is in-person consultations for more urgent care needs. In relation to online health records, the public want to be consulted on a regular basis on the design and layout and would like processes in place to ensure continual improvements.

6. The public want control over their online health record.

The public want control over their online health record and to know who is accessing their record, how often and for what purpose. The public are happy to share their online health record with a trusted family member or friend. However, the public indicated that it would increase their comfort sharing their information if they could easily remove a person's access (87% said this would increase their comfort), they could control what a person can see (79% said this would increase their comfort) and they could control who has access (76% said this would increase their comfort). The public would be comfortable sharing a variety of health information but a minority expressed reluctance sharing information about their mental health (32% would not be comfortable) or sexual health information (39% would not be comfortable).

7. The public need an online record to have more autonomy and to actively participate in decisions around their care.

At least 90% of the public think that having all information in one place and helping to manage their health between visits are two of the main benefits of an online health record. By having all their information in an online record, the public think they will be more knowledgeable about their health. As a result, they will be able to have more informed conversations with professionals working in health and social care and play a more active role in decisions around their care.

8. The public need an online record and digital care to be secure and ensure data privacy.

The public are concerned about the security of an online health record and this has been exacerbated by the cyberattack[*] on the HSE. The public want to know where their information will be stored and will need assurances that their

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[*] In 2021, there was a Conti ransomware cyberattack on the HSE. Further information available here: https://www.hse.ie/eng/services/publications/conti-cyber-attack-on-the-hse-full-report.pdf. This shall be referred to as the 'cyberattack' throughout the rest of the report.

information will be kept confidential and secure before they feel comfortable with their data being shared in an online format. The public want an online record to be password protected, with two-factor authentication. The public also highlight that education on data security will be important.

9. The public want online health records and digital care to be digitally inclusive to ensure equal access for all.

The public feel that support needs to be provided to people who are unable to use digital technologies, do not have access to a smartphone or laptop, do not have good broadband or phone signal, or are unable to afford phone credit or broadband. The public feel that not everyone is going to be prepared to move to accessing services and their own online health record digitally. The public think that there should be accommodations made, including education and training provided, or continued access to records via paper if needed.

10. The public think online health records are important to improve patient safety.

The public want an online health record to enable greater communication between different professionals and services across health and social care. The public feel this is important to enhance patient safety as very often professionals are reliant on the public to recall their past medical history and medications. This places significant responsibility on the patient, and they are often concerned they may forget key information that may be relevant to their care.

Main findings professional survey and focus groups

Professionals think that an online health record will empower people to be more in control of their health. However, many professionals who completed the survey feel that the public may not be ready to engage digitally. Professionals are aware of a number of barriers to implementation of digital care, including resource challenges, infrastructural barriers and governance issues around data security. Professionals would feel more comfortable providing services or information digitally if they know who to contact for technical support, were provided with clear guidance around digital clinical governance, were provided with training and education and if they have assurances that measures are in place to keep information private and secure. However, professionals do see the benefits of digital health and social care for both the public and service delivery. Key findings that emerged from the professional survey and focus groups are discussed further below:

1. Many professionals feel that the public may not be ready to interact with them digitally.

Of professionals surveyed, 32% feel that the people they treat or care for are not ready to interact digitally. Professionals elaborated on this in focus groups and indicated that they had concerns that a move to digital care might exclude some members of the public. Professionals also expressed concerns that if digital care delivery is accelerated, it could impact on person-centred care, with 36% of professionals surveyed reporting that they think when care is provided digitally, the relationships with the people they treat or care for will disimprove. Professionals indicated that work needs to be done to determine the best format for the delivery of care (in person, online or hybrid).

2. Professionals want decisions around digital delivery to be person centred and informed by the healthcare need and patient's choice.

Professionals emphasised that patient choice is paramount, patients must have choice over decisions around their care and the format of delivery. Professionals also suggested that decisions around delivery should be person centred and informed by the healthcare need. Professionals feel that there should always be an alternative in place that people are comfortable with, if they do not want to engage digitally.

3. Professionals want supports in place to ensure fair and equal access to online health and digital care by all members of the public.

Professionals noted concerns around digital exclusion and the importance of ensuring that a move to digital care does not disadvantage anyone who does not have the means or ability to access digital care. Participants identified supports that need to be put in place to ensure equal access for all, such as, providing IT support and training for people who use services on platforms for digital appointments. Professionals also feel that consideration needs to be given to a person's literacy level and that English may not be their first language. Professionals think information provided in an online record should be in plain English and easily understood.

4. Professionals need technical support and training in place prior to feeling comfortable interacting digitally with the public.

Professionals would feel more comfortable providing services or information digitally if they are clear about who to contact for technical support (92% of professionals said this would increase their comfort) and if they are provided with training in digital tools (83% of professionals said this would increase their comfort).

5. **Professionals need policy direction and guidance on clinical note taking prior to feeling comfortable sharing their clinical notes.**

   Of professionals surveyed, 66% said that they would be comfortable sharing their clinical notes. Professionals spoke about how currently they do not write their notes with the public in mind. Often, their notes are not of a high quality, are written quickly and can be ambiguous and use technical language. Professionals noted that in order to feel comfortable sharing their notes, their clinical note taking will need to improve. Professionals said they want support, education and training, alongside policy direction and guidance regarding the minimum standard required for a clinical note.

6. **Professionals want a national strategy that will enable greater sharing of information between health and social care services.**

   Professionals feel that there needs to be a system in place to facilitate the sharing of information between all health and social care services, including public and private services. Professionals feel that greater sharing of information is important for ensuring high quality, safe, integrated care and may reduce people being provided conflicting advice by different professionals. Professionals suggested that prior to the sharing of information across health and social care services, there needs to be a strategy at a national level that will inform and facilitate the sharing of information across health and social care services. This strategy needs to consider data access and data security.

7. **Professionals think it is important for the public to identify errors and omissions in their online health record to increase trust in the healthcare system.**

   Professionals (86%) think it would be helpful for the people they treat or care for to identify errors or omissions in their records. Participants noted that if people can make changes to their records, they will feel more in control of their health narrative and this will increase overall trust in the healthcare system. Professionals indicated that if a patient requests a change to their health information, it should be flagged on their record as 'patient reported' and in turn be verified by a professional in real-time or as soon as possible. Professionals, however, did acknowledge that this is a resource challenge.

8. **Professionals want up-to-date digital systems with measures in place to keep information private and secure.**

   Professionals are concerned about the safety and security of online records. Professionals would be more comfortable interacting with the public digitally if they are aware of what measures are in place to keep services and information private (89% of professionals said this would increase their comfort) and knowing what measures are in place to keep services and information secure from cyberattacks (86% of professionals said this would increase their comfort). The cyberattack* in the HSE made professionals more aware of the risks associated with online health records. Professionals think that there needs to be up-to-date systems with proper data security.

9. Professionals think that online records will empower people to be more in control of their health.

Professionals (88%) think when the public have access to their information in an online record they will be better informed about their health and will be better prepared to ask questions in appointments. Professionals also think that when people have access to their online health record they will have greater ownership of their healthcare journey.

Conclusion

The findings from this national engagement demonstrate that the public are positive about the move to digital health and social care. The public are keen to have access to their online health record and want to use their online health record in a practical way to support and manage their healthcare journey. The public feel that by having access to their online health record, they will be more knowledgeable about their health and could play a more informed role in decisions around their care. The public want to be consulted about the format and delivery of care and to ensure that there will be equal access for all. Many professionals feel that the public may not be ready to interact with them digitally. Professionals were more aware of the barriers and challenges to the delivery of care digitally, and highlighted key supports needed prior to implementation, including policy direction, and training and education. Professionals are positive about digital care and think it will be important to empower patients as partners on their healthcare journey.

What happens next?

The findings from this engagement provide insights and evidence to inform practice, policy, legislation and decision-making regarding development and provision of digital health systems and services in Ireland.

- HIQA will use the findings to inform their programme of work in relation to health information including the promotion and implementation of the National Standards for Information Management in Health and Social Care,(6) the development of national health information standards, and the dissemination, training and support to progress goals to inform the establishment of a data access body.

- The findings will be used by the Department of Health to inform legislation, national policy in digital health and social care being progressed under the Health Information Bill 2024 and the National Digital Health Framework 2024-2030.
- The HSE will use the findings to inform the delivery of key elements of the National Digital Health Strategic Implementation Framework 2024-2030 and Sláintecare vision including the patient app, patient feedback platform, digital health capacity building and electronic health record.

More information is available on www.hiqa.ie.

Thank you

Thank you to everyone who took the time to speak with us about your attitudes to digital health and social care and especially what you want, need, and are ready for in terms of the digitisation of health and social care services. Your contributions to the surveys and focus groups as part of the National Engagement on Digital Health and Social Care will be used to make improvements to how health and social care information is made available digitally and how digital services are implemented in Ireland. Without your support and participation, we would not have been able to gather this important information to support safer services and better care.

The National Engagement on Digital Health and Social Care ensures that your voice is heard by the people who can change and improve how digital health and social care is developed and implemented in Ireland. We want to put you at the centre of this process — we want to ensure that everyone's needs and wishes are taken into consideration and ultimately improve the quality of health and social care in Ireland.

Thank you to all the professionals across health and social care who took part in our engagement meetings and focus groups in the very initial phases of the project to inform the survey development. Your input was valuable in making sure that we gathered the most useful information on this topic.

Thank you to those working in representative organisations who helped to share information about our surveys and our focus groups. Your support is appreciated and helps to make sure that everyone's voice is heard.

Thank you to the members of the steering group and the partnership project team. Your direction and guidance throughout is valued. Appendix 1 lists the members of the steering group.

1. Introduction

1.1. Background

Digital technologies are integral to daily life, and there is immense scope for the use of digital health solutions.(1) Digital health and social care refers to how the public access their own health and social care information digitally, how information is shared digitally with the public, and what the public may share digitally with professionals. For example, in contrast to the traditional system of paper-based medical records, there is move to people accessing their health and social care information online via a website or mobile portal. Digital health and social care also refers to how professionals working in health and social care may communicate digitally with the public or provide services digitally, for example, general practitioner (GP) consultations by video. There are many benefits of digital health technology. Digital health services can be used anytime and anywhere. They are often more cost efficient and can reach more people than face-to-face care. They have a positive effect on the environment by reducing the necessity to travel. Moreover, digital care can empower people to manage their own health.(7)

The WHO promotes digital developments that are person centred, address identified health needs and are appropriate to a local context. The WHO highlights the importance of assessing local needs and context before the development of new digital health and social care systems.(1) To do so, it encourages engagement not only with the public, but also the health and social care professionals who need to be prepared to deploy or use digital health technologies in their work.(8,9) Engagement is crucial in order to learn what is acceptable to people and to help develop person-centred digital systems. It is also important to ensure that innovations in health and social care service provision have professionals' support, and improve the work environment for health and social care workers. International experience has proved that the success of the eHealth interventions are related to user involvement before and during the design phase.(10) Gathering and analysing views before the development and implementation process are essential to ensure that new healthcare technologies fit users' perspectives and needs.

In parallel, the European Commission aims to support Europe's digital transformation through establishing clear targets and objectives for 2030, including digitalisation of public services. In the Digital Decade policy programme, the European Commission sets a goal to provide access to medical records online for all citizens by 2030.(2) In addition, the European Commission has outlined plans to create a European Health Data Space (EHDS). The EHDS is an initiative that will enable people to access their electronic health data nationally and across borders. This will empower individuals to take control of their own health data.(11) The Commission is expected to publish the EHDS Regulation in autumn 2024.

From an Irish perspective, eHealth is identified as a 'critical enabler to implement the change required to deliver an integrated, universal, high quality health system' as envisioned in the Sláintecare healthcare reform programme.(12) The Health Information Bill 2024 provides a comprehensive legislative framework to ensure that Ireland has a fit-for-purpose national health information system that enhances patient care and treatment and supports better planning and delivery of health services into the future.(3) The Bill aims to achieve several important goals, including the development of digital health records and enhancing people's right to access to their own health information. A critical component to the establishment and success of digital health records is a reliable method to correctly identify people. Without a primary identifier, it will not be possible to link patient data from digital systems in different parts of the health service. The Bill will also provide the legislative basis for the use of the Personal Public Services Number (PPSN) as a method to easily identify people across the public and private health services in Ireland.

Digital improvements will lead to greater availability of health information, improvements in decision-making, and ultimately safer care and better outcomes for patients. The Department of Health's Digital Health Framework for Ireland 2024-2030 sets out a clear vision to digitally transform health services, focused on harnessing the power of new technologies, digital and data to transform how health and social care services are delivered in Ireland.(4) The Framework identifies patients as empowered partners and an enabled workforce as fundamental principles to achieve seamless, safe, secure, and connected digital health services. The HSE has developed a corresponding Digital Health Strategic Implementation Roadmap which sets out the digital initiatives which will deliver the vision and mission of the Framework.(5)

In the context of these developments and increased investment in digital care, HIQA in partnership with the Department of Health and the HSE conducted the National Engagement on Digital Health and Social Care. This project helped to gather the views of the people who will be impacted by digital transformations in health and social care, namely the public and professionals working in health and social care. This is particularly important in the context of changes to service delivery brought about by the COVID-19 pandemic and attitudes to eHealth information technologies in the aftermath of the cyberattack* in the HSE.

The findings from this engagement will provide insights to inform the development and provision of digital health systems and services in Ireland. HIQA will use the findings to inform their health information programme of work. The Department of Health and the HSE will also use the findings to inform legislation, national policy, and future developments in digital health and social care.

1.2. Aim of the National Engagement on Digital Health and Social Care

The aim of the National Engagement on Digital Health and Social Care was to understand the opinions and attitudes of the Irish public and professionals in relation to the digitalisation of health and social care services.

The key objective was to listen to the voice of the public and professionals working in health and social care and to use the findings to inform how digital health information and services are developed and provided so they are people centred and built for the Irish context.

1.3. Partnership approach

HIQA, in partnership with the Department of Health and the HSE, has conducted a National Engagement on Digital Health and Social Care. HIQA is an independent statutory body established to promote safety and quality in the provision of health and social care services for the benefit and welfare of the population. HIQA has a legislative remit under the Health Act 2007 to drive improvements in health information in Ireland. The Department of Health has overall responsibility for leadership and policy decision-making in the Irish health sector and the HSE's role is to provide Ireland's public health service in hospitals and communities nationally.

The engagement enabled the general public and professionals working in health and social care to voice their opinions on the digitisation of health and social care in Ireland. This feedback has provided a rich source of information that will allow the partner organisations to work towards improving how digital health and social care is progressed in Ireland.

The partnership was underpinned by a memorandum of understanding, clearly stating each partner organisation's role and responsibilities.

A governance model was developed to support the National Engagement on Digital Health and Social Care. This model included

- **The steering group for the National Engagement on Digital Health and Social Care:** The steering group was responsible for strategic direction and oversight of the national engagement. The steering group comprised of members from HIQA, the Department of Health, the HSE, and patient representatives. The membership of the steering group can be found in Appendix 1.
- **The partnership project team:** This team was responsible for the delivery of the project, developing the methodology, and analysing and reporting on findings. While the core team was based within HIQA, the partnership project

team also included representatives from the Department of Health and the HSE who reviewed documentation and joined team meetings as required.

1.4. Ethical approval

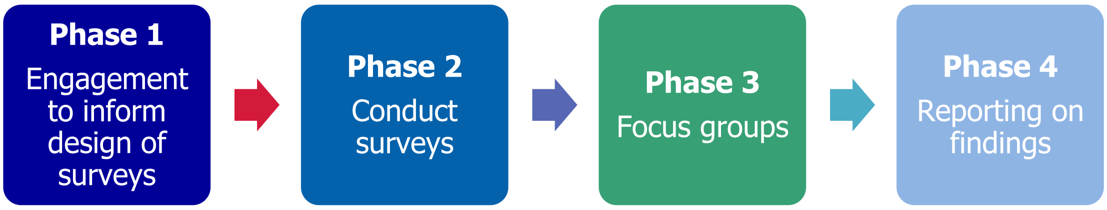
Ethical approval for the National Engagement on Digital Health and Social Care was obtained from the Royal College of Physicians of Ireland (RCPI).

1.5. Information governance

Information governance is a means of ensuring that all data, including personal information, is handled in line with relevant legislation, guidance, and evidence-based practices. In line with legislative requirements, a Data Protection Impact Assessment (DPIA) was conducted to ensure that all engagement activities were completed in a manner that is fair, secure, and respects the privacy of the research participants. Documentation was developed to explain why information was collected, how this data was processed and handled, and how research participants' privacy was protected. The Summary DPIA is available to download from HIQA's website here.

2. Methodology and participants

There were four phases to the National Engagement on Digital Health and Social Care which are outlined in this section of the report. A more detailed description of the methodology has been published in the technical report for the National Engagement of Digital Health and Social Care, which can be found on https://www.hiqa.ie/.



2.1. Phase 1: Engagement to inform the survey design

To inform the development of the survey questionnaires for the public and for the professionals working in health and social care, a review of international evidence was undertaken. Focus groups and engagement meetings were conducted to gain an understanding of the digitalisation of health and social care services for both the public and professionals. This provided an understanding of important issues that needed to be addressed in the survey questionnaires.

The engagement activities that informed the survey design for the public included:

- two focus groups with eight HIQA staff representing different functions across HIQA
- 10 cognitive interviews with the Irish public to assess the clarity and appropriateness of the proposed survey questions.

The engagement activities that informed the survey design for the professionals across health and social care included:

- two focus groups and one interview with 12 professionals
- 10 cognitive interviews with professionals across health and social care to assess the clarity and appropriateness of the proposed survey questions.

The public and professional surveys were developed by the HIQA project team in collaboration with the project steering group.

2.2. Phase 2: Conduct surveys

Public telephone survey methodology and participants

The public telephone survey was conducted with a representative sample of 2,009 people aged 18 and over, living in the Republic of Ireland. A managed service was contracted to administer the survey and to process the responses received.

The survey included 27 questions (see Appendix 2 for the full survey tool). Questions 1 to 14 collected information about people's opinions, expectations and readiness for the digitisation of health and social care services, including any potential benefits, challenges, and impacts. The survey addressed the following topics:

- Accessing information and sharing information digitally
- Sharing online health information
- Digital care.

Questions 15 to 27 collected key demographic information about participants and their health status. Table 1 includes a high-level overview of participant demographics. See Appendix 3 for more detailed information on participant demographics and characteristics.

Table 1[†]: Demographics of public survey participants

Demographic	Number of participants	%
Age category		
18 to 24	231	11
25 to 34	319	16
35 to 49	597	30
50 to 64	466	23
65 or older	396	20
Gender		
Male	982	49

[†] Please note that values in tables do not always add up to 100% exactly. This is due to rounding. Please note the figures in this table are weighted. For unweighted responses please see the published data file on www.hiqa.ie.

Female	1026	51
Other	>5	0.1
Long-term or chronic condition		
Yes	704	35
No	1281	64
Pass	24	1

Professional online survey methodology and participants

The professional online survey was conducted with a sample of 1,020 professionals working in health and social care, including those working in dentistry, medicine, nursing or midwifery, pharmacy, pre-hospital emergency care, psychology, or health and social care professionals registered with CORU (Ireland's multi-profession health regulator). The survey was promoted by HIQA through a variety of channels including social media posts and the link to the survey was shared with key stakeholders including representative bodies. Professionals who were interested could participate via the survey link.

The survey included 26 questions (see Appendix 4 for the full survey tool). Questions 1 to 19 collected information about professional's opinions, expectations and readiness for the digitisation of health and social care services, including any potential benefits, challenges, and impacts. The survey addressed the followings topics:

- Sharing health and social care information with the public
- The public providing information
- Providing services and communicating digitally with the public.

Questions 20 to 26 collected key demographic information, including current employment status and the primary area participants reported that they worked in. Table 2 includes a high-level overview of participant demographics and characteristics. See Appendix 3 for more detailed information on participant demographics and characteristics.

Table 2: Characteristics of professional survey participants[‡]

Data on who took part	Number of participants	%
Age		
18-24	6	1
25-34	124	13
35-49	430	46
50-64	363	39
65 or older	18	2
Gender		
Male	202	21
Female	742	78
Other	11	1
Area of work		
Acute	469	46
Community	352	35
Primary care	113	11
Not relevant to my role	77	8

2.3. Phase 3: Focus groups

Public focus groups methodology and participants

Between September 2023 and February 2024, seven focus groups and five one-to-one interviews (a mix of online, in-person and telephone) were held with 41 people.

Specific advocacy organisations from different locations across Ireland were invited to ask individuals they represent to take part in these focus groups. Young people from two schools, one from an urban location and one from a rural location, were asked to take part. Participants included members of the public and representatives of special interest groups including members of the Traveller and Roma

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[‡] Where column totals are less than 1,020 this because not all respondents answered each question. Please note that values in tables do not always add up to 100% exactly. This is due to rounding.

communities, family carers, people with intellectual disabilities, and young people aged 16 and 17. Participants were sent information on the engagement and focus groups in advance and were required to sign a consent form before taking part. To ensure all participants had the required support to give informed consent, the consent form and information sheet were available in a easy to read version.

The focus groups aimed to develop a deeper understanding of the findings of the surveys; ensure the opinions and attitudes gathered are representative of people living in Ireland; and capture the views of those who may have specific needs in relation to digital health and social care which may not have been fully captured in the survey. Focus groups and interviews addressed the following topics:

- Managing health by viewing and interacting with online health records
- Sharing your online record with a trusted family member or friend
- Digital care.

See Appendix 5 for further details on the public focus groups schedule of questions.

Professional focus groups methodology and participants

Between January and February 2024, three focus groups were held with 27 professionals across health and social care (see Table 3 for a breakdown of focus group participants).

Participants were asked in the survey if they wanted to take part in focus groups. HIQA then invited a random selection of participants to take part in the focus groups. Participants were sent information on the engagement and focus groups in advance and were required to sign a consent form before taking part.

The focus groups aimed to develop a deeper understanding of the findings of the professional survey; ensure the opinions and attitudes gathered are representative of professionals working in health and social care in Ireland; and capture the views of those who may have specific needs in relation to digital health and social care which may not have been fully captured in the survey. Focus groups addressed the following topics:

- Professionals sharing information with the public
- The public providing information
- Digital care and changing relationships.

See Appendix 6 for further details on the focus groups schedule of questions.

Table 3: Professional focus groups participants

	Participant group	Number of participants
1	Mix of professionals including; CORU registered professionals, medicine, nursing, pharmacy, psychology	7
2	Mix of professionals including; CORU registered professionals, medicine, nursing, pharmacy, pre-hospital emergency care, psychology	11
3	Mix of professionals including; dentistry, CORU registered professionals, medicine, nursing, pharmacy	9

2.4. Phase 4: Report on findings

The public and professional surveys questions included a mix of numerical and open-ended response options. For numerical survey data, the number of responses for each question was calculated and data are presented in charts in this report. For open-ended questions, answers were coded and findings were integrated into the analysis and write up of the focus group findings. In addition to the survey data presented in this report, survey data files have also been published and are available on www.hiqa.ie.

To analyse data from the public and professional focus groups, coding frameworks were developed, information was categorised into findings and key quotes were identified for inclusion in the report.

Further information on the analysis of the public and professional survey responses and the public and professional focus groups can be found in the technical report published on www.hiqa.ie.

3. National Engagement on Digital Health and Social Care – public survey and focus groups

This section of the report describes the findings from the National Engagement on Digital Health and Social Care public survey, focus groups and interviews (referred to as focus groups hereafter).

Information is presented under the three topics, which were covered in the public survey and further explored in the public focus groups, as follows:

- The public accessing and sharing information digitally
- Sharing health and social care information
- Digital care.

For each topic, an overview of results and key findings are presented followed by the results for individual survey questions and focus group findings. Survey results are presented in charts with a description of the highest and lowest-rated response options. Related focus group findings are presented alongside the survey results and additional focus group findings are presented at the end of each section. Focus group findings include direct quotes from participants. The section concludes with a summary of the overall findings from the survey and focus groups.

3.1 The public accessing and sharing information digitally

The first section of the survey explored the public's comfort with using digital technology and the type of information the public would like to view in their online health record. Questions also asked the public how important different functions of an online health record are for managing their health, the benefits of having online access to health and social care information and what types of information the public would like to add to their online health record. In the focus groups, topics discussed included comfort with an online health record, additional information the public would like to add to an online health record and the benefits and challenges of an online health record.

Overall, the majority of people surveyed were comfortable with using digital technology. The public would like to have one centralised record that contains information from all services that they attend. The public would like to have access to all types of information related to their health in their online health record; however, mental health and sexual health information were rated as less important in this regard. In the focus groups, the participants noted more specific information they would like to see in a record for example prompts about health checks.

Members of the Traveller community emphasised they would like an ethnic identifier included in their record.

Being able to contact a professional about information missing, or errors in their record was rated by the public as the most important function of an online health record. The public noted it would be most useful to add information to their online health record and rated health information not diagnosed by a medical professional as most important. Focus group participants felt that adding information and correcting errors in an online record is important, but they would like any changes made to their record to be overseen by a professional working in health and social care.

The public saw a number of benefits to having access to their health and social care information and having all information in one place was rated most highly. In the focus groups, participants further elaborated on this point, they felt by having an online health record, they would have more control over their health and it would empower people on their healthcare journey. By having access to an online record, they would be more knowledgeable about their health and would be able to have more informed conversations with professionals working in health and social care. However, the public also spoke about their concern relating to the data security and privacy, and would like assurances that any information stored in an online health record would be kept confidential and secure.

Key findings regarding the public accessing and sharing information digitally

- The public surveyed rated emergency contact details (**93%**), details about blood tests, X-rays or other scans (**92%**), current prescribed medications (**91%**) and current health conditions or diagnosis (**91%**) as most important to have in their online record.
- The public would like a centralised online health record that contains information from all health and social care services they attend.
- The public felt that having all information in one place to help understand their health (**91%**) was the main benefit of an online health record. The public think they will have more control over their health and will be able to have more informed conversations with professionals working in health and social care about their care.
- The public think it would be beneficial to identify errors (**90%** rated this an important) and to add information not yet diagnosed by a professional (**83%** rated this as important) to their online record, however, the public want a professional to oversee any edit to their record.
- Data privacy and security is the greatest concern mentioned by the public of an online health record. The public would like assurances that their information will be stored safely and kept confidential.

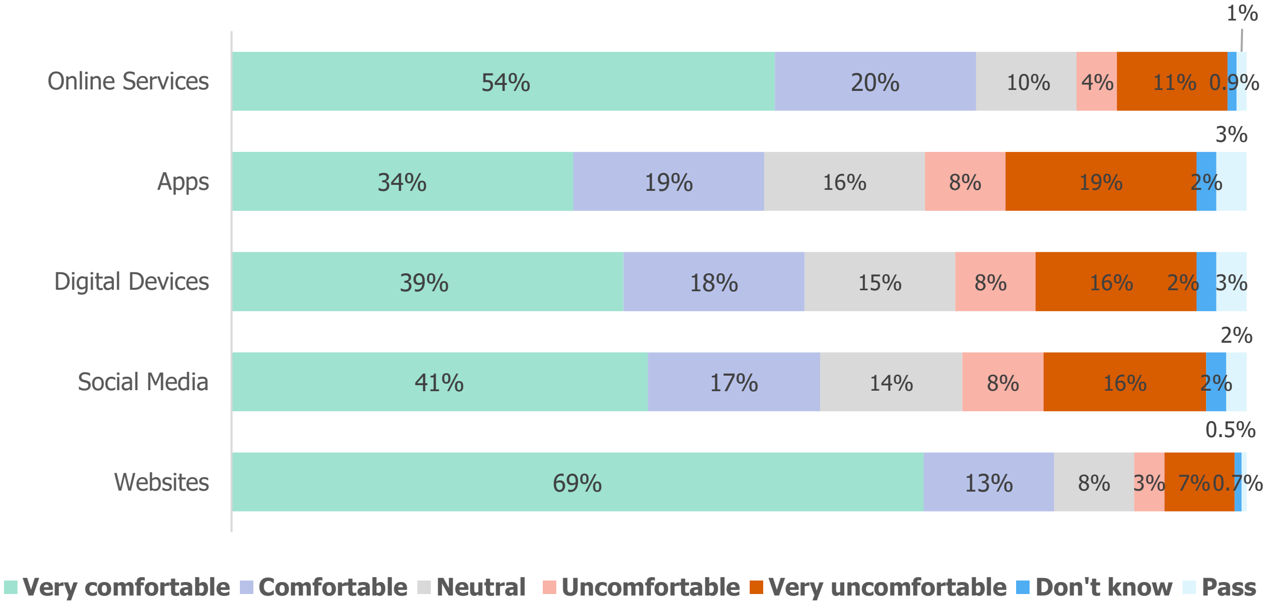
3.1.1 The public's comfort using digital technologies

Question 1: The public were asked about their level of comfort using digital technologies across five different areas.

- **82%** of people indicated they were comfortable or very comfortable using websites like google.
- A lower proportion of respondents reported being comfortable or very comfortable using digital devices related to health, such as smart watches **(57%)** or health apps **(53%)**.

See figure 1 for a more detailed breakdown of information on the public level of comfort using digital technologies.

Figure 1: Public level of comfort using digital technology



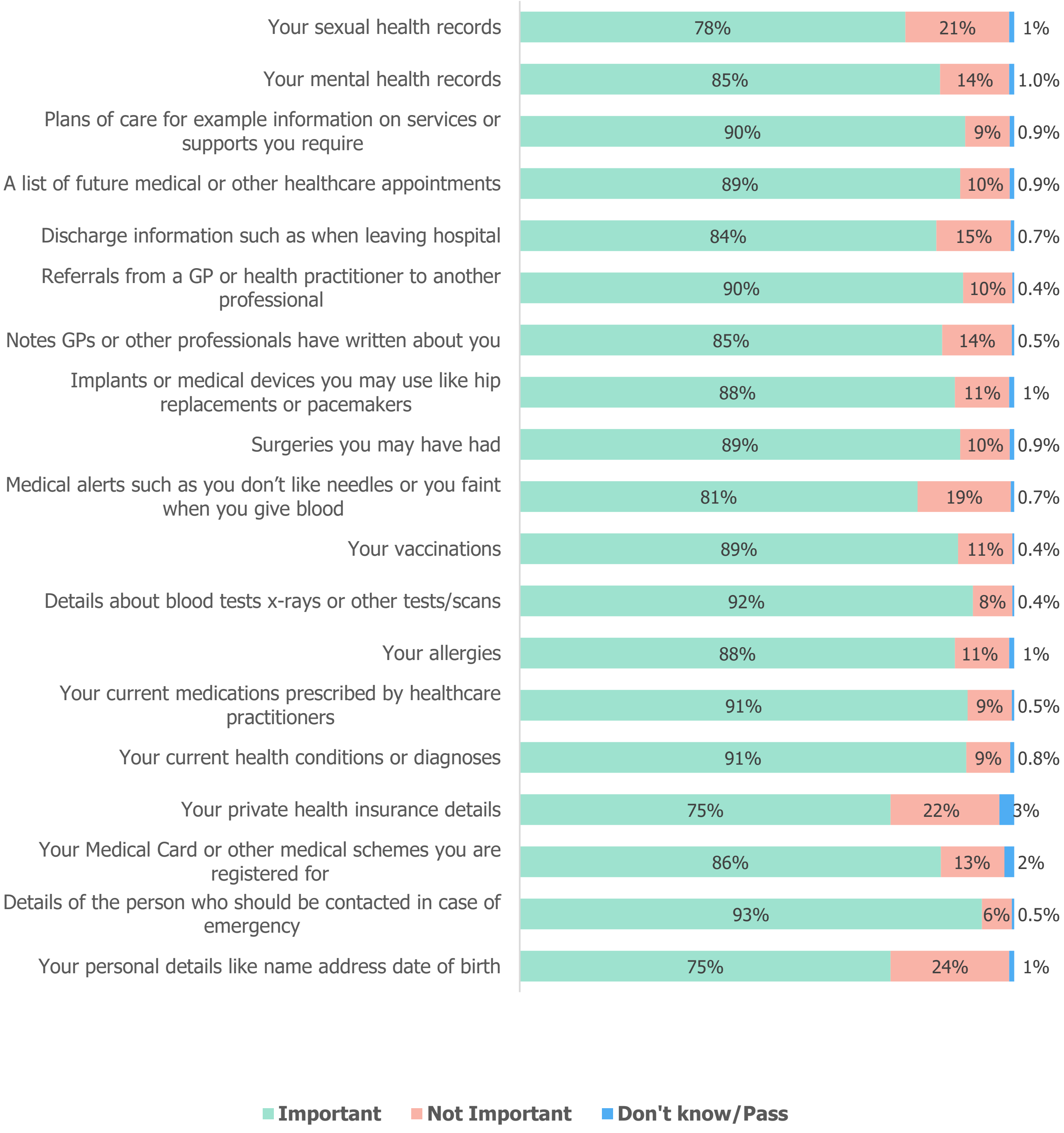
3.1.2 Types of information that should be added to an online record

Question 2: The public were asked about the types of information (19 categories) they would like to see added to their health record after they visit a GP, other health professional or a hospital.

- At least **90%** of respondents (over 1,800 people) indicated that it would be important to include the following four types of information in their online health record: emergency contact details; details about blood tests, X-rays or other scans; current prescribed medications and current health conditions or diagnosis.
- A lower proportion of respondents, **78%** (1,571 people) identified sexual health records as being important to include in their online health record.

See figure 2 for a more detailed breakdown of information the public want added to their online health record.

Figure 2: Types of information the public would like to see added to their online health record



Focus group finding regarding information in an online health record:

The public identified further information that they think is important to include in an online health record.

In addition to survey feedback, focus group participants also identified other types of information they would like included in their online health record. Being able to include their wishes and information on power of attorney in the event of not being able to advocate for themselves was highlighted. The public would also like a function in their record that would give reminders and prompts about any outstanding health tests required, for example, if they are due a blood test or breast screening. People who use disability services indicated they would like a fear of needles to be included in their online record. Carers highlighted how it would be important to note on their online health record that they are in a 'caring role', so in the event that they were in an accident or had a medical emergency, someone could see on their record that there is a person that they are caring for and support could be provided. Inclusion of an ethnic identifier was identified as important by members of the Traveller community.

> *"Digital health is coming in, I think there's no good going back in five years' time saying oh well we should have put the [ethnic] identifier into it, they need to do that before when this is being set up." (member of the Traveller community)*

Participants also indicated that they would like to be asked on a regular basis for their input on the design and layout of an online record and that they would like processes in place to ensure continual improvements.

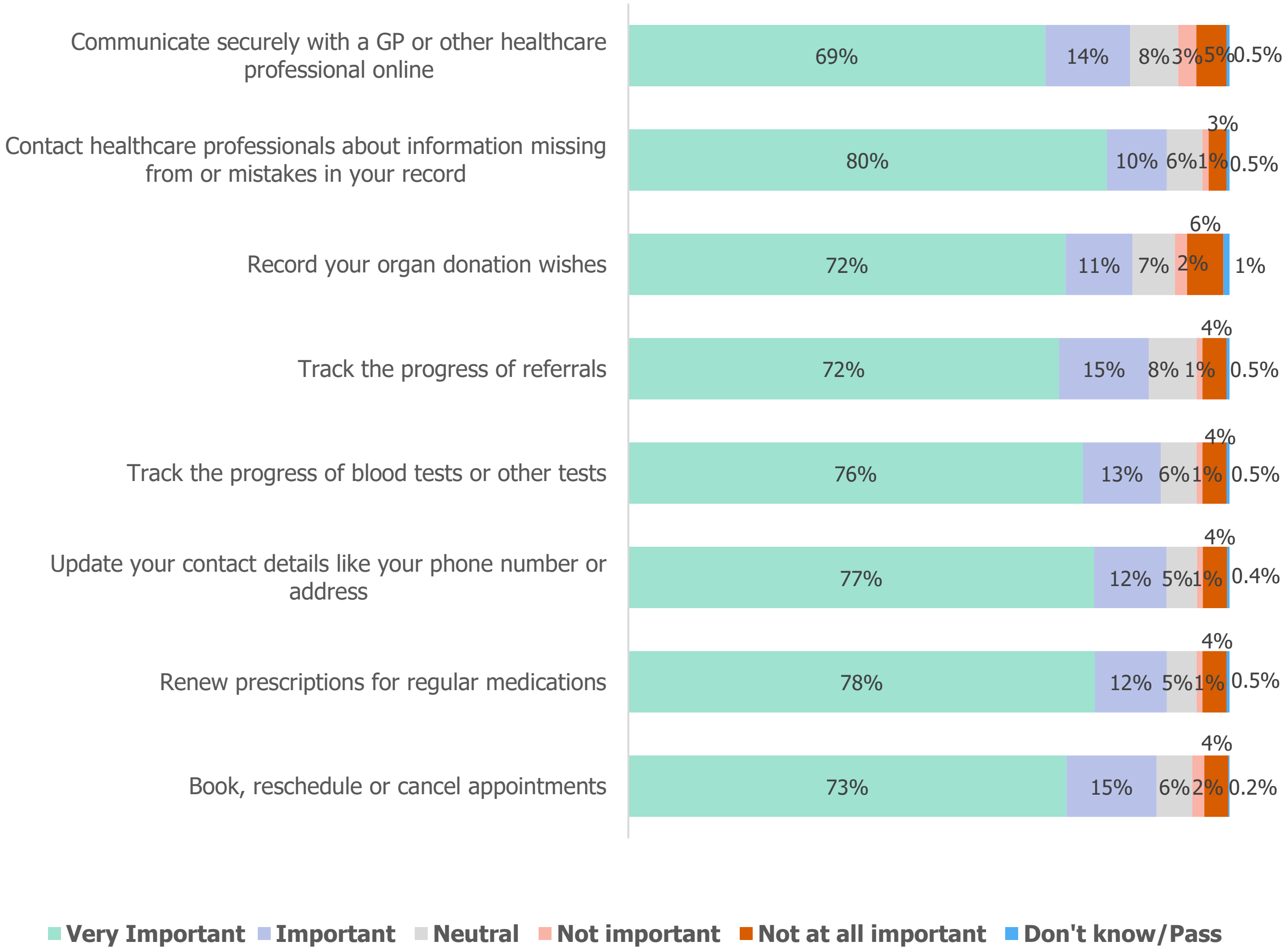
3.1.3 The functions of an online health record

Question 3: The public were asked to rate the importance of eight different functions of an online health record that could help them to manage their health.

- **90%** of people identified being able to contact healthcare professionals about information missing from or mistakes in their record, and being able to renew prescriptions for regular medications as two important or very important functions of an online health record.
- A lower proportion of respondents, **83%** (1,669 people) said being able to communicate securely with a GP or other health professional online would be an important or very important function.

See figure 3 for a more detailed breakdown of different aspects of an online health record that the public would find important to help manage their health.

Figure 3: Online health record functions the public think are important



The public were asked if there were any additional functions they would like in an online health record. The public mentioned the following additional functions:

- access to all medical records or one overall record that is transferrable
- access to children's or older parents’ records
- access to support services or relevant information, including health insurance options, social welfare, revenue.

Focus group finding regarding online health record functions:

The public would like to flag errors in their records and add information to their online record, however, they would like this to be overseen by a professional.

In addition to the functions captured under question 3, focus group participants identified that they would also like to be able to add notes to their record to provide the professional they are seeing with any updates about their health or to add information they may think is relevant, such as family history of cancer, lifestyle information.

> *"you remember to tell one doctor [your family history] but possibly not the next..having that readily available to anyone reading your [online record] would be really nice." (Public group)*

In line with survey feedback, focus group participants indicated that they would like to be able to flag any errors or omissions in their online health record. Additionally, participants indicated that they would like changes to their record to be overseen by a professional.

> *"For example to correct missing information, that a medical professional would have to confirm that the information is incorrect or missing before having it removed." (16-18 year old)*

3.1.4 Benefits of having online access to health and social care information

Question 4: The public were asked to rate six potential benefits to having online access to health and social care information in the future.

- At least **90%** of people (over 1,800) agreed or strongly agreed that having all information in one place and helping to manage health between visits were two of the main benefits of having online access to their health and care information.
- A lower proportion of respondents **86%** (1,712 people) agreed or strongly agreed that an online record could help them prepare questions or information they want to share during an appointment.

See figure 4 for a more detailed breakdown of how the public rated the potential benefits of having online access to their health and social care information.

Figure 4: Public perceived benefits to having online access to your health and social care information

Focus group findings regarding perceived benefits to having online access to health records

The public think an online record will help them have more autonomy and to actively participate in decisions around their care.

In line with survey feedback, focus group participants felt that having access to their online record would help them be more knowledgeable about their health, and have more informed conversations with a professional working in health and social care.

> *"Everybody would have the same view, that the more information you can get about your own care and your own records, the more it puts things in your own control to a certain extent. And that you are effectively managing your own health." (Public group)*

Participants indicated that they would still like professionals to explain their health information to them in an easy-to-understand format. However, if they forget something from an appointment, having an online record would give them the option to look up and review the information online afterwards.

> *"[the doctor] has explained something and two or three minutes later when I've left I kind of go eh…what did he say? What did he write down? I can't remember half the stuff, I end up ringing him again. So that would take time from him seeing other people, so the idea of having medical records available for people to view online, I agree with." (Public group)*

In addition to survey feedback, participants identified that having access to their medical history will help them to track their health over time, for example to compare results of current blood tests to past blood tests. Participants also indicated they would like to have oversight of their health information to be able to research and understand any diagnosis they receive.

The public think online health records are important to improve patient safety.

In addition to survey feedback on benefits, participants indicated that having an online record of a person's medical history could improve patient safety. Participants noted that there is a lot of pressure and responsibility put on patients to recall their healthcare information and they are often concerned that they could miss information that would be important or relevant to decisions around their care. Concerns regarding presenting to hospital unconscious and doctors having no awareness of their past medical history or any allergies were also discussed.

> *"The other side is vaccinations… you get asked and you can't remember when was the last time you had a tetanus shot or whatever." (Public group)*

> *"If someone has an allergy to penicillin and are unconscious, they mightn't be able to give the information. So if there's records to be accessed, it will hopefully improve people's care." (Public group)*

Focus group participants felt that if technology can be used effectively, it will lead to efficiencies and reduced wait times for appointments. Participants noted that telephone and video consultations have a purpose for quick, routine appointments, for example, renewing prescriptions or receiving results of blood tests, but that in-person appointments should be prioritised for those with more urgent care needs.

> *"If it was over the phone and they could work a mini-triage system after that. So you only went in if you needed to go in. It means people can get through more patients in one level, and then they can give the time to the patients that need the actual one-to-one consultations."* (Public group)

People in the focus groups also felt that moving to online health records will improve the overall standard of care delivered with professionals being able to track their medical history, for example, a professional could track a person's mental health over time, which could have an important impact on decisions around their care.

> *"Doctor writes down all those notes, you know, so he is getting a better picture of whether a person is getting better over time or whether the person is getting worse." (Public group)*

Some people did express concern that if doctors are aware that the public will be reading their professional notes, they may be less honest or leave out some key details.

> *"I feel they might be less honest about it if they know their patient will be reading what they are writing, if this is for mental health also. They might feel like if the patients read what they say after they might be offended or insulted in some way they might not be as honest as they would be." (16-18 year old)*

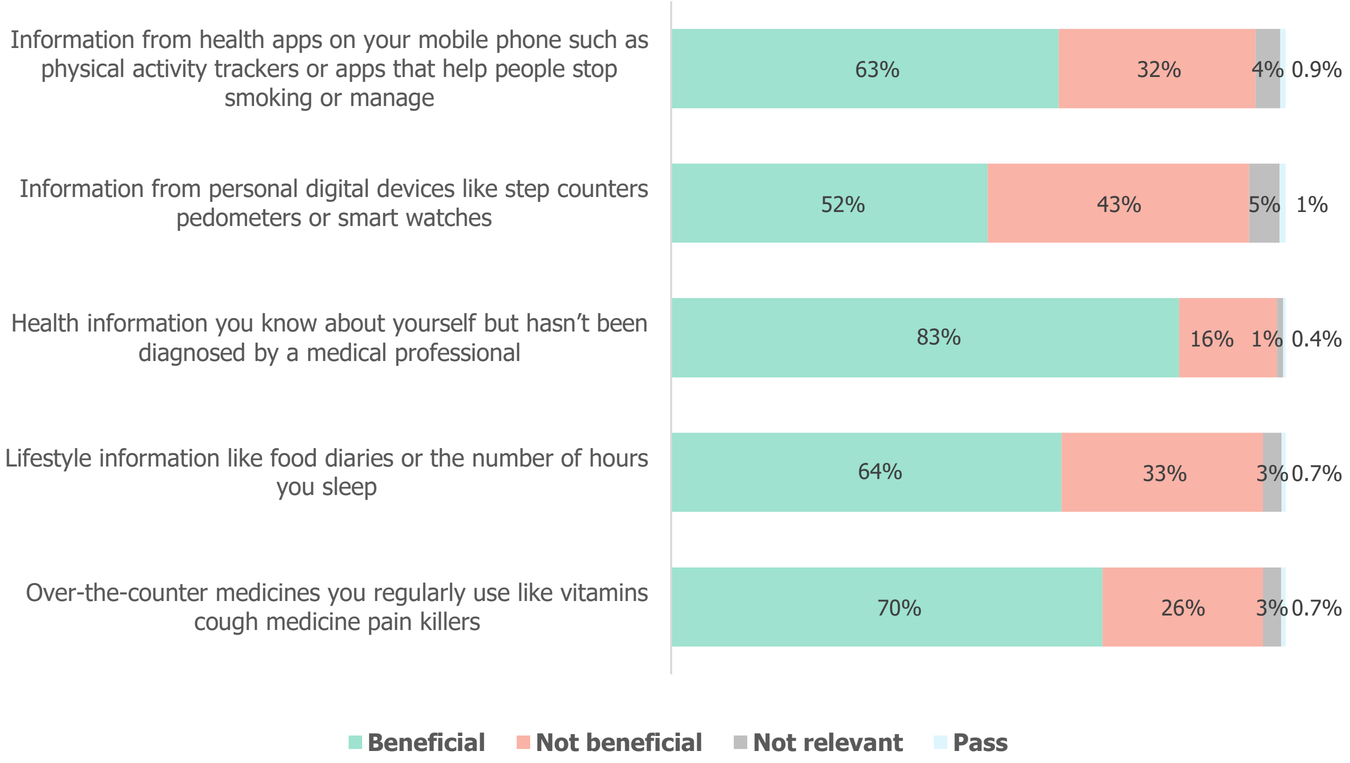
3.1.5 Adding information to an online health record

Question 5: The public were asked if they thought it would be beneficial for them to be able to add certain types of information (five types) to their online health record.

- 1,662 people (**83%**) thought it would be beneficial to add health information that has not yet been diagnosed by a medical professional for example, food intolerances, and allergies.
- A lower proportion of respondents, **52%** (1,034 people) thought it would be beneficial to be able to add information from personal digital devices, like step counters pedometers or smart watches.

See figure 5 for a more detailed breakdown of the type of information people thought would be beneficial to add to their online health record.

Figure 5: Public perceived benefits to adding information to online health record



The public were asked if there were other types of information they would like to add to an online record. Types of information people mentioned included:

- alcohol and or drug consumption
- anxiety or mental health information
- current health issues or record of illnesses, or injuries
- family history
- height and or weight
- test results that are accessible to patients for example blood pressure reading; periods, menstrual cycle tracker, fertility tracker, or symptom tracker
- personal requests.

Additional focus group findings regarding online health records

The public would like an online health record that contains information from all health and social care services that they attend.

Focus group participants indicated that they would like to see greater cohesiveness and communication between different professionals and services across health and social care (public, private and general practitioners [GPs]) and hope that this will be facilitated through a centralised online record.

> *"The problem we have come across is that attending services, for example, that are housed in the same building with a common reception desk, when we had a consultation with a consultant in one, we walked five meters across the corridor to a second and all the same information had to be given again. We had to list off the drugs, the scans, all that stuff." (Public group)*

> *"There does need to be a central archive or a central system where you can join up BreastCheck with …oncology or whatever." (Public group)*

There was mixed opinion regarding who should have responsibility for sharing the online health record among different professionals who may have input to a patient's care. Some focus group participants said they want oversight and to provide the information to any professionals that may need access to their online health information. Other focus group participants think that this should be led by the main professional they are attending. Overall, the public want a functionality within their online health record to inform them what professionals are accessing their records, how often and information viewed.

> *"I mean surely someone just can't go in and look at your information without your consent. I presume it would be all driven by the patient" (Public group)*

The public need an online record to be secure and ensure data privacy.

In addition to survey feedback on the benefits of an online record, focus group participants also identified challenges of an online record, in particular concerns regarding data security which have been exacerbated by the cyberattack* on the HSE. Participants noted that they would want to be fully informed of the steps that will be taken to keep their data secure, to know where their information is stored and will need reassurance that their information is secure before they feel comfortable with their data being shared in an online format. Data security measures including password-protected official online systems, and providing education on data security were highlighted as important by participants. Participants indicated that they would only download an app if it was advised by their doctor and would also want assurances that the app was approved by the health service.

> *"I would still be sceptical about it, because at the end of the day, you will always get someone that will be able to hack into and everything is there for that person to see." (Person who uses disability services)*
>
> *"You have where the IT system in the HSE was hacked. Like all this could happen and all your personal information is dragged out … and that can be published anywhere. I have that fear." (Public group)*
>
> *"when you are connecting all of your stuff to a computer it can be accessed by anyone who has your password….You wouldn't want a similar thing with medical records, so like proper two factor authentication and like notifying people when someone goes into their account." (16-18 year old)*

Participants also noted concerns regarding their information being shared incorrectly with the wrong person. This was of particular concern to members of the Traveller community, who said that people often have the same name, date of birth and similar address. They referenced experiences in the past where information has been sent incorrectly to the wrong person.

> *"If you have two lads there around the same age bracket, and they have the same name probably nearly the same date of birth, I wouldn't feel comfortable with all that." (member of the Traveller community)*

3.2 Sharing health and social care information

The second section of the public survey asked their attitudes and opinions on sharing online health information. The public were asked their level of comfort sharing their information with a trusted family member or friend in an online health record, and what actions would increase their comfort sharing an online health record with a trusted friend or family member. The focus group further captured participants' views on sharing information in an online health record with a trusted family member or friend.

The majority of participants were comfortable sharing a variety of health information with a trusted family member or friend. The public would like to control the level of information that is shared with a trusted family member or friend, in particular, the public are less comfortable sharing information about mental health or sexual health. The public would also like to be informed of any information about their health prior to it being uploaded on their shared online health record. The public would like to be able to remove someone's access and control what a person could see in their online record.

Key findings regarding sharing health and social care information

- The public would be comfortable sharing a variety of health information with a trusted individual, including details of the person to contact in case of emergency (**82%**), information about allergies (**81%**) and information about implants or medical devices they may use like hip replacements or pacemakers (**79%**).
- The public would not be as comfortable sharing sensitive information about their health, including information about their sexual health or mental health.
- The public want control of their record and they want to see any information added to their record prior to it being shared with a trusted family member or friend. The public also want the option to restrict a trusted friend or family member's access to information that they are not comfortable sharing.

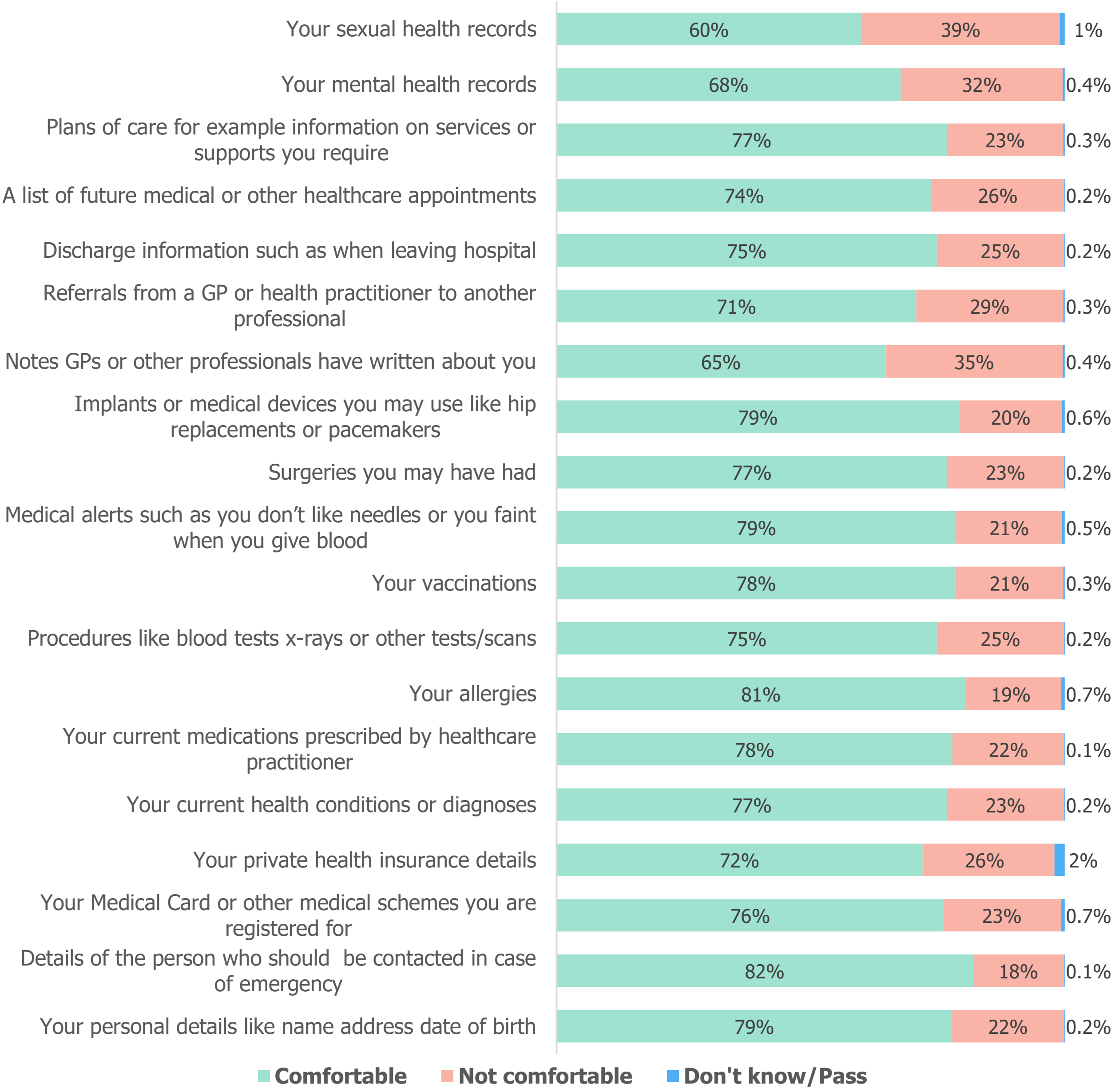
3.2.1 Sharing information with a trusted family member or friend

Question 6: The public were asked about the type of health information they would be comfortable sharing with a trusted individual in an online health record.

- **Over 80%** people (over 1,600 people) reported that details of the person who should be contacted in case of emergency and information about allergies were two types of information that they would be comfortable to share with a trusted individual in an online health record.
- A lower proportion of respondents, **60%** (1,203 people) indicated that would be comfortable sharing sexual health records.
- 333 people (**17%**) said that they would not be comfortable sharing anything.

See figure 6 for a more detailed breakdown of the type of information people would be comfortable sharing with a trusted individual in an online health record.

Figure 6: Public comfort sharing health and social care information with a trusted individual in an online health record



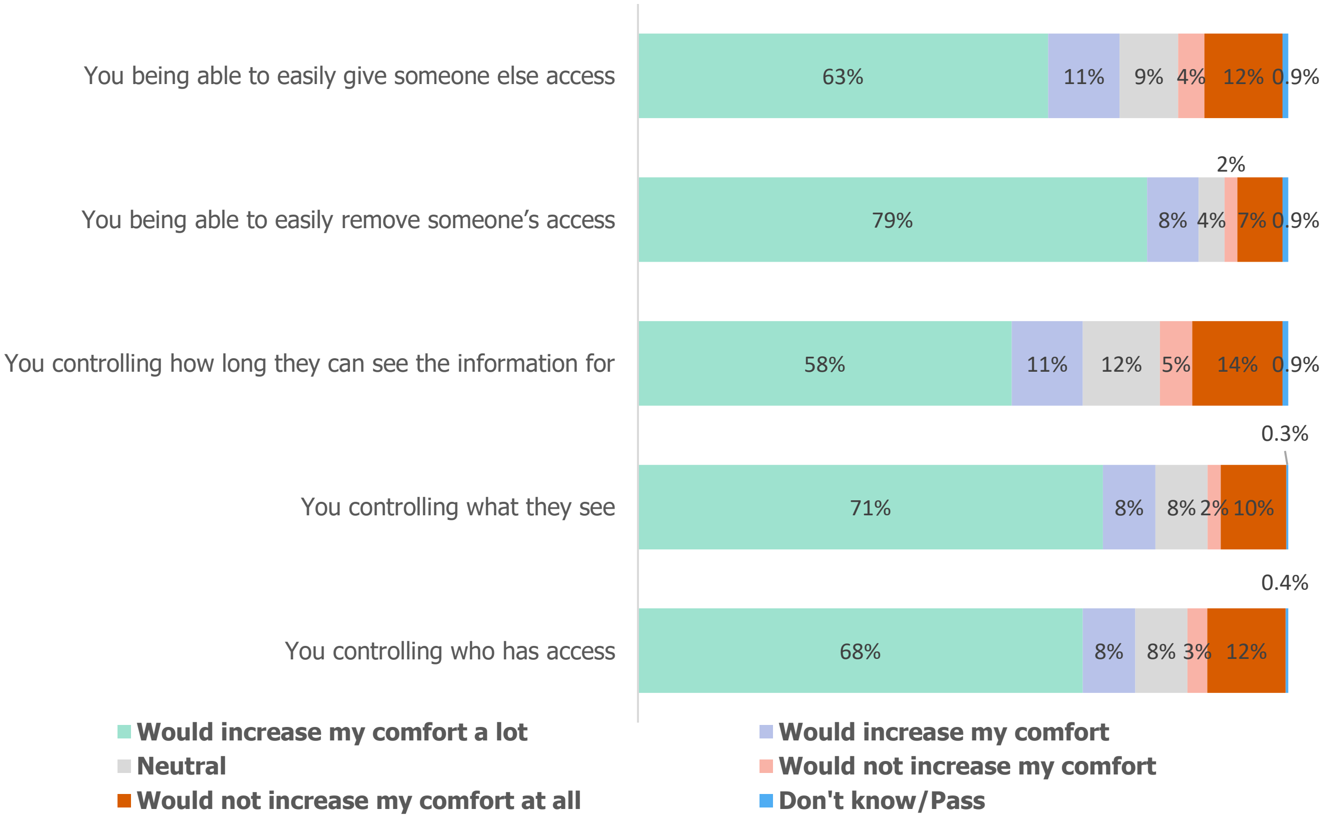
Question 7: This was a follow-on question to question 6. The respondents who reported feeling uncomfortable sharing at least one type of information with a trusted individual in an online health record in question 6 (989 people) were asked whether certain actions would increase their levels of comfort.

- 851 people (**87%**) said that being able to easily remove someone's access would increase their comfort.

- A lower proportion of respondents, **69%** (679 people) stated that having control of how long someone else can see the information for would increase their comfort.

See figure 7 for a more detailed breakdown of the actions that would increase comfort around sharing information with a trusted individual in their online health record.

Figure 7: Actions to increase comfort sharing health information with a trusted individual in an online health record



Focus group finding regarding sharing information with a trusted family member or friend:

The public want control over their online health record.

In line with survey feedback, focus group participants reported that they would be happy to share their online health record with a trusted family member or friend. Nonetheless, the participants indicated that they want control over who can access the record and want the ability to update and add new family members or friends depending on their medical situation. The public also want to be able to remove and update a trusted family member or friend's access immediately if required, for example, if their partner dies or in the case of divorce.

> *"to be able to update it through changes in family circumstances, be it death or divorce, or whatever the case may be…it needs to be updateable." (Public group)*

In addition to survey feedback, participants indicated that they would like to be able to view when their trusted person accesses their record, how often, and to be able to see if someone screenshots or copies the information.

Most focus group participants indicated that they would be happy to have their next-of-kin as the person who is assigned access, but in general, would not be happy for their information to be shared with multiple family members or friends, however there may be times when this is necessary.

> *"obviously just your next of kin. I wouldn't be in favour of say four or five people being able to access it, unless they are a medical professional." (Public group)*

In relation to the type of information that the public would be comfortable sharing, similar to survey feedback, participants indicated they were happy to share general health information, but expressed reluctance to share more sensitive health information, including, sexual health information, or information about their mental health. The public would like to decide the extent to which their medical history is shared, for example, for more sensitive information, the public would like the option to hide this.

> *"when I get into the doctor, I could have something completely private and let it be say contraception or something completely different that I don't want my parents to be aware of." (member of the Traveller community)*
>
> *"you could get diagnosed with depression or something, you wouldn't want everyone knowing that. You can tell someone if you want to, but it's obviously private and you are less inclined to tell someone then, it's not like having a broken bone." (16-18 year old)*

Participants indicated that they would want to have access to their health information first, prior to a trusted family member or friend accessing the information, in particular, if they receive bad news about their health or a new diagnosis, for example, a cancer diagnosis.

> *"you get bad news or something, suppose you are told you have cancer and maybe not terminal cancer, but you are told you have cancer, and you don't really want to worry your wife about it or your kids about it. I'm just wondering does this automatically go onto the system which you have already agreed to share with them. Could some safeguards be built in there." (Public group)*

People with caring responsibilities noted it would be very beneficial to see the online health record of the person they are caring for. They feel they would be more informed of the person's medical history, better able to support the individual, or advocate on their behalf.

> *"I would be his co-decision maker. And I would have a status in that to be able to say these are my brother's records and he's not able to explain it himself, but here's the record. I can just see that benefiting myself hugely and my brother." (Carers group)*

3.3 Digital care

The third section of the public survey explored the public's experience and opinions of digital care. The public were asked if they have ever had a telephone or video consultation and if they felt comfortable engaging with a professional digitally compared to in person. The public were also asked to rate their level of comfort with other types of digital care such as text message reminders. The public were asked if they would be comfortable providing personal information in order to be correctly identified when linking their health information across services. If health and social care information was made available online, the public were asked how likely they would be to engage. The focus groups further explored people's attitudes and opinions toward digital care and in particular their levels of comfort having consultations with professionals online or over the phone.

The public think digital care will be important for improving the efficiency of the health service and for reducing wait times for appointments. The majority of the public have had a telephone consultation with a professional working in health and social care, a smaller percentage have had a video consultation. The public reported higher levels of comfort with video consultations compared to telephone consultations. The public's preference is for in-person appointments, but the public are happy to have an online consultation for routine appointments, for example, receiving the results of a blood test. The public want accommodations to be made for anyone who does not have access to or may have difficulties with accessing digital care, for example, providing support to ensure access or reverting to in-person.

In relation to other types of digital care, the public like receiving text message reminders about upcoming appointments and are also comfortable receiving a prompt to say the results of medical tests are available. The public were least comfortable communicating with a chat feature on a website. The public were happy sharing personal information to identify them when accessing services. While the public were most comfortable using their name and date of birth as a form of identification, they expressed lower levels of comfort regarding using their Personal

Public Service Number (PPSN) and MyGovID. The ability to correctly identify an individual using a unique identifier is essential for patient safety. A safe and secure means to identifying people, such as the PPSN, is crucial to the delivery of high quality, integrated services. Education and supports may be required to increase public comfort providing their PPSN for identification purposes.

Key findings regarding digital care

- The majority of the public (**59%**) have had a telephone consultation with a professional working in health and social care, a minority have had a video consultation (**20%**).
- Overall, the public's preference is for in-person appointments compared to online, **55%** of the public said they would be likely to access a video consultation. The public think online consultations should be used for quick, routine appointments.
- The public want fair and equal access to online health records and digital care by all members of the public. The public want accommodations to be made for those who are unable to access digital technologies.
- The majority of the public said they would be likely to access their online health record when it is made available online (**74%**).
- The public were happy providing personal information in order to correctly identify them when accessing health services. The public were most comfortable providing their name and date of birth (**88%**). The public expressed lower levels of comfort regarding providing their PPSN (**62%**) or MyGovID (**58%**) as a form of identification.

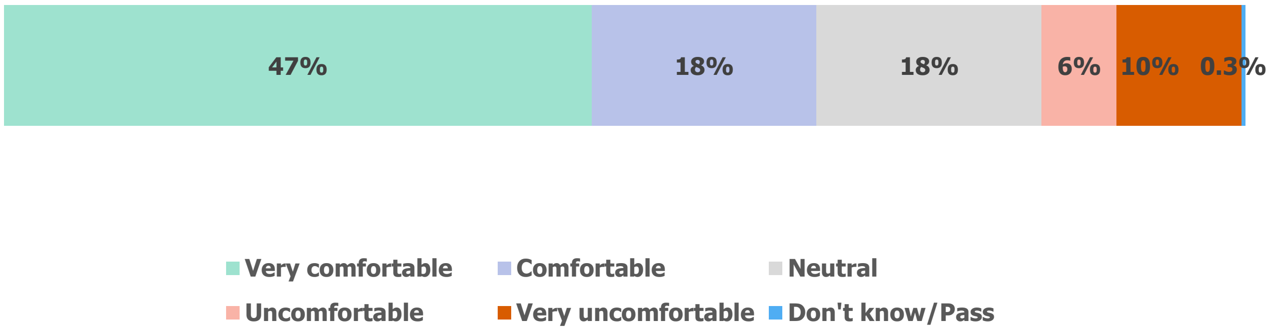
3.3.1 Telephone consultations

Question 8: The public were asked if they have ever had a telephone appointment with a GP or any other professional working in health and social care rather than seeing them in person. For people who indicated they have previously had a telephone appointment, they were asked how comfortable they were speaking by phone rather than having the appointment in person.

- 1,189 people (**59%**) said that they have had a telephone appointment with a GP or another professional working in health and social care rather than seeing them in person. The remaining **41%** of respondents indicated they had not had a telephone appointment.

- Of the 1,189 people who had previously had a telephone appointment, **65%** felt comfortable or very comfortable speaking with a professional on the phone rather than seeing them in-person. See figure 8 for a more detailed breakdown of the public comfort levels with telephone appointments.

Figure 8: Public comfort levels with telephone appointments

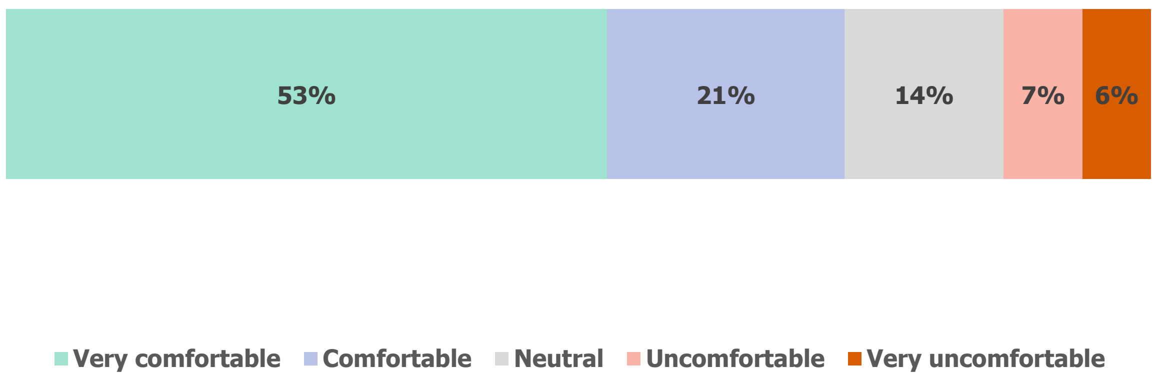


3.3.2 Video Consultations

Question 9: The public were asked if they have ever had an online video consultation with a GP or any other professional working in health and social care rather than seeing them in person. For people who indicated they had experienced an online video consultation, they were asked how comfortable they were speaking by video rather than having the appointment in person.

- 405 people (**20%**) said they have had an online video consultation with a GP or another professional working in health and social care rather than seeing them in-person. The remaining **80%** of respondents indicated they had not had a video consultation.
- Of the 405 people who previously had an online video consultation, **74%** felt comfortable or very comfortable speaking with a professional by video rather than seeing them in-person. See figure 9 for a more detailed breakdown of the public comfort levels with video consultations.

Figure 9: Public comfort levels with video consultations



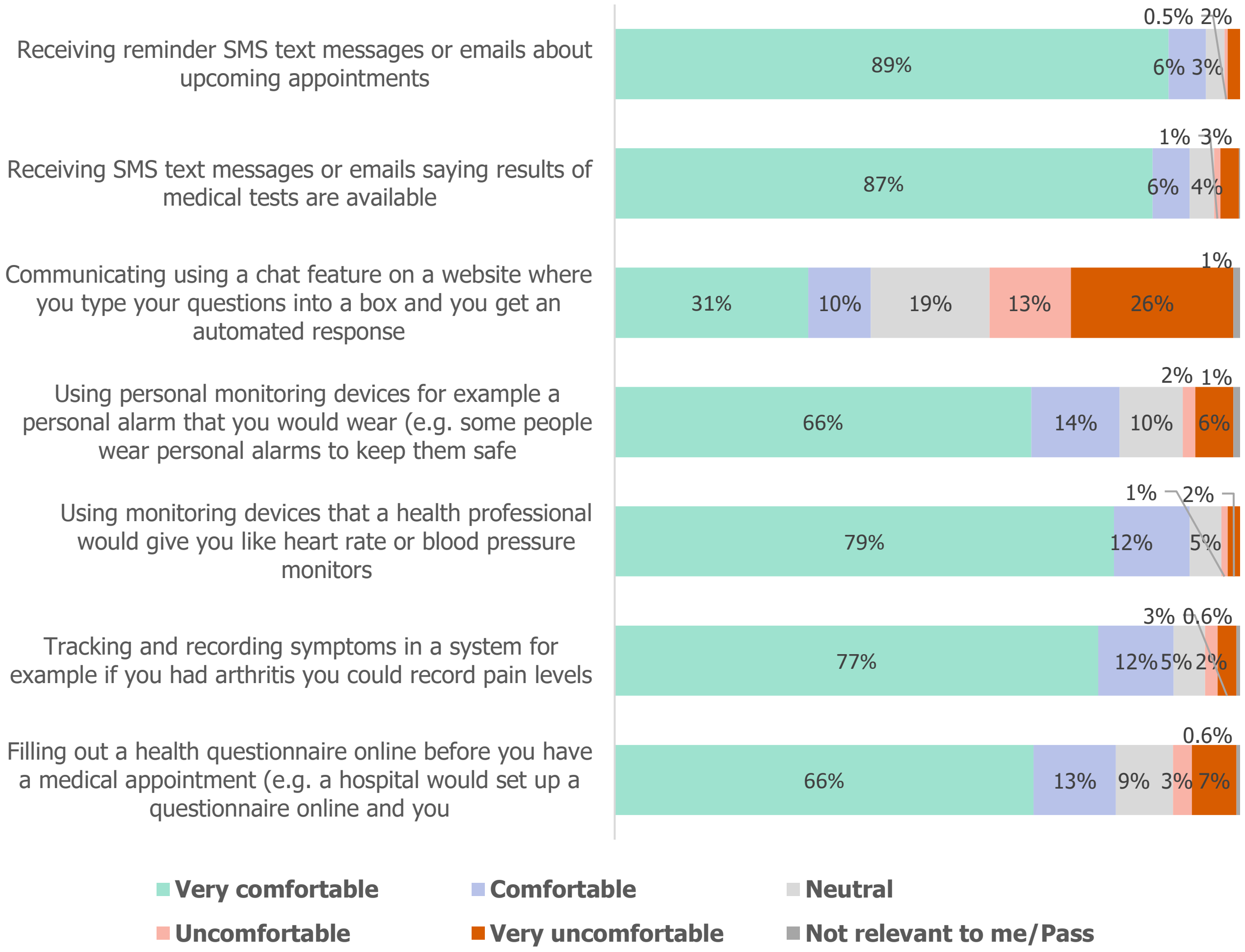
3.3.3 Other types of digital care delivery

Question 10: The public were asked to rate their comfort levels with other types of digital care delivery (seven types).

- **Over 90%** of respondents (over 1,800 people) identified that they would be comfortable or very comfortable with the following three types of digital care: receiving reminder SMS text messages or emails about upcoming appointments; receiving SMS text messages or emails saying results of medical tests are available or using monitoring devices like heart rate or blood pressure monitors.
- A lower proportion of respondents, **41%** (824 people) would be comfortable or very comfortable with communicating using a chat feature on a website.

See figure 10 for a more detailed breakdown of public comfort levels with other types of digital care.

Figure 10: Public comfort with different types of digital care



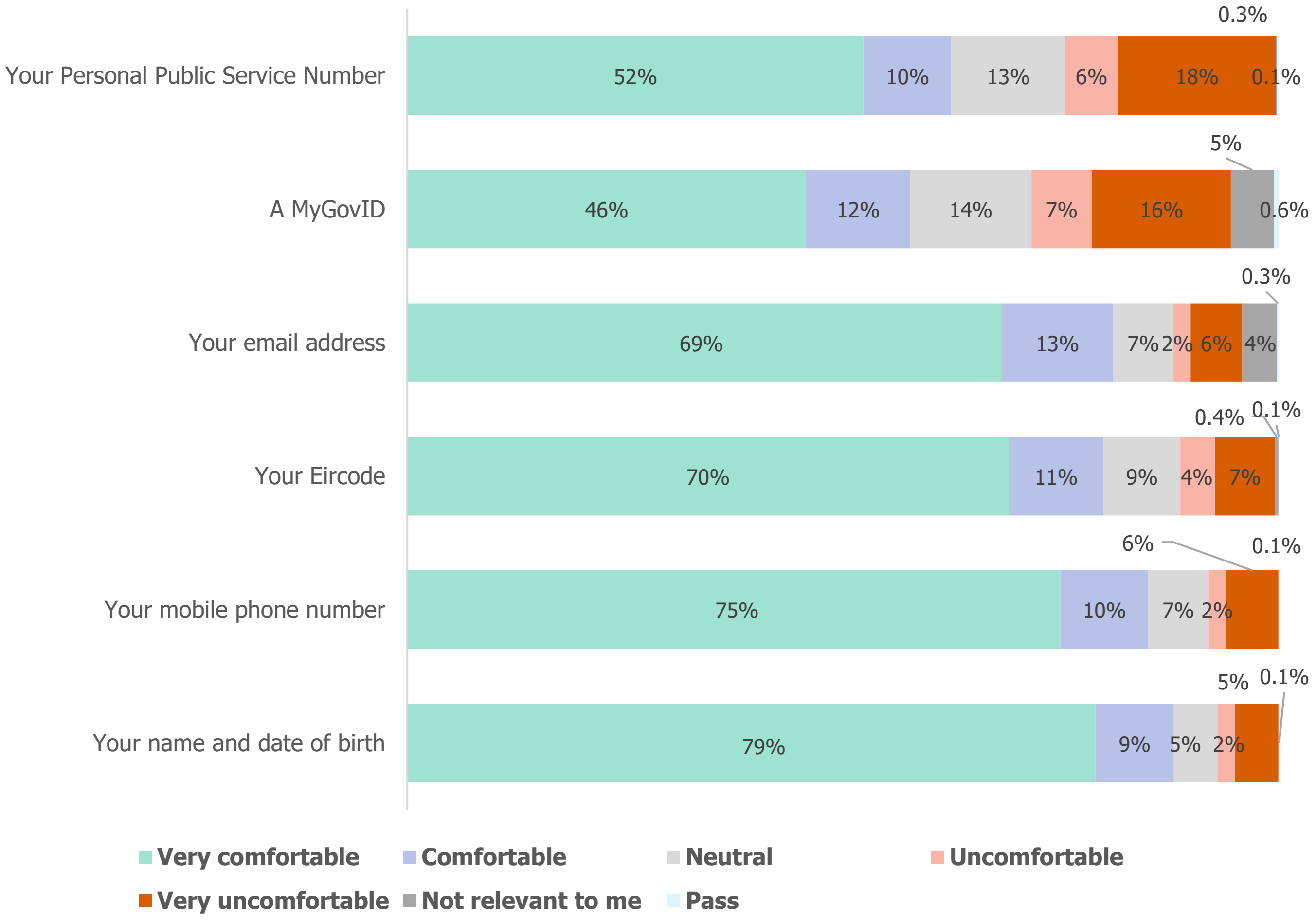
3.3.4 Use of personal information as identification in health services

Question 11: The public were asked how comfortable they would be in providing different types of personal information in order to correctly identify them when accessing health services.

- **Over 85%** of respondents (over 1,700 people) reported being comfortable or very comfortable providing their name and date of birth or mobile phone number to correctly identify them.
- A lower proportion of people reported being comfortable or very comfortable with providing their PPSN (**62%**) or MyGovID **(58%)** to correctly identify them when accessing health services.

See figure 11 for a more detailed breakdown of public comfort levels with providing different types of personal information to correctly identify them when accessing health services.

Figure 11: Public comfort providing other personal information to correctly identify them when accessing health services



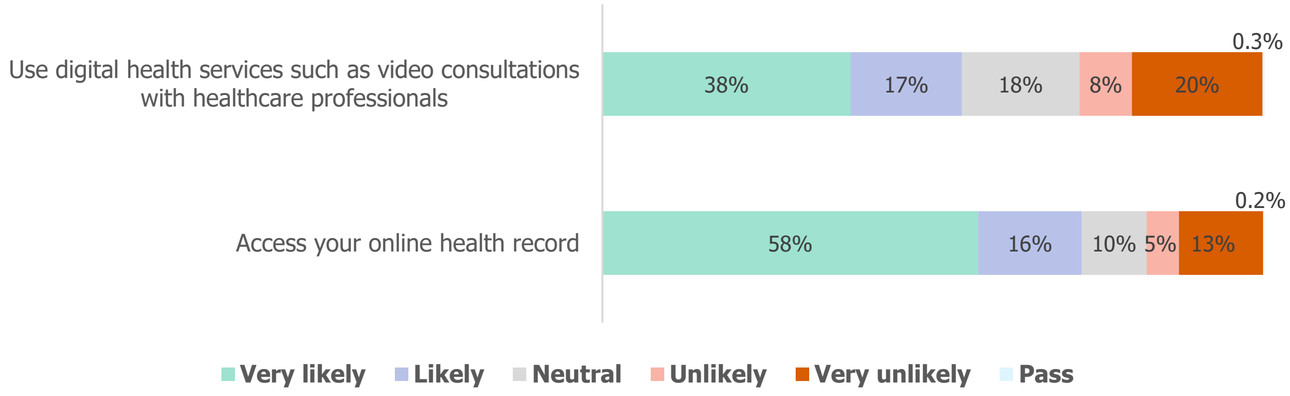
3.3.5 Likelihood of accessing an online health record or digital care

Question 12: The public were asked about how likely they would be to access their online record and use digital health services if their health and social care information was made available online and digital care was made more available.

- 1,470 people (**74%**) said that they are likely or very likely to access their online health record if their health and social care information was made available
- A lower proportion of respondents, 1,095 people (**55%**), said that they are likely or very likely to use digital health services such as video consultations.

See figure 12 for a more detailed breakdown on how likely people would be to access their online record and use digital health services.

Figure 12: Public likelihood to access online health record or use digital services



3.3.6 Challenges to accessing an online health record or digital care

Question 13: The public were asked if there are any perceived challenges to accessing health information online or with digital health and social care. The most frequently reported challenges included:

- ease of access
- fear of forgetting passwords
- issues with internet and broadband
- lack of interest
- no availability of equipment
- security fears.

Additional focus group findings regarding the provision of care digitally

The public need digital care to be secure and ensure data privacy.

Focus group participants expressed concern in relation to the privacy and security of digital care. Some members of the public felt that they would not have a private space in their home where they would feel comfortable having an online consultation with a doctor. Members of the Traveller community in particular spoke about the challenges of finding a private space on a halting site to have a consultation, as people are always coming and going. The public feel that if they do not have a private space to have a consultation, their consultation may not be as effective as they may hold back on providing information due to concern that people may overhear.

> *"at any given time of the day the door can open your child can come in and out, someone could be passing. In halting site settings, there's always someone coming in and out." (member of the Traveller community)*

Young people also expressed concerns around the security of an online consultation. Young people are concerned that someone could hack the call and listen in on the personal information discussed about their health.

> *"I'd prefer going in, because you never know who would be listening to the call, someone could hack into the call." (16-18 year old)*

The public want digital care to be digitally inclusive to ensure equal access for all.

Focus group participants noted concerns regarding digital exclusion, particularly for older people or minority groups. People felt that there needs to be consideration for people who are unable to use digital technologies, do not have access to a smartphone or laptop, do not have good broadband or phone signal or are unable to afford phone credit or broadband.

> *"You have to think of people's own income in that as well, if you are dependent on phone data, you might not be, you might not have the €20 to top up your phone until the following week, so therefore you are being left behind. You can't just pop into the doctors and make that appointment." (member of the Traveller community)*

Participants also highlighted the need to put supports in place for those with limited literacy levels and to cater for people whose first language is not English, including translating information into different languages.

> *"Everything is going to be online, right, there is going to be people left behind, but how do you educate people what's coming up for them." (member of the Traveller community)*

> *"You really need to look at the people who can use it, how do they avail of what's on it, how can they get into it, lots of people mightn't have phones, literacy is another problem. No English for the Roma is another problem." (member of the Traveller community)*

People who use disability services also spoke about how they need help and support with using online apps and for some online services, like booking appointments, and therefore would need support with digital care. People who use disability services are often given support, for example help with appointments, by a key worker. Key workers may only be available at certain times during the day, therefore, people who use disability services would like accommodations made that if they have an appointment online at a time that their key worker is not available, that they would be provided with alternative support. People who use disability services would like information to be presented in a way that could be easily understood including; use of plain English; keeping writing short and simple; information broken down into different sections or use of pictures.

> *"I don't do it online, my support worker would help me with that." (Person who uses disability services)*
>
> *"You could miss your online doctor's appointment, that's another thing...So in my house they might say to you oh there's no staff here 'til 2 o'clock." (Person who uses disability services)*

Participants felt that while some older people's skills are limited, others are able to use their phones for calls and text messages and use social media. While some older people would struggle with technologies and would not know how to use them, others would be keen to learn to engage with digital care and spoke about how they could draw on the support of family members.

> *"Phone calls, text messages… most old people can get them. But email and social media, that type of stuff, they wouldn't really be up to speed with a lot of them. But it would surprise you, I know some older people and they are on Facebook, you know about thirty years older than me. Some of them are really with it." (Carer group)*

Participants felt that not everyone is going to be prepared to move to digital care and online health records. The public think there should be education and training including how to access and navigate an online health record. Participants suggested that if people struggle with technologies, there should be arrangements for them to access their records via paper, for appointment reminders to be made by post and in-person should always be accommodated.

> *"my dad now, if I showed him, he could probably do stuff. He uses a tablet and he watches YouTube and he's all into this stuff, and he's ninety-five but he wouldn't be able to send an email, but he does bits and pieces. Not everyone is, it shouldn't be a one-size-fits-all, there is other people out there that need to be catered for." (Public group)*

The public think the digitisation of health and social care will have benefits for the public.

Focus group participants indicated that they already see the benefits of technology for accessing healthcare, for example text message reminders to prevent missing upcoming medical appointments and the electronic transfer of prescriptions between the GP and pharmacy reducing the need to attend the GP surgery.

> *"They scan [the prescription] over to the chemist and then you just go in and pay for it and then bring it home." (Person who use disability services)*

The convenience of digital care was noted by participants. Benefits highlighted included people living in more rural areas not having to travel long distances to appointments, people being able to have an online consultation on their break at work, minimising disruption for older people to attend routine appointments. At a societal level, some people referenced that the reduction in travel will also have a positive impact on the environment.

> *"I think it should be as much digital as allowed, a lot of people don't have cars, they don't have the luxury of being able to leave work in the middle of the day but they could probably log onto a twenty minute consultation" (Public group)*

The public want their needs and preferences to be considered in any decisions regarding the format and delivery of their care.

Focus group participants reported positive attitudes towards online health records, they like receiving text message reminders about appointments and are happy to have a digital device such as a blood pressure monitor fitted by a professional. The public would not be happy to fit a medical device such as a heart rate monitor themselves, and reported some concerns about using the heart rate monitor correctly. Some members of the public would still like their health record to be available on paper as well as online and a minority would not like their records digitalised at all.

> *"Just knowing that they [a professional] knows exactly how to use them [medical device] rather than you, because even if you had a tutorial or something to show me how to use it, I'd be too scared it wasn't doing it correctly." (Young person group)*

Participants reported that for the most part, they are happy to have routine appointments online. There are certain conversations too that the public think are easier to have in person rather than over video, for example, conversations about their mental health. The public think that in-person is more personable and it is easier to open up to the doctor. The doctor can probe and ask questions to get a proper sense of how a person is feeling.

> *"If you say have a continuous health issue that can be easily explained over the phone or can be easily explained through a video, then that is something that is continuous. It could be a review on a dosage of a prescription, or it could be maybe a reduction or could be an increase."* (*Public group*)

Participants noted that in-person appointments were preferable in the case of more serious or urgent appointments, or where a physical examination is required. It was felt that it is important for the professional to speak to the individual in person and to ensure that the person has understood their medical condition and course of treatment. They felt it is important from the patient's perspective to check the professional is listening and understands what they are saying. However, as a last resort, people said they would be happy to have a telephone or video call if it was urgent, rather than having to wait for an in-person appointment.

> *"I feel like I might be a bit more wary of how accurate a phone appointment would be, if it was something that I was really worried about and what if I'm not saying the symptoms, or I'm not describing what's going on." (Public group)*

Young people indicated that they feel self-conscious having video consultations and would prefer to have an appointment in person. Being able to build a relationship with the professional was also referenced by young people as a reason why in-person appointments are preferable.

> *"I know for me personally… I'd rather be in person than people seeing your video. I don't know why that is, I think it's because if I can see myself, I wouldn't be comfortable." (Young person group)*

People with intellectual disabilities indicated their preference is in-person, as it is easier for the doctor to explain and help them to understand their condition and the medication they are on.

> *"I like to meet the doctor in person and then explain what I want, it's not what the doctor wants really at the end of the day, and then whatever he puts you on he has to explain to you what he's putting you on, what kind of tablets and then how many times a day, or medicine you're put on." (Person who use disability services)*

Participants noted that there is no one size fits all, and it is important to ensure that people are given a choice around the format and delivery of care in line with their personal preference.

> *"I also think text messaging from the GP or from somebody else saying it's a reminder for your appointment says to me that I'm not responsible, and I can't remember that stuff myself." (Public group)*

3.4 Overall findings of the public survey and focus groups

The findings from the public survey and focus groups demonstrate that the public would be very keen to have an online health record that contains information both past and present from all health and social care services that they attend. The public feel that by having all their healthcare information available to them in an easily-accessible online format, they will be more knowledgeable about their health and will be able to have more informed conversations with professionals working in health and social care.

The public would like key information about their health to be included in an online health record with emergency contact details, details about blood tests, X-rays or other scans, current prescribed medications and current health conditions or diagnosis rated as most important. The public would be happy to share their record with a trusted family member or friend, however, they would like to have to control over the level the information a trusted family member or friend could see and would like to have the option to restrict access if necessary. The public would be least comfortable sharing information about their mental health or sexual health with a trusted family member or friend (**39%** and **32%** for sexual health and mental health respectively) and overall, a minority felt this information is not important to include in an online record. One of the public's biggest concerns with having an online record is data privacy and security, and the public would like assurances that their information stored in an online record will be kept confidential and secure.

The majority of the public (**55%**) would be happy to have digital consultations, however, the preference is for in-person. The public feel that for quick, routine appointments, such as receiving the results of a blood test, video consultations are useful. However, for more urgent appointments, for example, if the person is very unwell, requires a physical examination or is due to receive bad news in relation to their health, in-person is preferable.

Overall, the public think that online health records will have benefits for both service delivery and for patients attending services. Patients will no longer have to repeat their health information to each professional that they attend, and professionals will be more easily able to access information about a patient's medical history. The public see benefits for digital care too. In relation to service delivery, the public think digital appointments are more efficient and will reduce waiting lists. For the public, digital appointments reduce the need to travel sometimes long distances to appointments. The public are concerned that in any move to online health records and digital care, some members of the public may be left behind due to limited digital literacy skills or no access to technologies. The public want supports put in place to ensure equal access for all.

4. National Engagement on Digital Health and Social Care – professional survey and focus groups

This section describes the findings from the National Engagement on Digital Health and Social Care professional survey and professional focus groups.

Information is presented under the three topics covered in the professional survey and further explored in the professional focus groups as follows:

- Sharing health and social care information with the public
- The public providing information
- Providing services and communicating digitally with the public.

For each topic, an overview of results and key findings are presented followed by the results for individual survey questions and focus group findings. Survey results are presented in charts with a description of the highest and lowest rated response options. Related focus group findings are presented alongside survey results and additional focus group findings are presented at the end of each section. Focus group findings include direct quotes from participants. This section concludes with a summary of the overall findings.

The below findings are reflective of the collective views of professionals working across health and social care services who completed the survey. Anonymised survey data is available for further analysis to explore whether there are any differences in professionals' opinions depending on the sector they work in or if they are in a management position or direct care.

4.1 Sharing health and social care information with the public

The first section of the survey asked questions to understand professionals' attitudes and opinions regarding the public having access to their health information. The questions asked professionals what information would they be comfortable with the public having access to, if the public should have access to new and or backdated records, when the public should have access to radiology reports and laboratory tests, if the public having access would affect how and what information professionals record, and what professionals think are the benefits of the public having access to their health and social care information in an online health record. The focus groups further elaborated on key findings of the survey and, in particular, focused on professionals' thoughts on sharing information with the public through an online health record.

The top five types of health information that professionals were most comfortable with the public having digital access to included allergies, future appointments, vaccinations, plans of care, and discharge information. Professionals were least comfortable sharing their clinical notes. Professionals feel their clinical notes will need to improve and they identified that they need training and education on note taking before they would feel comfortable sharing their notes with the public.

The majority of professionals felt that people should have access to backdated information or records alongside new information. When asked if the public having access to their digital health and social care information would affect how and what professionals record about their interactions with the people they treat and care for, the majority of professionals indicated that it would not change the amount, language or content of the records they keep.

The top three benefits, as rated by professionals, of the public having access to information in an online health records included people would be more informed about their health, people would be better able to prepare questions to ask in appointments and people would have the ability to identify errors and omissions in their information. Overall, professionals feel the public will be more knowledgeable about their health, will be more in control of their healthcare journey and will be able to play a more informed role in decisions around their care. Professionals also feel that online health records will increase transparency and improve patients' trust in the healthcare system. The patient will have confidence that the information they see in their record is the same information accessed by a professional.

In order to enable the sharing of information with the public via an online health record, professionals think that there needs to be a strategy and system in place at a national level that will inform and facilitate the sharing of information across health and social care services.

Key findings regarding sharing health and social care information with the public

- Professionals were most comfortable with the public having access to information about future appointments (**86%**), allergies (**86%**), and plans of care (**85%**) in their online health record. Professionals were least comfortable with the public having access to their clinical notes (**66%**).
- Professionals do not feel prepared to share their clinical notes and want training and education alongside policy direction on the standard required for clinical notes.
- Professionals working in health and social care (**66%**) think the public should have access to backdated records or information alongside new information about them.
- The majority of professionals did not expect the public having access to their information in an online health record to change the amount, language or content of information that they record about a consultation with the people they treat or care for.
- Professionals think that by having access to their information in an online record, the public will be more in control over their health, will be more knowledgeable and can ask more informed questions in their consultations.
- In order for information to be shared with the public in an online record, professionals think that there needs to be a national strategy and systems in place to inform and enable the sharing of information across health and social care services.

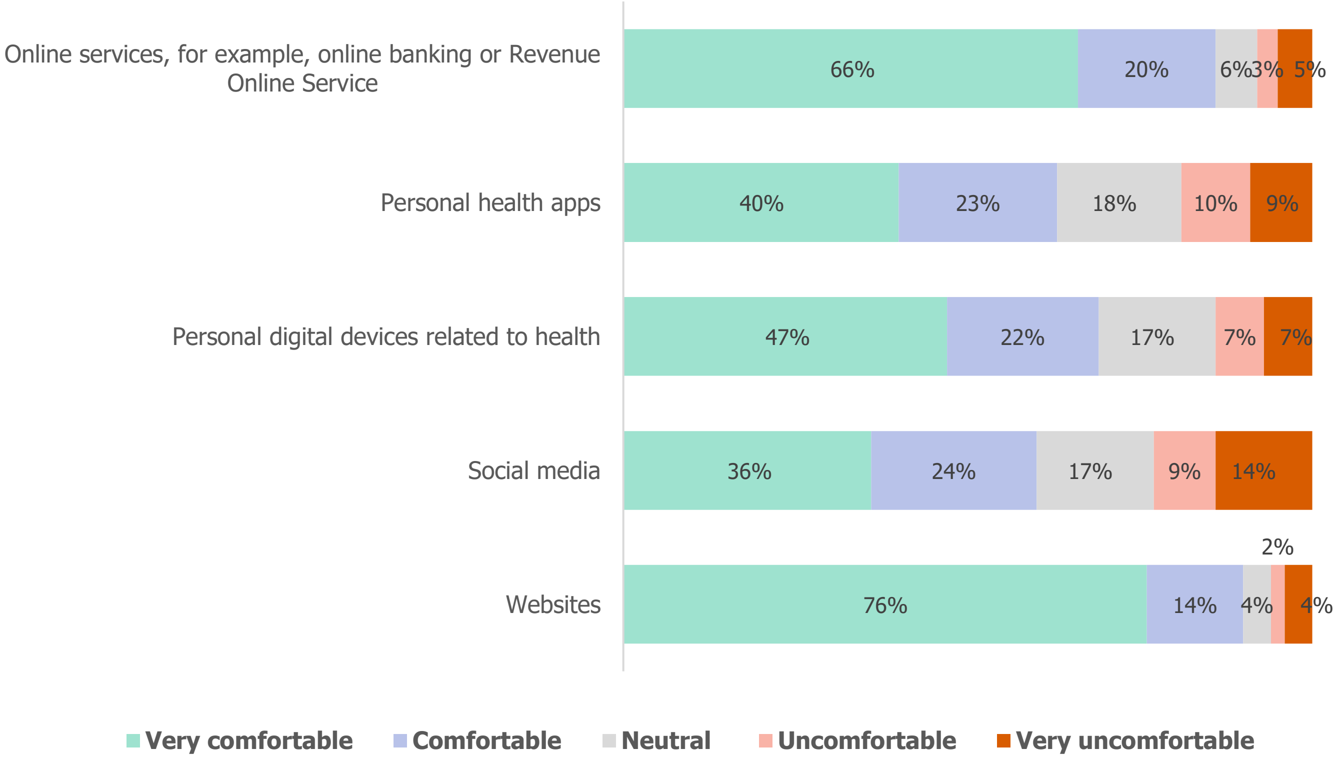
4.1.1 Professionals working in health and social care comfort using technology

Question 1: Professionals were asked about their level of comfort using digital technologies.

- **Over 85%** of respondents indicated they were comfortable or very comfortable using websites like Google and interacting with online services, such as, online banking or renewing their passport online.
- A lower proportion of respondents, reported being comfortable or very comfortable using personal digital devices related to health (**69%**), using personal health apps on their mobile phone (**63%**) and using social media like Facebook or TikTok (**60%**).

See figure 13 for a more detailed breakdown of professional comfort levels using different types of technology.

Figure 13: Professional comfort levels using technology in general



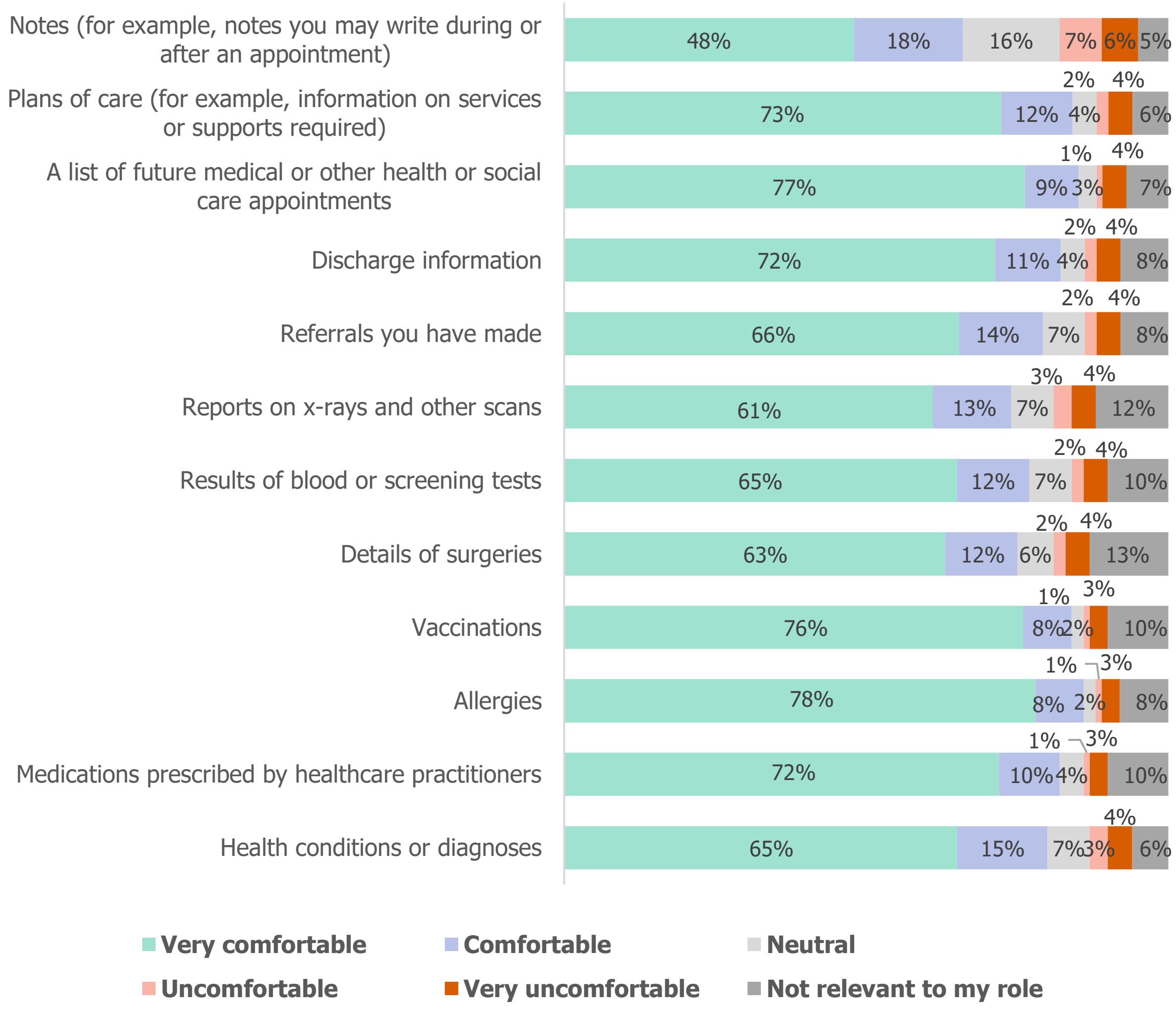
4.1.2 The public having digital access to their own health information

Question 2: Professionals were asked about how comfortable they were with the people they treat or care for having digital access to their medical records:

- At least **85%** of professionals (over 850 people) said they would be very comfortable or comfortable with the people they treat or care for having access to three types of information: information recorded about future medical or other health or social care appointments, information recorded about plans of care and information recorded about any allergies.
- A lower proportion of professionals **66%** (675 people) said they would be comfortable or very comfortable with the people they treat or care for having access to information recorded in their notes (notes written during or after an appointment).

See figure 14 for a more detailed breakdown of different information that professionals would be comfortable with the public having digital access to in an online health record.

Figure 14: Professional comfort with the people they treat or care for having digital access to the information recorded about them



Professionals were further asked to specify other types of information they would be comfortable with the public having digital access to. This question was optional. Key themes that emerged included:

- appointments, care plans and notes
- communication between services
- family history
- medical history
- referral and wait times

- test results.

Professionals were also asked to specify other types of information they would be uncomfortable with the public having digital access to. This question was optional. Key categories that emerged included:

- clinical notes
- diagnosis or results before explanation
- professional or staff information
- sensitive information
- sexual health information.

Focus group finding regarding the public having digital access to their medical records:

Professionals need policy direction and guidance on clinical note taking prior to feeling comfortable sharing their clinical notes.

In line with survey feedback, there was general agreement among focus group participants, from across professionals working in health and social care services, that the public should have access to their health related information. However, participants expressed some hesitation about sharing their clinical notes as they may include sensitive information about the individual in their care, including, speculation about a health diagnosis or matter that requires further investigation, for example a child protection concern.

> *"In situations like safeguarding, or if we were working in adult mental health with people… those multi-disciplinary team discussions are incredibly sensitive and still need to be recorded in the client record. So how do we go about doing that, whilst still giving access, it's kind of complicated but it can be done." (Psychologist)*

Professionals also indicated that their notes are often written quickly, for their own benefit and as a result may be ambiguous, and use clinical language that may not be easily understood by the people they treat or care for. Furthermore, as the notes may be written in an objective manner it may appear cold, and out of context insensitive to the reader. Professionals expressed concern that if a person they treat or care for was to receive their notes, they may be misunderstood out of context and this could cause unnecessary stress or upset to the individual under their care, and could potentially undermine the therapeutic relationship.

> *"think that we probably need to do a bit of work to make sure we are prepared for that because I was always really worried what if I've written something in a note and it looks ambiguous, it's clear to us but this particular language could cause upset or confusion or you know undermine the trust or relationship." (Fellow in ophthalmic surgery)*

Participants noted that in order for professionals to feel comfortable sharing their notes that their clinical note taking will need to improve. Professionals indicated that they would require support, training and education to write notes with the person they care for in mind, but also there needs to be clear policy direction and standards set for all aspects of note writing such as using appropriate language. Participants also noted, that from a management perspective, consideration also needs to be given to the amount of time it will take clinicians to write comprehensive notes that can be easily understood and are accessible to the people they treat or care for.

> *"I do think that going forward there would have to be some kind of formal mandatory training for healthcare professionals on how to conduct themselves on note taking..." (Nurse manager)*

Some participants expressed a preference for a partnership approach where the clinical note is written in conjunction with the person they are providing treatment or care to. However, other participants questioned the logistics and feasibility of writing a clinical note in partnership with the patient.

> *"I would see it more like a partnership with your patient. Where they can read a summary of the consultation they mightn't necessarily need the detail but there would be an agreement in place with the patient and the healthcare professional in that they would have opportunities to collaborate and be able to feedback to you if they agree or disagree or want to add anything to it." (Nurse)*

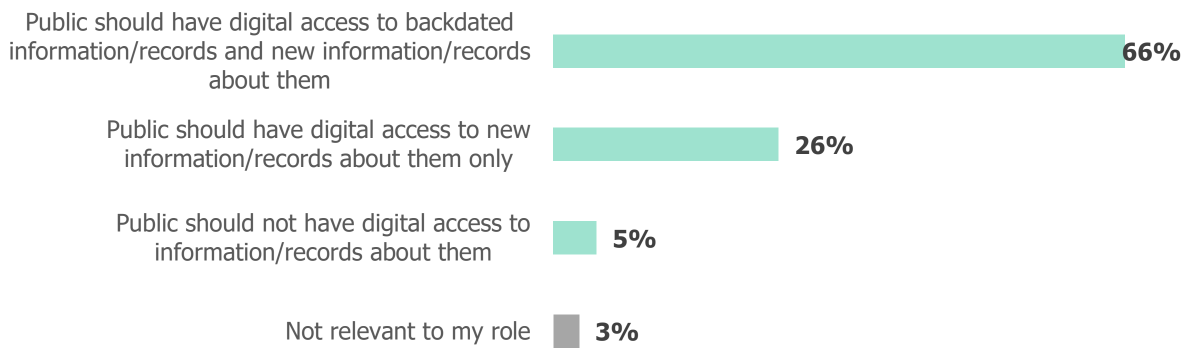
4.1.3 Access to backdated information and records, or new information and records

Question 3: Professionals were asked if the public should have access to backdated information and records, and or new information and records about them.

- 671 professionals (**66%**) think that people should have access to backdated information and records, and new information and records about them.
- 269 professionals (**26%**) think that people should have access to new information and records about them only.

See figure 15 for a more detailed breakdown of professionals' opinions on public access to backdated and new information.

Figure 15: Professional views on public access to backdated information or new information



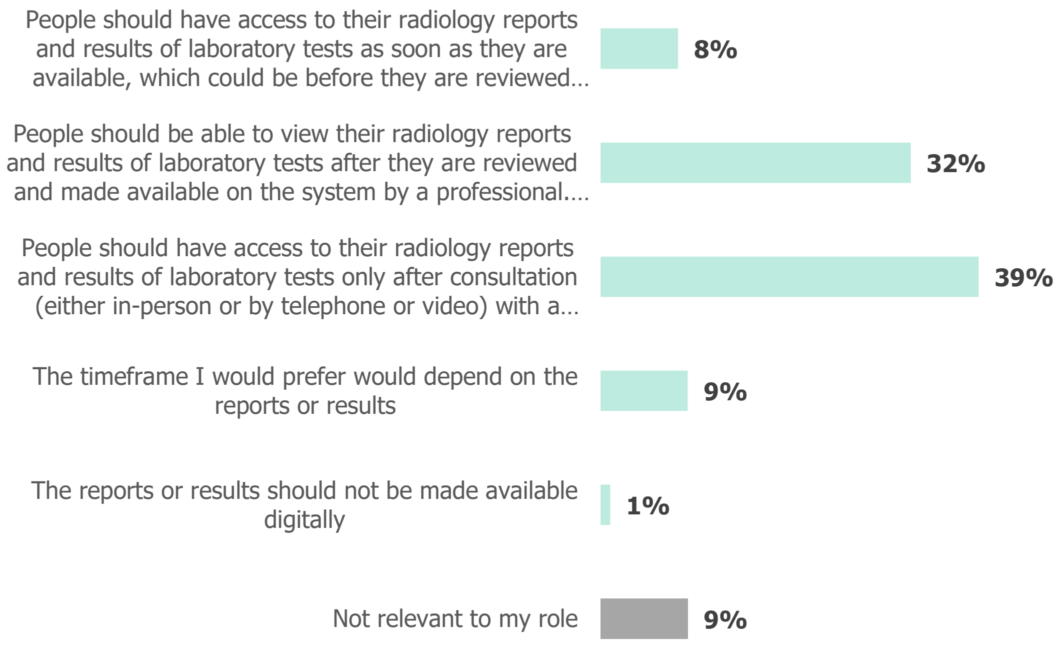
4.1.4 Radiology reports and laboratory tests

Question 4: Professionals were asked their opinion on when radiology reports and results of laboratory tests should be made available online to the people they treat or care for.

- 401 professionals (**39%**) thought that people should have access to their radiology report and results of laboratory tests only after consultation (either in-person or by telephone or video) with a professional. The professional then makes them available on the system.
- 96 professionals (**9%**) thought that the timeframe would depend on the reports or results.

See figure 16 for a more detailed breakdown of professionals' opinions on when radiology reports and results of laboratory tests should be made available online to the people they treat or care for.

Figure 16: Professional views on when radiology reports and results of laboratory tests are made available online to the people they treat or care for



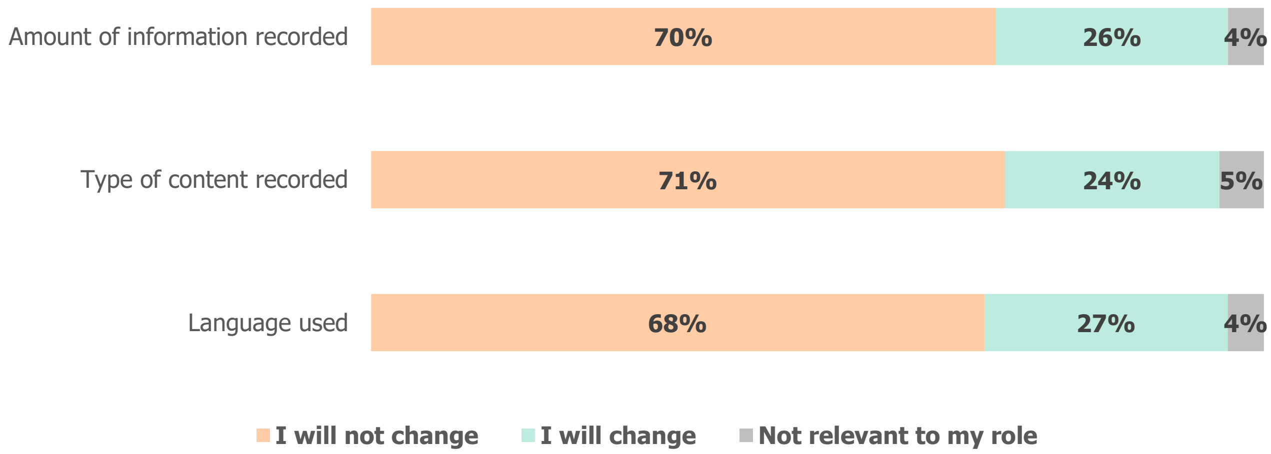
4.1.5 Changes to recording behaviour for health and social care information

Question 5: Professionals were asked if they would change what they record (amount of information, language and type of content) if people who they care for and treat have digital access to their health and social care information.

- 717 professionals (**70%**) said they will not change the amount of information they record (they will record the same amount of information). Of the **26%** of professionals who indicated they will change the amount of information they record, **16%** said they will record less information and **10%** said they will record more information, **4%** of professionals indicated that it was not relevant to their role.
- 697 professionals (**68%**) said they will not change the language they use.
- 725 professionals (**71%**) said they would not change the type of content they record.

See figure 17 for a more detailed breakdown regarding changes to the amount of information, language and type of content that professionals would record.

Figure 17: Professional changes to recording behaviour - amount of information, language used and content of records



Professionals were asked if there are other ways the public having access to their health and social care information may affect how and what information they record about the people they treat or care for. Two themes emerged:

- Less use of technical jargon (technical terms, abbreviations and acronyms).
- Recording more conscious, objective accurate and evidence based notes.

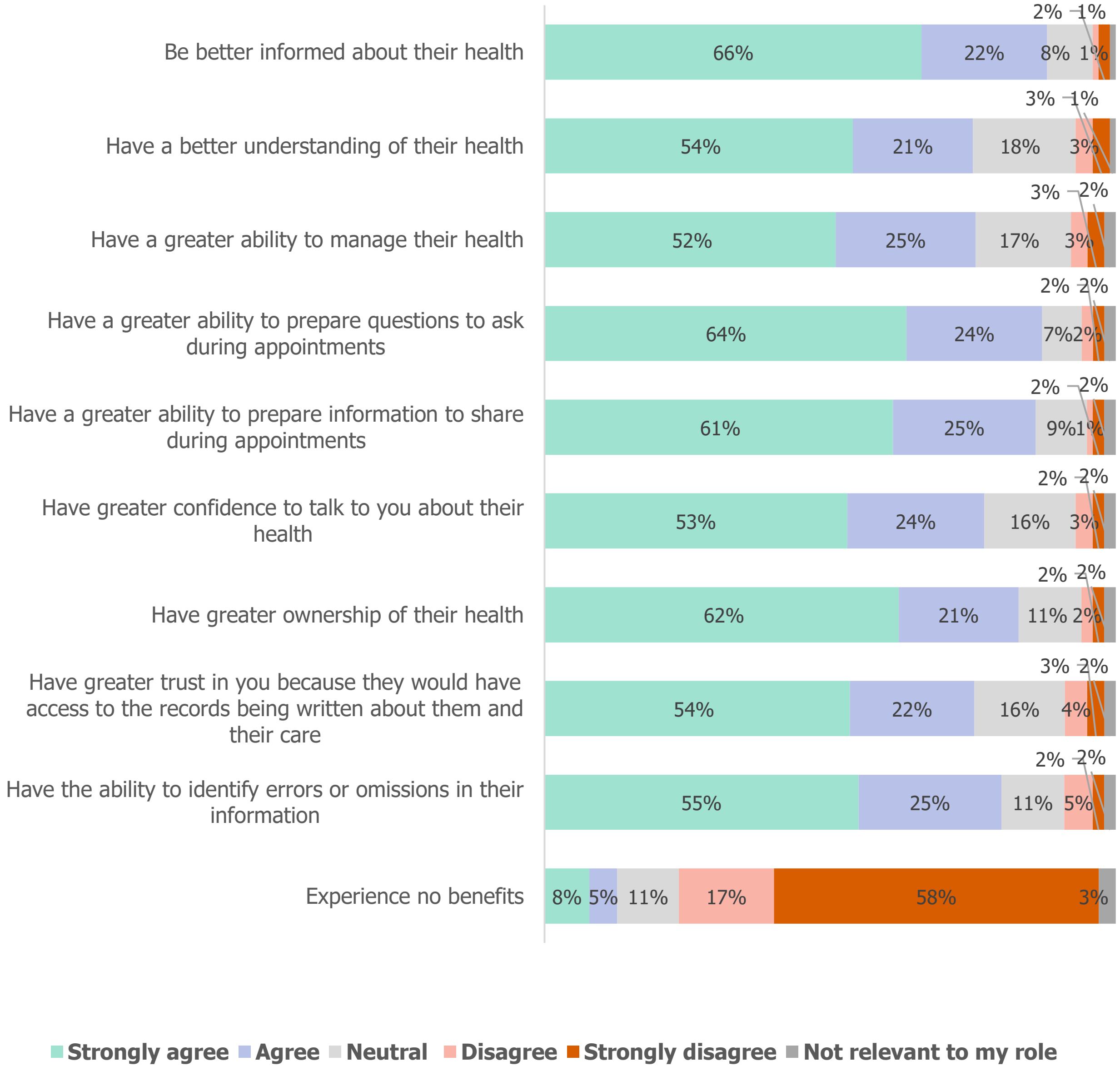
4.1.6 Benefits of an online health record

Question 6: Professionals were asked about the potential benefits to the public having access to their health and social care information in an online health record.

- **Over 85%** of professionals (over 890 people) agreed or strongly agreed that people being better informed about their health and people having a greater ability to prepare questions to ask during appointments were two potential benefits.
- A lower proportion of professional, **75%**, agreed or strongly agreed that people having a better understanding of their health was a potential benefit.
- 126 professionals (**13%**) agreed or strongly agreed that people will experience no benefits.

See figure 18 for a more detailed breakdown of what professional’s view as the potential benefits to the public having access to their health and social care information in an online record.

Figure 18: Professional views on potential benefits for the people they treat or care for having access to their health and social care information in an online health record



Professionals were asked to specify if there are any additional benefits that people will experience by having access to their information in an online health record. Key themes that emerged included:

- better understanding of their health
- easier to share healthcare information
- improved patient experience (people will not have to repeat their medical history)
- instant access to information

- promoting transparency and improving trust in the system.

Professionals were asked to specify if there are any challenges that people will experience by having access to their information in an online health record. Key themes that emerged included:

- difficulties understanding the health record
- issues accessing the online record and potential for digital exclusion
- misinterpretation of information in the record
- patient may disagree with diagnosis
- relying on information online prior to talking to a professional.

Focus group finding regarding benefits to the public having access to their health and social care information in an online health record:

Professionals think that online records will empower people to be more in control of their health.

In line with survey feedback on the potential benefits of people having access to their online health record, focus group participants thought that when people have access to their online health record they will feel more in control of their healthcare journey, they will be better able to understand their condition, they will be able to ask more informed questions and play a role in managing decisions around their care. Focus group participants noted that as it stands people are not informed about their health status, any allergies, or procedures they have had done. By having access to information in an online format, professionals think the public will be better able to understand their condition, do their own research and address any concerns with a professional.

> *"[when people readily have access to their health information] I think people's outcomes are way better, they have more choice, they feel freer and it improves the relationship because you know they know what you are saying about them." (Fellow in ophthalmic surgery)*

Focus group participants noted the importance of ensuring that people fully understand and can follow the information in their record. Participants indicated that any information about a patient's health should be explained to them by a professional prior to the patient having access to that information. Consideration regarding a person's literacy level, that English may not be their first language and ensuring information is in plain English were also noted.

> *"We have seen in community pharmacy sometimes the way in which the vaccination record for example is presented that the person may not actually realise that they received a flu vaccine for example, because it might be the generic name of the flu vaccine. Then they go to their GP to seek the flu vaccine again" (Pharmacist)*

Question 7: Professionals were asked to identify the benefits to them when a system is in place where the public will have access to their health records. Some of the key benefits identified included:

- improved communication
- improved decision-making
- increased efficiency
- increased sharing of information between health and social care providers
- more collaborative relationships with patients.

Focus group finding on benefits to professionals when the public have access to their online health records:

Professionals feel that digital access to healthcare records will improve transparency and trust in the system.

In addition to survey feedback on benefits, focus group participants suggested that digital records will increase transparency in the health system and will overall increase people's levels of trust. Many professionals feel that the information the patient sees in their record should be the same information a healthcare professional can access and can input to. However, professionals do feel consideration should be given to the situation, the nature of the information, and if the patient will benefit from receiving the information.

> *"I'd share the idea of if you have a consult or interaction with the clinician that the same letter goes to everybody and there's no difference." (Neuropsychologist)*

Participants feel that by having access to all their information in an online record, patients will feel more informed and in control as patients can review their information after a consultation and go back to the professional to question any element of the information they are unsure about.

> *"it's there so somebody can go back in then and say 'well actually I was expecting something different', and you can still go back to your healthcare*

> *professional and say 'look actually that wasn't what I took from that conversation or I expected something different.'" (Service manager)*

Professionals feel it would be useful to include service-level information in a record for example wait times and progress of referrals. This will improve transparency in the system and patients will feel more informed about the status of their care.

> *"they are left out of the process decisions, so that could be a positive of being able to access your own data, to see your journey, to be able to roadmap your journey." (Physiotherapist)*

Professionals feel that any information that is to be included in a digital health record should be shared with the patient as soon as possible and there should be no delay. However, professionals do feel that any information that is to be added to a record should be discussed with the patient first. This is particularly important for sensitive conversations about a person's health status.

> *"there is processes in place that they are getting it almost immediately as opposed to a week or three weeks later. I think that feeds into the public satisfaction remit as well." (Clinical audit coordinator)*

> *"My patients with lymphomas, imagine they see a report that says relapse of lymphoma. And they are not going to see me until three or four days later, I think that wouldn't be good for them, I think we need to see the results, discuss them with them and then they can have access to them." (Haematologist)*

Professionals expressed concern about the data privacy and security of online digital health records. The cyberattack* in the HSE made professionals more aware of the risks associated with online health records especially if appropriate security measures are in not place. Professionals feel there needs to be an up-to-date system with proper data security before digital health records are available.

> *"with the cyberattack, the HSE hadn't mitigated properly with the up-to-date software, so absolutely if this e-health came in, the protections would have to be maximised and reviewed." (Paramedic supervisor)*

Professionals think that there must always be consent from the patient regarding who has permission to access their data and what data can be accessed. Professionals feel that data must always be used for its intended purpose and people must be informed of who has viewed their records and for what purpose.

> *"I think there needs to be some degree of informed consent with the patient and it has to be voluntary. It should never be mandatory that you must allow*

> *your data to be aggregated across multiple sources, or if it is, that they are in plain language told why that is being done and how that helps." (Pharmacist)*

Additional focus group findings regarding online health records

Professionals want a national strategy that will enable greater sharing of information between health and social care services.

Focus group participants noted that prior to sharing health and social care information with the public, there needs to be a system in place to facilitate the sharing of information between all health and social care services, including public and private services. Participants noted that currently people may be visiting multiple health and social care services, including consultants in both public and private hospitals, pharmacy, GP and there is no sharing of information. This can cause confusion for a patient if they are provided with different or conflicting advice. Professionals spoke about how they change a patient's medication and these changes are often not communicated with the other health and social care professionals managing the patient's care.

> *"often you are talking to patients and they are telling you the story that you know consultant X said this and my GP said that and my pharmacist is telling me this, so sometimes that silo of information that goes on can be a bit confusing and distressing for patients." (Pharmacist)*

Participants indicated that from a resource perspective, the lack of a system to share information across health and social care providers means there is often duplication of tests such as scans, tests, blood tests. Professionals noted how patients are asked to provide the same information about their health by multiple professionals and if professionals could access a patient's health record, it would save professionals time and reduce the burden and responsibility of the patient to provide information about their health.

> *"if we had one system for all my allied health colleagues, all didn't have to ask the same questions, how much time would that save in the HSE. Multiply that by each hospital and each community, each RHA, it's a huge amount of time wasted asking the same questions." (Dietician)*

Participants suggested that prior to development of an online national system, there needs to be a strategy at a national level that will inform and facilitate the sharing of information across health and social care services. The strategy needs to take into account concerns around data access and data security.

> *"we will never have a proper system with proper data security and everything unless we have a national strategy towards it". (Children's disability network manager)*

4.2 Public providing information

The second section of the survey focused on the public identifying errors or adding information to their health record. Professionals were asked to rate what information would be useful for people to add to their health record. Professionals were also asked their thoughts on the public identifying errors or omissions in their records. The focus groups expanded on this topic further and asked professionals to discuss their thoughts regarding the public adding information or correcting errors in their online health record.

Key findings on the public providing information

- Professionals (**86%**) think it would be helpful for the people they treat or care for to identify errors or omissions in their online health record.
- Professionals report that it would be useful or very useful for people to add information to their online health record, including details of a person to contact in case of emergency (**89%**), personal details (**83%**), details of medical cards or other medical schemes (**79%**).
- Professionals think it is important for the public to have ownership of their health record and to flag errors or omissions in their record. However, professionals think that any change to a record should be verified and updated by a professional working in health or social care.

The majority of professionals indicated that it would be helpful for the public to identify errors or omissions in their online health record. The three most common types of information professionals thought the public should add to their medical record included details of an emergency contact, personal details and details of medical cards or other medical schemes. Data from personal devices or apps on phones were considered to be less useful. Professionals overall think it is important for the public to have ownership of their records and to have the ability to identify and correct errors or omissions in their healthcare record. However, professionals do not think patients should be directly editing their record, rather that any change must be verified and updated by a professional working in health or social care.

4.2.1 The public adding information to their own online health record

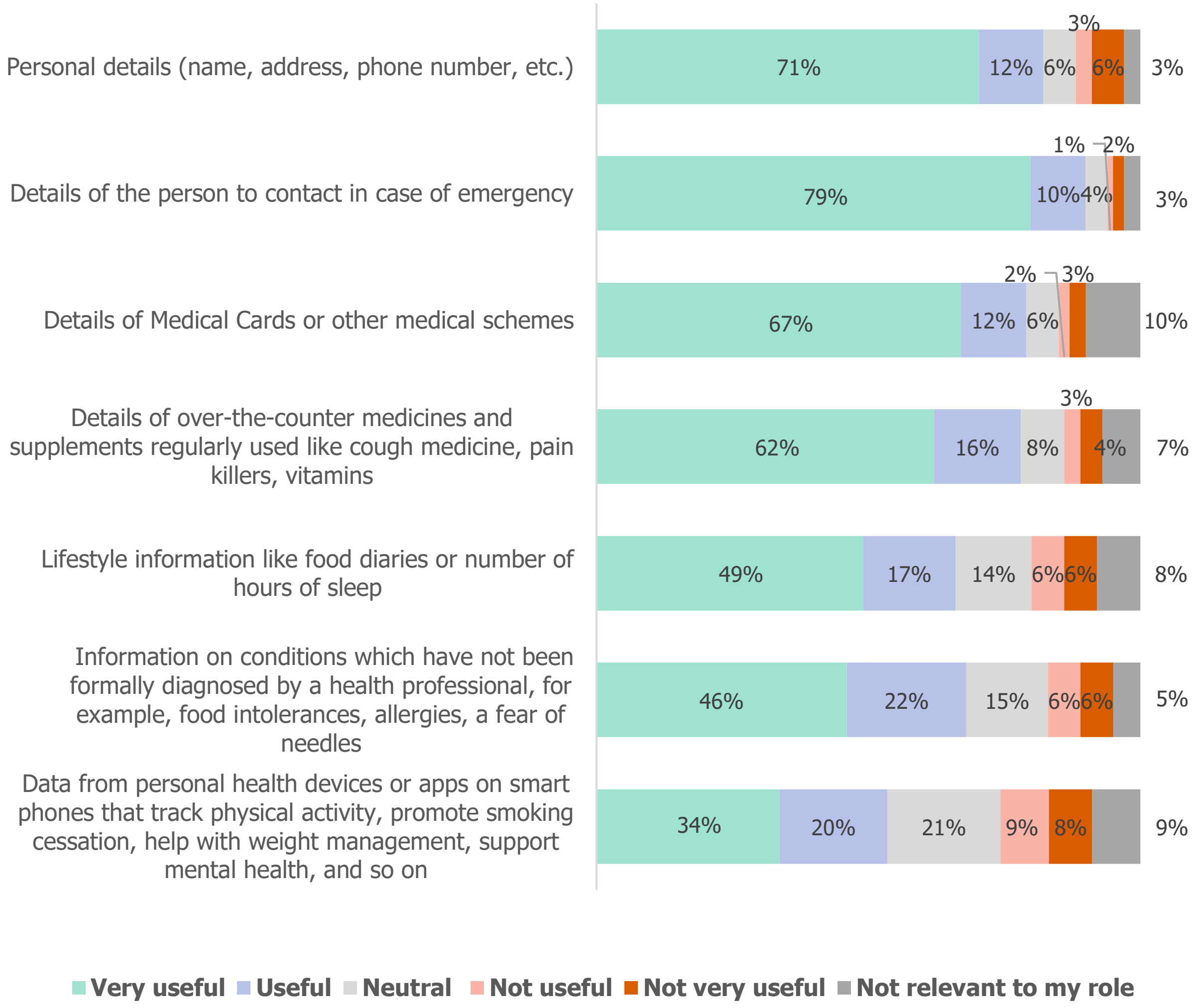
Question 8: Professionals were asked about the usefulness of different types of information added by an individual to their online health record.

- **Over 80%** professionals identified that details of the person to contact in case of emergency and personal details (name, address and phone number) would be useful or very useful to them.

- A lower proportion of professionals, **54%** (554) said that data from personal health devices or apps on smart phones that, for example, track physical activity or promote smoking cessation would be useful or very useful to them.

See figure 19 for a detailed breakdown of information that professional's rated as useful or very useful for the public to add to their online health record.

Figure 19: Information that professional's rated as useful or very useful for the public to add to their online health record



Professionals were asked about other additional types of information they would find useful. Additional information identified included information on medical devices such as glucometers or blood pressure readings, family medical history, preferred pronouns, details about their symptoms for example levels of pain, preferences for end of life care, vaccination history, GP and pharmacy details, and information on adherence to medications.

4.2.2 The public identifying errors or omissions

Question 9: Professionals were asked to rate if it would be helpful or unhelpful for people to identify errors or omissions in their online health records.

- The majority of professionals, **86%** indicated it would be helpful, **8%** indicated it would not be helpful and **6%** indicated it was not relevant to their role.

Focus group finding regarding the public identifying errors or omissions:

Professionals think it is important for the public to identify errors and omissions in their online health record to increase trust in the healthcare system.

In line with survey feedback, focus group participants were strongly in favour of people they treat or care for having the opportunity to identify errors and add additional information to their healthcare record. Participants noted that if people can make changes to their records, they will feel more in control of their health narrative and this increases overall trust in the healthcare system.

> *"You feel more in control of your story because people complain all the time not only are you asking them for the same information over and over but they almost feel interrogated because you say 'you had you know a heart attack five years ago', 'no I didn't, I had stents in three years ago'. 'Well your file says it was five years ago and it was a heart attack'." (Fellow in ophthalmic surgery)*

Focus group participants were also in favour of patients adding information to their health record, particularly if it may impact or influence decisions around their care, including, any over-the-counter medication they are taking, alternative therapies they are attending or if they have stopped taking medication but it still appears on their prescription. Professionals indicated that the public providing updated demographic and contact information is important to preventing data breaches and to ensure that details are up-to-date and that people receive healthcare notifications or reminders of appointments.

> *"I would see it a huge advantage for people to be in charge of their own demographics and to be updating when they change their address, change their GPs, their pharmacist, and even you know name changes through marital status or other status as well." (Nursing and midwifery information and e-health specialist)*

Participants indicated that do not think a patient should have full responsibility for editing their health information as they may not have the clinical expertise about their condition. Professionals indicated that if a patient requested a change to their health information, it should be flagged on their record as patient reported and in turn be verified by a professional in real-time or as soon as possible. Professionals acknowledged that updating patient health records in real-time is a huge resource challenge. Clarity on who should be responsible for verifying the update to the health record, for example, the last professional the person saw or a healthcare professional who oversees the overall healthcare of the patient, were raised by participants as areas for further consideration.

> *"I suppose it's protecting the integrity of the information and making sure there is some sort of quality control there or some sort of verification of how that information is changed." (Children's disability network manager)*
>
> *"if you have a healthcare professional that sees you know in excess of four hundred patients per week they can't obviously take phone calls from four hundred patients and then go back and correct you know various errors. So, if we are going to do that then again it needs to be resourced and there needs to be someone put in place to actually do that or it just wouldn't be possible otherwise." (Cardiologist specialist registrar)*

4.3 Providing services and communicating digitally with the public

The final section of the survey focused on professionals' attitudes and opinions on providing services and communicating digitally with the public. Questions explored professionals' attitudes and opinions on:

- the public's readiness to interact digitally
- experience of providing care through telephone and video consultations
- the use of technology to provide clinically effective care
- supports that need to be in place to increase professionals' comfort providing services and information digitally
- if relationships with the people they treat or care for will change when information and care is provided digitally.

The focus groups further expanded on professionals' opinions on the delivery of care digitally and how digital care may influence their relationships with the people they treat or care for.

Professionals had mixed opinions of the public readiness to interact digitally. A minority of professionals reported that they think the public are ready to interact digitally. Most professionals have had telephone consultations with the people they treat or care for, while a smaller percentage had video consultations. Of the professionals who have previously had telephone or video consultations, the majority reported that these had decreased since the pandemic. Professionals reported similar levels of comfort with telephone and video consultations compared to in-person. Professionals think there is still work to do to determine the most appropriate format for the delivery of care. Professionals are keen to have the first appointment and appointments that require a physical examination in person. Overall, to prevent anyone from being disadvantaged by a move to digital, professionals want the public to have choice around the format and delivery of their care.

Overall, professionals have more positive attitudes to digital technologies since the COVID-19 pandemic. Knowing who to contact for technical support and knowing what measures are in place to keep services and information private, would make professionals more comfortable providing services or information digitally. Most professionals feel their relationship with the people they treat or care for will improve when information is shared digitally. Of professionals that had less positive attitudes towards digital care, the majority feel the relationship with the people they treat or care for will disimprove or remain the same when care is provided digitally.

Key findings regarding providing services and communicating digitally with the public

- Many professionals (**32%**) feel that the public may not be ready to interact digitally.
- The majority of professionals (**61%**) have had a telephone consultation with the people they treat or care for and of those, (**57%**) indicated they felt comfortable having telephone consultations rather than in-person consultations.
- A minority of professionals (**29%**) have had a video consultation with the people they treat and care for and of those (**58%**) indicated that they felt comfortable having video consultations compared to in-person consultations.
- Professionals (**61%**) think that text messages for administrative tasks (appointment management) are an effective or very effective way to provide clinical care.
- Professionals (**60%**) feel that since COVID19 they have more positive attitudes to digital technologies. Although professionals feel there is still work to do to determine the most appropriate format for delivery of care (in-person vs digital, telephone vs video).
- A minority of professionals (**36%**) feel that when care is provided digitally the relationship with the people they treat or care for will disimprove.
- To ensure equal access for all people, professionals want the public to have choice around the format and delivery of their care.

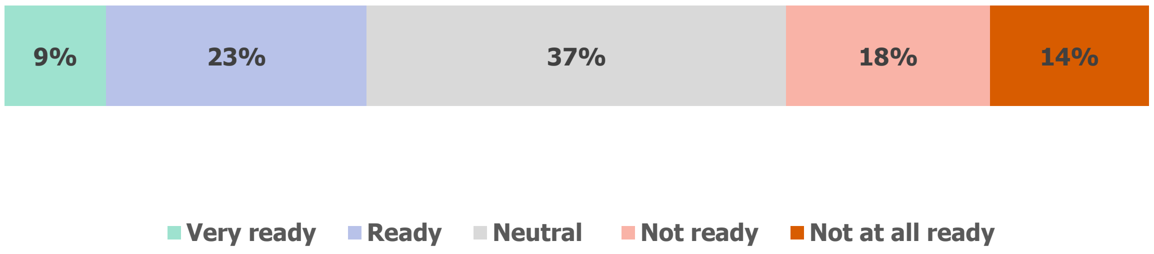
4.3.1 Public readiness to interact digitally

Question 10: Professionals were asked if the people they treat or care for are ready to interact digitally through telehealth, email, text message.

- 324 professionals (**32%**) feel that the people they treat or care for are ready or very ready to interact digitally.
- 323 professionals (**32%**) feel that the people they treat or care for are not ready or not ready at all to interact digitally.

See figure 20 for a breakdown of professional views on whether the people they treat or care for are ready to interact digitally with them.

Figure 20: Professional views on whether the people they treat or care for are ready to interact digitally with them



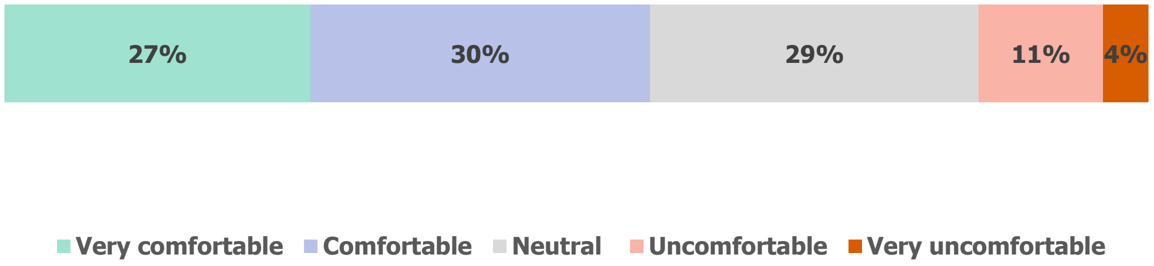
4.3.2 Telephone consultations

Question 11: Professionals were asked if they have had telephone consultations with the people they treat or care for and their experience of them.

- 627 professionals (**61%**) reported that they have had telephone consultations with the people they treat or care for. The remaining **39%** of respondents indicated they had not had a telephone consultation.
- Of the 627 professionals who reported that they had telephone consultations,
    - 333 (**53%**) reported that the telephone consultation began post the onset of the COVID-19 pandemic compared to 294 (**47%**) who reported that telephone consultations started pre the onset of the COVID-19 pandemic.
    - 275 of the professionals (**44%**) reported that the frequency of the consultations had decreased since the pandemic, **27**% reported that the frequency had increased and **29%** reported they had remained the same.
    - 353 professionals (**57%**) indicated they felt comfortable having telephone consultations compared to in-person consultations.

See figure 21 for a more detailed breakdown of professional comfort levels with telephone consultations.

Figure 21: Professional's comfort levels with telephone consultations



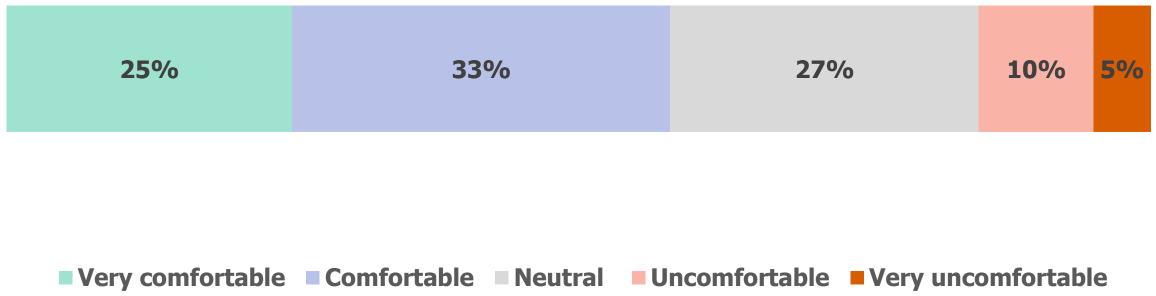
4.3.3 Video consultations

Question 12: Professionals were asked if they have had video consultations with the people they treat or care for and their experience of them.

- 295 professionals (**29%**) reported that they have had video consultations with the people they treat or care for. The remaining **71%** of respondents indicated they had not had video consultations.
- Of the 295 professionals who reported that they had video consultations,
    - 251 (**85%**) reported that the video consultations began post the onset of the COVID-19 pandemic compared to 44 (**15%**) who reported that video consultations started pre the onset of the COVID-19 pandemic.
    - 195 (**66%**) reported that the frequency of the consultations had decreased since the pandemic, **18%**, reported that the frequency had increased and **16%** indicated that the frequency remained the same.
    - 173 professionals (**58%**) indicated they felt comfortable or very comfortable having video consultations compared to in-person consultations.

See figure 22 for a more detailed breakdown of professional comfort levels with video consultations.

Figure 22: Professional's comfort levels with video consultations



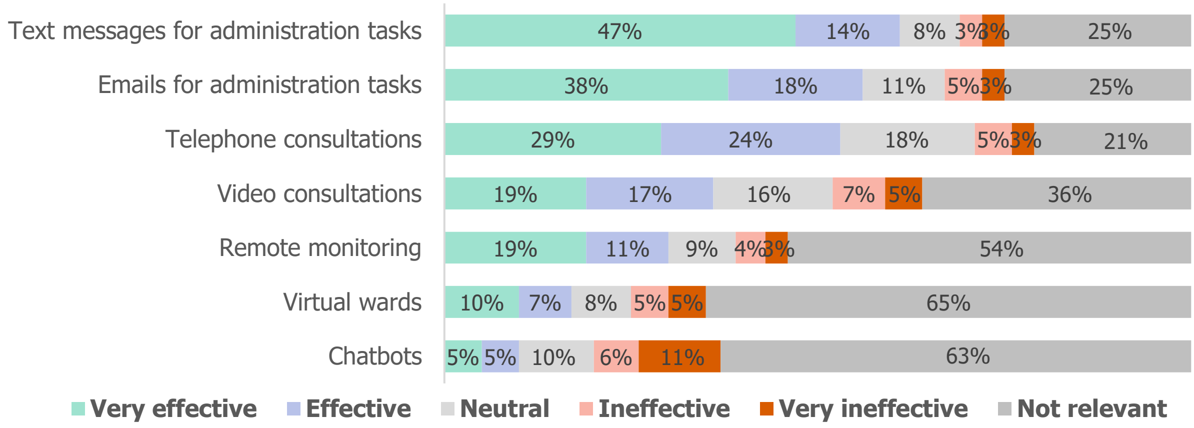
4.3.4 Digital interactions with the public

Question 13: Professionals were asked their opinion on the effectiveness of technology for providing clinical care:

- 622 professionals (**61%**) reported that text messages for administrative tasks (appointment management) are an effective or very effective way to provide clinical care.
- A lower proportion of professionals identified virtual wards **(17%)** and Chatbots **(10%)** as effective or very effective technology to provide clinical care.

See figure 23 for a detailed breakdown of professionals' views of the effectiveness of different types of technology for providing digital care.

Figure 23: Professional views on digital interactions to provide clinically effective care



Professionals were asked if there was any additional digital interactions that would enable them to provide clinically effective care to the people they treat or care for. Professionals identified online educational videos, such as exercise videos or training, or education to share with parents and teleconferencing for multi-disciplinary team meetings, as useful.

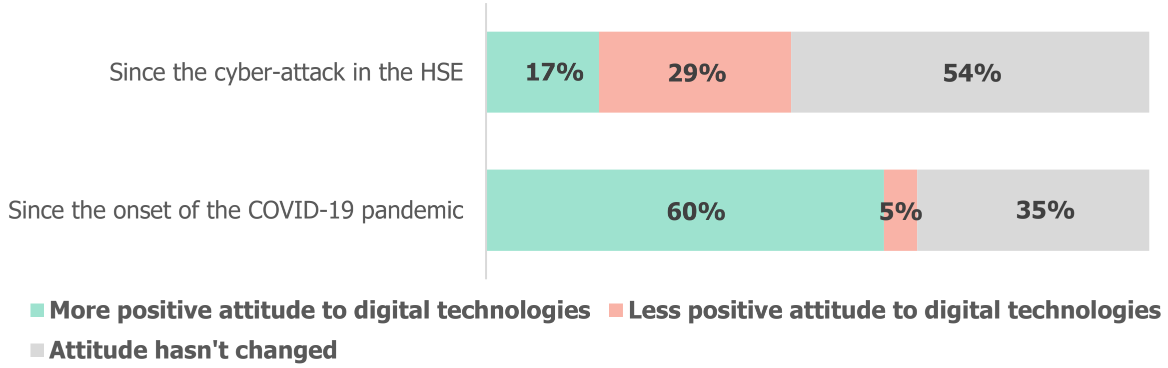
4.3.5 Attitudes to digital technologies

Question 14: Professionals were asked if their attitudes towards digital technologies in health and social care had changed since the onset of the COVID-19 pandemic and after the cyberattack* in the HSE.

- 610 professionals (**60%**) have more positive attitudes towards digital technologies since the onset of the COVID-19 pandemic. 362 professionals (**35%**) attitudes have not changed since the onset of the COVID-19 pandemic.
- 171 professionals (**17%**) have more positive attitudes towards digital technologies since the cyberattack* on the HSE. 553 professionals (**54%**) attitudes have not changed since the cyberattack* on the HSE.

See figure 24 for a detailed breakdown of professional attitudes since the COVID-19 pandemic and after the cyberattack* on the HSE.

Figure 24: Changes in professionals’ attitudes to digital technologies in health and social care



4.3.6 Increase comfort levels

Question 15: Professionals were asked if certain actions (five options) would increase their levels of comfort providing services or information digitally.

- 937 professionals (**92%**) said being clear who to contact for technical support would increase their comfort.
- A lower proportion of professionals **79%** (798) said that having protocols in place which identify when, as part of a care pathway, it is appropriate or inappropriate to provide services or information digitally would increase their comfort.

See figure 25 for a detailed breakdown of professionals’ ratings of how actions would increase their comfort levels providing services or information digitally.

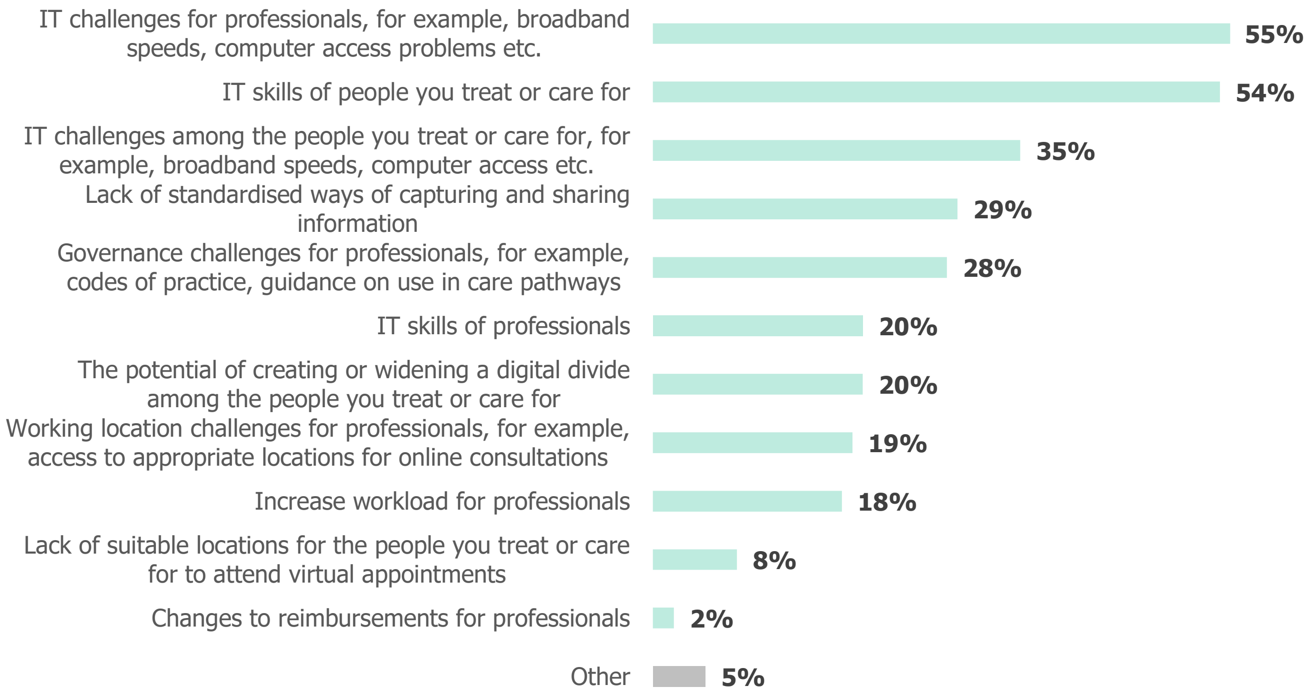
Figure 25: Actions that would increase professional comfort levels providing services or information digitally

Question 16: Professionals were asked to rate challenges to providing services and communicating digitally with the people they treat or care for. The most commonly selected challenges included:

- Over **50%** of professionals rated IT challenges for professionals and the IT skills of people they treat or care for as one of the top three challenges to providing services and communicating digitally with the public.
- 179 professionals (**18%**) rated increased workload as of one their top three challenge.

See figure 26 for a detailed breakdown of professionals’ ratings of the challenges to providing services and communicating digitally with the public.

Figure 26: Challenges to providing services and communicating digitally reported by professionals



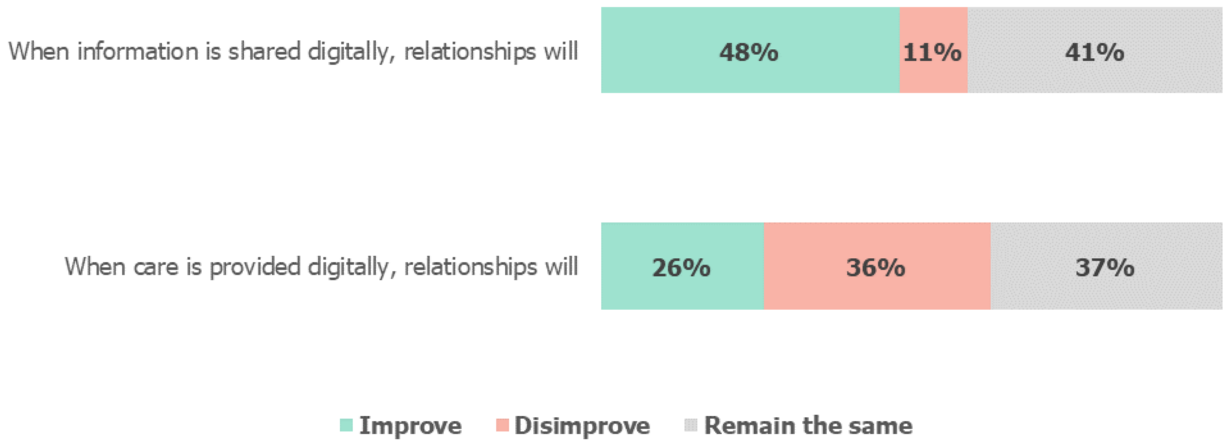
4.3.7 Your relationship with the public

Question 17: Professionals were asked if they feel their relationship with the people they treat or care for will improve when information is shared digitally and when care is provided digitally.

- 487 professionals (**48%**) felt that when information is shared digitally, their relationships with the people they treat or care for will improve, **41%** felt that will remain the same and **11%** felt that their relationship would disimprove.
- 372 professionals (**36%**) felt that when care is provided digitally, their relationships with the people they treat or care for will disimprove. **37%** felt it will remain the same and **26%** felt their relationship will improve.

See figure 27 for a detailed breakdown of professional views on the impact of sharing information digitally and providing care digitally on the relationship with people they treat or care for.

Figure 27: Professional views on impact of sharing information digitally and providing care digitally on relationship with people they treat or care for



Professionals were asked if they had any additional comments on whether their relationship with the people they treat or care for will change when information is shared digitally and care is provided digitally. Key themes identified included:

- A hybrid approach to care is preferred
- Access to digital information will improve communication and transparency
- Information may be misunderstood in a digital context
- It may make care less personal.

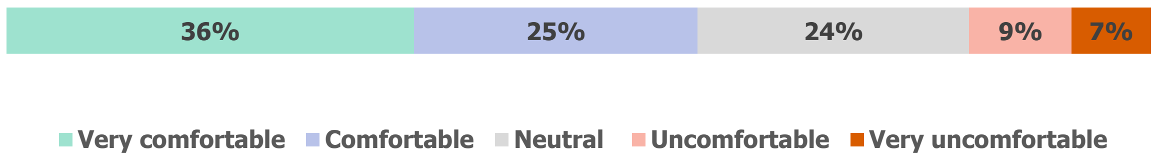
4.3.8 Professional comfort with the public knowing who had accessed their record

Question 18: Professionals were asked to rate how comfortable or uncomfortable they would be with the public knowing which professionals had accessed their digital records.

- 623 professionals (**61%**) said they would be comfortable or very comfortable with the public knowing which professionals had accessed their digital records.
- **16%** of professionals indicated they would be uncomfortable or very uncomfortable.

See figure 28 for a more detailed breakdown of professional comfort levels with the public knowing which professionals accessed their digital records.

Figure 28: Professional comfort levels with the public knowing which professionals had accessed their digital records



Additional focus group findings regarding digital care

Professionals want decisions around digital delivery to be person centred and informed by the healthcare need and patient's choice.

Focus group participants were positive about the move to digital care, seeing benefits for both service delivery and the patient. Participants highlighted that COVID-19 accelerated advances in the delivery of care digitally. They noted that the attitudes of professionals who may have been previously reluctant to move to digital care shifted when they saw the benefits in a short space of time for the delivery of care. However, professionals suggested that implementation of digital care should not occur too quickly as it may have an impact on relationships with their patients. Participants also expressed concern that there can be a lack of oversight and regulation of online digital health services and this is a risk to the health and welfare of patients.

> *"it is always about the patient and the personal interaction, it's important not to lose that in the rush to digitise." (Pharmacist)*

Professionals feel there is still work to do to determine the most appropriate format for the delivery of digital care. Participants suggested that decisions around delivery should be person centred and informed by the healthcare need and patient choice. Professionals expressed a preference for video calls over phone calls, as they are easier for building a rapport with the people they treat or care for. Professionals also expressed a preference for the first initial appointment to be face-to-face to get to know the patient and build a relationship. In-person appointments are also important where a physical assessment is required.

> *"one of the problems with digital care is you can't actually take vitals. And something like dermatology, if someone comes in with an issue there's really only so much you can see with a photo" (GP)*

Professionals want supports in place to ensure fair and equal access to online health and digital care by all members of the public.

The move to digital care was seen as a positive by focus group participants as it is a quicker way to see a higher number of patients. However, professionals emphasised that an important aspect of the delivery of digital care is patients' choice, patients have to have choice over decisions around their care and the format of delivery (such as in person, virtual, hybrid, electronic or paper based). There should always be an alternative in place that people are comfortable with if do not want to engage digitally.

> *"we just need to try and figure out how to be in a position to offer people as much as possible in as varied a way as possible [when providing services digitally]. As long as it's their choice I think that's the key." (Principal social worker)*

Focus group participants noted the potential for digital exclusion and the importance of ensuring that the move to digital care does not disadvantage anyone who does not have the means or ability to access digital care. Participants identified that supports need to be put in place to ensure equal access for all, such as providing IT support and training for people who use services on platforms for digital appointments.

> *"There is a certain cohort of the population for whom they cannot or will not engage in that particular format. And you don't want to widen that chasm of inequality any further." (Pharmacist)*

Participants highlighted that for certain cohorts of the public, the move to digital care will be transformational and improve access to healthcare, such as people living in remote areas, and individuals who struggle with face-to-face appointments.

4.4 Overall findings of the professional survey and focus groups

The findings from the professional survey and focus groups demonstrate that professionals think it is important for the public to have access to their information in an online health record. The majority of professionals think the public should have access to all their medical information including backdated records and new information about them. Professionals think that the public have the right to access their own information, and foresee a number of benefits including that the public will be more knowledgeable and have more control over their health, they will be able to have more informed conversations with professionals and will be able to play a role in decisions around their care. Professionals also think that the public having access to their medical records will increase transparency and trust in the healthcare system overall.

Professionals would be most comfortable with the public having access to information about care plans, allergies and information about future medical appointments in their online health record. Professionals would be least comfortable with the public having access to their clinical notes. Professionals noted that this was because they feel their notes are not of a high quality, may be ambiguous and they often use clinical or technical language. Prior to professionals feeling comfortable sharing their clinical notes, they would like training and education, alongside policy direction and guidance on the minimum standard required for a clinical note.

Overall, professionals think it would be helpful for the public to identify errors or omissions in their online health record. Professionals think it would be most useful for the public to update their personal details, such as change of address, in their online record. Professionals think this is important to prevent data breaches and ensure that the public receive reminders about upcoming appointments. Professionals do not think it should be the public's responsibility to amend their health information in their online record, any changes should be requested by the person and should be verified and updated by a professional working in health and social care.

The majority of professionals have had a telephone consultation and a small percentage have had a video consultation. Professionals said that overall the number of digital consultations had decreased since the pandemic. Professionals have mixed views regarding how ready they think the public are for interacting with professionals digitally. Professionals think that there is still work to be done to determine the most appropriate format for the delivery of care digitally compared to in person. Professionals feel that in-person appointments are required for initial consultations and when a physical exam is required. Professionals also think that personal choice is paramount when deciding the format and delivery of care. Most professionals feel that when information is shared digitally, their relationships with the people they treat or care for will improve or remain the same. A strong minority of professionals think that when care is provided digitally, the relationship with the people they treat or care for will disimprove.

5. Overall findings

The findings from the National Engagement on Digital Health and Social Care demonstrate the public's readiness for the digitalisation of health and social care services. One of the key principles of the Digital Health Framework for Ireland is 'patients as empowered partners',(4) and this was a theme reflected in the findings of this engagement. The public want to have access to their information in an online health record (74% said they would access an online health record if it was made available) and would like the option to access video consultations if available (55% said they would access video consultations).

In line with a human rights-based approach to health and social care delivery,(13) the public feel that by having access to their online health information, they will be more knowledgeable about their health, will be able to have more informed conversations with professionals. As a result, they will have more autonomy and will be better able to participate in decisions around their care or treatment. The public have a right to access timely, accurate and complete information about their health.(13) The findings of this report demonstrate that while the public want to have access to their health information in an online health record, they want their record to do more than keep them informed of their health information. The public want to use an online record for practical tasks related to their health.

While the public are positive about the move to digitalisation of health and social care services, they identified areas where additional support and consideration should be given:

- The public want equitable access to online health records and digital care by all. The public feel support should be put in place for those who may struggle to access digital services by providing equipment or education or training in digital literacy.
- The public want the digitalisation of health and social care services to be person centred and want to have input in decisions around the format and delivery of their care. The public also want to be consulted on the design and layout of an online health record and want processes in place to ensure continual improvements.
- The public are happy to share information in an online health record with a professional and a trusted family member or friend. However, the public want control over their information and want transparency regarding who accessed their information and for what purpose. The public voiced concerns about the privacy and security of an online health record and they will need assurances that their information will be kept secure and confidential.

The findings from the National Engagement on Digital Health and Social Care demonstrate that while professionals see the benefits of online health records and digital care for empowering patients on their healthcare journey, professionals are aware of the barriers to implementation and foresee areas where support and infrastructure will be required.

One of the six key principles of the Digital Health Framework for Ireland, 'digitally enabled workforce and workplace', focuses on having a digitally skilled and supported workforce and a modern fit-for-purpose workplace environment.(4) Professionals rated the greatest challenges of providing services and communicating digitally as IT challenges, for example, broadband speeds and the IT skills of people they treat or care for. Professionals in this research outlined areas where they feel additional consideration and support will be required:

- In order to feel more comfortable providing care digitally, professionals will need to be clear on who to contact for technical support.
- Professionals expressed concerns about the privacy and security of online health records. Professionals indicated that it would increase their comfort providing services or information digitally if they know what measures are in place to keep services and information private and secure from cyberattacks.
- Professionals want the move to digital care to be inclusive to all and want to ensure that nobody is disadvantaged if they do not have the means or ability to access digital care. Professionals want supports put in place to ensure equal access for all, including IT support and training in digital literacy skills.
- Some professionals expressed reluctance sharing their clinical notes. Professionals would like support, training and education in clinical note taking alongside clear policy direction and guidance regarding the minimum standard required for a clinical note.

6. Conclusion and next steps

6.1. What were people’s views on accessing and sharing online health records and accessing and provider services digitally in Ireland?

The findings from the National Engagement on Digital Health and Social Care demonstrate the public’s readiness for online health records and digital care. The public want to use an online health record to support them in managing their healthcare journey, such as, renewing prescriptions, contacting professionals about errors in their records and cancelling or rescheduling appointments. The public think that by having access to their information in an online record they will be more knowledgeable about their health, have more informed conversations with professionals and be in a position to play a more active role in decisions around their care.

Professionals have positive attitudes to digital technologies and think that digitalisation of health and social care services will have benefits for the public and increase transparency and trust in the system. Professionals think that online health records will enable the public to be better informed about their health and better prepared to ask questions in appointments overall empowering people on their healthcare journey. However, professionals are concerned about the barriers to implementation and foresee areas where support and improvements in infrastructure are required.

6.2. What happens next?

The findings from this engagement provide insights and evidence to inform practice, policy, legislation and decision-making regarding development and provision of digital health systems and services in Ireland.

- HIQA will use the findings to inform their programme of work in relation to health information including the promotion and implementation of the National Standards for Information Management in Health and Social Care,(6) the development of national health information standards, and the dissemination, training and support to progress goals to inform the establishment of a health data access body.

- The findings will be used by the Department of Health to inform legislation, national policy in digital health and social care being progressed under the Health Information Bill 2024 and the National Digital Health Framework 2024-2030.

- The HSE will use the findings to inform the delivery of key elements of the National Digital Health Strategic Implementation Framework 2024-2030 and the Sláintecare vision including the patient app and patient feedback platform, digital health capacity building, and electronic health record.

More information is available on www.hiqa.ie.

7. Appendices

Appendix 1: Membership of Steering Group

Steering group for the national engagement on digital health and social care

Name	Title Organisation
Rachel Flynn (Chair)	Health Information and Quality Authority *Director of Health Information and Standards*
Kevin O'Carroll	Health Information and Quality Authority *Health Information Manager - Standards and Technology*
Sarah Gibney	Department of Health *Principal Officer, Head of Health Information Policy*
Helen Conroy[§]	Department of Health *Assistant Principal Officer, Health Information Policy*
Niall Sinnott	Department of Health *Principal Officer, eHealth and Health Information Systems*
Kathryn Kissane	Health Service Executive *Deputy Delivery Director; Engagement & Delivery; Standards & Shared Care Records*
Richard Greene	Health Service Executive *Professor of Clinical Obstetrics (UCC); Chief Clinical Information Officer (HSE); Director of The National Perinatal Epidemiology Centre*
Tiberius Periera	National Patient Forum *Patient Representative (Patients for Patient Safety Ireland)*
Mary Brigid Collins	National Patient Forum *Patient Representative (Pavee Point)*

[§] **Helen Conroy replaced Sarah Gibney in June 2024**

Appendix 2: Public telephone survey tool

Information Access and Sharing

Situation 1: readiness to access digital health information online

I will now go through some questions. If there are some you'd prefer not to answer, please say Pass.

Q1. Thinking first about how comfortable you are using technology in general right now.

How comfortable or uncomfortable are you with each of the following? Please answer on a scale of 1 to 5, where 1 is very uncomfortable and 5 very comfortable. If you don't use a particular item or service please indicate how comfortable you would expect to be using it.

	(Instruction to interviewer: read out and tick all that apply.)	Very uncomfortable				Very comfortable	Don't know	Pass
		1	2	3	4	5		
a.	Using websites like Google							
b.	Using social media like Facebook or TikTok							
c.	Using digital devices related to health such as smart watches like Fitbits (Interviewer prompt e.g. step counters, pedometers, fitness bracelets)							
d.	Using health apps on your mobile phone such as to monitor sleep or calorie intake (Interviewer prompt e.g. to support medication intake or							

	measure physical activity.)							
e.	Interacting with online services such as online banking, renewing your passport online, or Revenue Online Service							

Q2. Every time you visit a GP or other health professional, or when you go to a hospital, details about that visit are added to your health record. If these records were to be made available to you online, what information would you want to be able to view?

(Instruction to interviewer: tick all that are mentioned. If not mentioned, probe the remaining responses: "Do you think it would be important or not important to view ...?)

No		Spontaneous Response	Prompted Important	Prompted Not Important	Pass
a.	Your personal details like name, address, date of birth				
b.	Details of the person who should be contacted in case of emergency				
c.	Your Medical Card or other medical schemes you are registered for (Interviewer prompt: e.g. Drug Payment Scheme, General Medical Scheme, Long-Term Illness Scheme)				
d.	Your private health insurance details				
e.	Your current health conditions or diagnoses				

f.	Your current medications prescribed by healthcare practitioners				
g.	Your allergies				
h.	Details about blood tests, x-rays or other tests/scans				
i.	Your vaccinations				
j.	Medical alerts such as you don't like needles or you faint when you give blood				
k.	Surgeries you may have had				
l.	Implants or medical devices you may use like hip replacements or pacemakers				
m.	Notes GPs or other professionals have written about you				
n.	Referrals from a GP or health practitioner to another professional				
o.	Discharge information, such as when leaving hospital				
p.	A list of future medical or other healthcare appointments				
q.	Plans of care, for example information on services or supports you require				
r.	Your mental health records				
s.	Your sexual health records				
t.	Other (Interviewer instruction: record verbatim what the respondent				

	says if not in the above list. These will be categorised as Spontaneous Responses.)				

Situation 2: what people would like to see and do with digital health and social care information

Q3. There are some things you could do in an online health record that could help you manage your health.

Using a scale of 1-5, where 1 is not at all important, and 5 is very important, how important would it be if you could do the following in an online health record?

No	(Instruction to interviewer: read out and tick all that apply.)	Not at all important				Very important	Pass
		1	2	3	4	5	
a.	Book, reschedule, or cancel appointments						
b.	Renew prescriptions for regular medications						
c.	Update your contact details like your phone number or address						
d.	Track the progress of blood tests or other tests						
e.	Track the progress of referrals						
f.	Record your organ donation wishes						
g.	Contact healthcare professionals about information missing from or mistakes in your record						
h.	Communicate securely with a GP or other healthcare professional online						

i.	Can you think of any other things you'd like to be able to do in your online health record? *(Instruction to interviewer: The emphasis here is on being able **to do** things with the health information record. It is not about viewing information.*	
	Record what they say verbatim)	

Q4. There are benefits to having online access to your health and social care information. We'd like to see if you think it would benefit you to have access in the future.

I'll read out a number of benefits and I'll ask you to rate them from 1-5, where 1 is where you strongly disagree, and 5 is you strongly agree.

No	(Instruction to interviewer: read out and tick all that apply.)	Strongly disagree				Strongly agree	Pass
		1	2	3	4	5	
a.	Having all your information in one place could help you understand your health.						
b.	An online record could help manage your health between visits by reminding you what you were told during appointments.						
c.	An online record could help you prepare questions or information you want to share during an appointment.						
d.	Knowing what's recorded about you may help you talk to a professional about your health.						
e.	You would feel more in control of your health because you would know what is in your record.						

f.	You would have greater trust in professionals because you would have access to the records they are creating about you and your care.						

Q5. As well as being able to see what’s written about you in a record, in some countries, people can add their own information to their online health record. Which of the following do you think would be beneficial or not beneficial for you to add to your online health record?

No	(Instruction to interviewer: read out and tick all that apply.)	Beneficial	Not beneficial	Not relevant	Pass
		1	2	3	
a.	Over-the-counter medicines you regularly use like vitamins, cough medicine, pain killers				
b.	Lifestyle information like food diaries or the number of hours you sleep				
c.	Health information you know about yourself but hasn’t been diagnosed by a medical professional; For instance food intolerances, allergies, that you dislike needles				
d.	Information from personal digital devices like step counters, pedometers, or smart watches				
e.	Information from health apps on your mobile phone such as physical activity trackers or apps that help people stop smoking or manage their				

	weight				
f.	Can you think of other health information you know about yourself that you'd like to be able to record in an online health record *(Instruction to interviewer: Record what they say verbatim.)*				

Section two: sharing online health information

Situation 3: sharing online health information with family and friends

Now, let us move on and we'll talk about potentially giving a trusted family member or friend access to your online health and social care information.

Q6. Can you think of the kinds of health and social care information you would be comfortable sharing with a trusted family member or friend in an online health record?

(Instruction to interviewer: tick all that are mentioned. Number the order of spontaneous responses. If not mentioned, probe the remaining responses: "Would you be comfortable or not comfortable sharing ...?

If they say option 1, they would not be comfortable sharing anything, move to the next question, question 8.)

No		Spontaneous Response	Prompted Comfortable	Prompted Not Comfortable	Pass
a.	I would not be comfortable sharing anything. (Interviewer instruction, if they give this option, move to **question 8** below.)				
b.	Your personal details like name, address, date of				

	birth				
c.	Details of the person who should be contacted in case of emergency				
d.	Your Medical Card or other medical schemes you are registered for (Interviewer prompt: e.g. Drug Payment Scheme, General Medical Scheme, Long-Term Illness Scheme)				
e.	Your private health insurance details				
f.	Your current health conditions or diagnoses				
g.	Your current medications prescribed by healthcare practitioner				
h.	Your allergies				
i.	Procedures like blood tests, x-rays, or other tests/scans				
j.	Your vaccinations				
k.	Medical alerts such as you don’t like needles or you faint when you give blood				
l.	Surgeries you may				

	have had				
m.	Implants or medical devices you may use like hip replacements or pacemakers				
n.	Notes GPs or other professionals have written about you				
o.	Referrals from a GP or health practitioner to another professional				
p.	Discharge information, such as when leaving hospital				
q.	A list of future medical or other healthcare appointments				
r.	Plans of care, for example information on services or supports you require				
s.	Your mental health records				
t.	Your sexual health records				
u.	Other (Interviewer instruction: record verbatim what the respondent says if not in the above list. These will be categorised as				

	Spontaneous Responses.)				

ASK Q.7 TO THOSE UNCOMFORTABLE ABOUT AT LEAST ONE ITEM AT Q.6

Q7. Thinking of that trusted family member or friend, I'd next like to see what might make you more comfortable giving them access to your online health information. On a scale of 1 to 5, where 1 is would not increase my comfort and 5 is would increase my comfort a lot, how much would each of the following increase your comfort?

No	(Instruction to interviewer: read out and tick all that apply.)	Would not increase my comfort				Would increase my comfort a lot	Pass
		1	2	3	4	5	
a.	You controlling who has access						
b.	You controlling what they see						
c.	You controlling how long they can see the information for						
d.	You being able to easily remove someone's access						
e.	You being able to easily give someone else access						
f.	Is there anything else that might help you feel more comfortable giving someone else access to your online health information? (Instruction to interviewer: Record what they say verbatim.) (Instruction to the interviewer: respondent may spontaneously say that **nothing will make**						

	them comfortable. If so, record this verbatim.)		

Section four: Digital care

Situation 4: digital care, the types of digital care the public want or would be happy to use.

Now, we are going to move onto our last topic and talk about digital care. For example, traditionally you would have face-to-face appointments with a GP but digital care can mean having appointments by phone or online video. Digital care can also mean using devices and technology at home to help monitor or manage conditions.

We would first like to know how you feel about having telephone or video appointments.

Q8. Can I ask if you've ever had a telephone appointment with a GP or any other health or social care professional rather than seeing them in-person?

No	(Instruction to interviewer: tick what applies.)	
1.	Yes	
2.	No	
3.	Pass	

(Instruction to interviewer: If **Yes**, ask question a below. If **No** or **Pass**, skip to question 10.)

a. **Using a scale of 1-5, where 1 is very uncomfortable, 5 is very comfortable, how comfortable were you speaking to them by phone rather than seeing them in-person?**

(Instruction to interviewer: tick what applies.)	Very Uncomfortable	Uncomfortabl	Neutral	Comfortable	Very comfortable	Pass
	1	2	3	4	5	

Q9. Have you ever had an online video consultation with a GP or any other health or social care professional rather than seeing them in-

person?

No	(Instruction to interviewer: tick what applies.)	
1.	Yes	
2.	No	
3.	Pass	

(Instruction to interviewer: If **Yes**, ask question **a** below. If **No** or **Pass**, skip to question **11.**)

a. **Using a scale of 1-5, where 1 is very uncomfortable, 5 is very comfortable, how comfortable were you speaking to them by video rather than seeing them in-person?**

(Instruction to interviewer: tick what applies.)	Very uncomfortable	Uncomfortable	Neutral	Comfortable	Very comfortable	Pass
	1	2	3	4	5	

Q10. I'm now going to call out a few other examples of digital care and I'd like you to rate how comfortable you would be with each. Using a scale of 1-5, 1 being very uncomfortable, 5 being very comfortable, how comfortable would you be with:

No	(Instruction to interviewer: read out and tick all that apply.)	Very uncomfortable				Very comfortable	Not relevant to me	Pass
		1	2	3	4	5		
a.	receiving reminder SMS text messages or emails about upcoming appointments?							
b.	Receiving SMS text messages or emails saying results of							

	medical tests are available?							
c.	communicating using a chat feature on a website where you type your questions into a box and you get an automated response?							
d.	using personal monitoring devices, for example a personal alarm that you would wear? (Interviewer prompt: e.g. some people wear personal alarms to keep them safe at home e.g. if they had a fall)							
e.	using monitoring devices that a health professional would give you, like heart rate or blood pressure monitors?							
f.	tracking and recording symptoms in a system, for example if you had arthritis, you							

	could record pain levels?							
g.	filling out a health questionnaire online before you have a medical appointment? (Interviewer prompt: e.g. a hospital would set up a questionnaire online and you'd fill it in before an appointment.)							

Q11. There are several ways that could be used to link your health information to you and correctly identify you when accessing health services. On a scale of 1-5, where 1 is very uncomfortable and 5 is very comfortable, how comfortable would you be in providing the following information to correctly identify you and your information?

No		Very uncomfortable				Very comfortable	Not relevant to me	Pass
		1	2	3	4	5		
a.	Your name and date of birth							
b.	Your mobile phone number							
c.	Your Eircode							
d.	Your email address							

e.	A MyGovID (Interviewer prompt: MyGovID is an online account that lets you access different government services like social welfare payments, apply for a driving licence, or pay property tax.)							
f.	Your Personal Public Service Number (PPSN)							

Q12. If your health and social care information is made available online and digital care is made more available, on a scale of 1-5, where 1 is very unlikely and 5 is very likely, how likely are you to:

	Very unlikely	Unlikely	Neutral	Likely	Very likely	Pass
	1	2	3	4	5	
access your online health record?						
use digital health services such as video						

consultations with healthcare professionals?						

Q13. Can you tell me any challenges you think you may have with accessing your health information online or with digital health and social care?

Free text field

Q14. Overall, do you have any additional comments in relation to accessing health records online or to digital care?

Free text field

Demographic questions

And finally, I would like to ask you a few more questions for classification purposes. It will not be possible for the answers to be linked back to you in any way.

If there are any questions you would rather not answer, please say “Pass”.

Q15. What county do you live in?

Note the county.

(Or record if they pass on this question.)

Q16. Do you reside in a…

- City (interviewer prompt if necessary: like Dublin, Cork, Limerick, Waterford, Galway)

  or

- A large town (interviewer prompt: with a population of 5000+)

  or

- A small town (interviewer prompt: with a population of 1500 to 4999) or

- A rural area

(Or record if they have pass on this question.)

Q17. How old were you on your last birthday?

Note person's age:

Note to interviewer: If they are reluctant to give their exact age, ask "Are you between:

a. 18 and 24

b. 25 and 34

c. 35 and 49

d. 50 and 64

e. 65 or older?"

f. (Or record if they pass on this question.)

Q18. Are you?

g. Male

h. Female

i. Other

j. Pass (Do not read out)

Q19. What is the highest level of education/training which you have completed?

Interviewer prompt

- No formal education/training
- Primary
- Lower secondary (Group; Inter; Junior Certificate)
- Upper secondary (Leaving Certificate)
- Technical or vocational
- Advanced certificate/completed apprenticeship

- Higher certificate
- Ordinary Bachelor Degree or National Diploma
- Honours Bachelor Degree or Professional Qualification or both
- Postgraduate Diploma or Master's Degree
- Doctorate (Ph.D.) or Higher (Or record if they pass on this question.)

Q20. The next question I will ask is about ethnicity. It is asked solely so that we can properly describe the general characteristics of the people who responded to the survey. May I ask what your ethnic or cultural background is? Is it…

White

- Irish
- Irish Traveller
- Roma
- Any other White background (Please specify.)

Black or Black Irish:

- African
- Any other Black background (Please specify.)

Asian or Asian Irish:

- Chinese
- Indian
- Pakistani
- Bangladeshi
- Any other Asian background (Please specify.)

Other, including mixed group/background:

- Arabic
- Mixed, please specify
- Other, please specify.

- Pass (Do not read out.)

Q21. Do you have a long-term or chronic health condition that has been confirmed by a medical diagnosis?

- Yes
- No
- Pass

Q22. In the last 12 months, how many times, if at all, have you been to:

No	Type	Number of times	Pass
1.	a GP, consultant, dentist, or other health or social care professional? (Interviewer prompt, if necessary: optician, physiotherapist, speech and language therapist, psychologist, dietician, occupational therapist, podiatrist, social worker, etc.)		
2.	hospital as a day patient or inpatient? (Interviewer prompt: as a day patient, you were admitted to hospital for diagnosis, treatment, or other types of healthcare, but you didn't stay overnight; As an inpatient, you stayed at least one night.)		

Q23. For the past 12 months or more, have you been limited in everyday activities due to health problems, i.e. an on-going physical or mental health problem, illness, or disability?

- Yes
- No
- Don't know
- Pass

Q24. Do you have a full medical card?

- Yes

- No
- Pass

Instruction to interviewer: if **No** or **Pass**, ask:

a. Do you have a GP visit card?

  - Yes
  - No
  - Pass (Do not read out.)

Q25. Do you have private health insurance?

- Yes
- No
- Pass (Do not read out.)

Q26. Do you have a formal qualification such as a diploma or degree in a medical, nursing, or health or social care profession?

- Yes
- No
- Pass (Do not read out.)

Q27. Do you have a formal qualification such as a diploma or a degree in information technology or computer science?

- Yes
- No
- Pass (Do not read out.)

Appendix 3: National Engagement on Digital Health and Social Care participant demographics and characteristics

Public survey and focus groups

For the public survey, a total number of 2,009 interviews were conducted by phone by using randomly selected numbers. The participants were the members of the public in Ireland aged 18 years and over. Table 4 includes the public survey participant characteristics.

Between September 2023 and February 2024, eight focus groups and four one-to-one interviews were held with members of the public and representatives of different service user groups. A total of 41 people took part in these groups.

Table 4: Public survey participant characteristics[**]

Geographical location	Number (N)	%
Connaught / Ulster	350	17
Rest of Leinster	536	27
Munster	538	27
Dublin	584	29
Age category	**N**	**%**
18 to 24	231	11
25 to 34	319	16
35 to 49	597	30
50 to 64	466	23
65 or older	396	20
Gender	**N**	**%**
Male	982	49
Female	1026	51
Other	>5	0.1

[**] Please note the figures in this table are weighted. For unweighted responses please see the published data file on www.hiqa.ie. Please note that values in tables do not always add up to 100% exactly. This is due to rounding.

Highest level of education or training	**N**	**%**
No formal education or training	13	0.6
Primary	144	7
Lower secondary (Group; Inter; Junior Certificate)	273	14
Upper secondary (Leaving Certificate)	359	18
Technical or vocational	57	3
Advanced certificate/completed apprenticeship	71	4
Higher certificate	67	3
Ordinary Bachelor Degree or National Diploma	254	13
Honours Bachelor Degree or Professional Qualification or both	313	16
Postgraduate Diploma or Master's Degree	359	18
Doctorate (Ph.D.) or Higher	25	1
Pass	72	4
Ethnic group	**N**	**%**
White Irish	1609	80
White Irish Traveller	>5	0.1
Roma	7	0.3
Other White Background	179	9
Black or Black Irish		
Black or Black African Irish	35	2
Other Black Background	>5	0.1
Asian or Asian Irish		
Chinese	8	0.4
Indian/Pakistani/Bangladeshi	48	2
Other Asian Background	14	0.7
Other, including mixed group/background		

Arabic	10	0.5
Mixed	38	2
Other	26	1
Pass	33	2
Long-term or chronic condition	**N**	**%**
Yes	704	35
No	1281	64
Pass	24	1
Number of times in last 12 months attended	**N**	**%**
A GP, consultant, dentist, or other health or social care professional		
Never	179	9
1	268	13
2-5	971	48
6-10	392	19
More than 10	178	9
Pass	21	1
Hospital as a day patient or inpatient		
Never	1165	58
1	360	18
2-5	370	18
6-10	53	3
More than 10	29	1
Pass	33	2
For the past 12 months or more, limited in everyday activities due to health problems	**N**	**%**
Yes	511	26

No	1480	74
Don't know	6	0.3
Pass	12	0.6
Full medical card user	**N**	**%**
Yes	698	35
No	1296	65
Pass	15	0.7
GP Visit Card User	**N**	**%**
Yes	133	10
No	1159	89
Pass	5	0.4
Private health insurance user	**N**	**%**
Yes	1109	55
No	875	44
Pass	25	1
Formal qualification in a medical, nursing, or health or social care profession	**N**	**%**
Yes	240	12
No	1759	88
Pass	10	0.5
Formal qualification in information technology or computer science?	**N**	**%**
Yes	209	10
No	1789	89
Pass	12	0.6

Professional survey and focus groups

For the professional survey, a total of 1,020 professionals working in health and social care services took part in the online survey. Table 5 includes the professional survey participant characteristics.

Between January and February 2024, three focus groups were held with a mix of professionals across health and social care. Focus groups were held online with a total of 27 professionals taking part.

Table 5: Professional survey participant characteristics[††]

Data on who took part	Number (N)	%
Age		
18-24	6	1
25-34	124	13
35-49	430	46
50-64	363	39
65 or older	18	2
Gender		
Male	202	21
Female	742	78
Other	11	1
Role		
Nursing and Midwifery Board		
Nurse	496	49
Midwife	26	3
Medical Council		
General Practitioner	22	2
Non-consultant specialist doctor	22	2
Consultant or specialist	66	6

[††] Please note that values in tables do not always add up to 100% exactly. This is due to rounding.

CORU		
Dietitian	22	2
Dispensing Optician	>5	>1
Medical Scientist	20	2
Occupational Therapist	24	2
Optometrist	11	1
Physiotherapist	32	3
Podiatrist	4	0.4
Radiographer	16	1.6
Radiation Therapist	4	0.4
Social Worker	34	3
Speech and Language Therapist	40	4
Pre-Hospital Emergency Care Council		
Advanced paramedic	24	2
Emergency Medical Technician	16	2
Paramedic	21	2
Pharmaceutical Society of Ireland		
Community Pharmacist	34	3
Hospital Pharmacist	31	3
Psychological Society of Ireland		
Psychologist	26	3
Psychotherapist	>5	>1
Dental Council of Ireland		
Dental Hygienist	>5	>1
Dental Nurse	>5	>1
Dental Specialist	7	1

Dentist	9	1
Area of work		
Acute	469	46
Community	352	35
Primary Care	113	11
Not relevant to my role	77	8
Sector		
Public	723	73
Private	166	17
Voluntary	97	10
Employment status		
Permanent employee	906	89
Contract employee	55	5
Agency contract employee	10	1
Self employed	42	4
Management/Direct Care		
Management/administration	386	38
Direct care	566	56
Other	64	6

Appendix 4: Professional online survey tool

National Engagement on Digital Health and Social Care

A. Do you consent to taking part?

Yes ☐ (*Survey continues.*)

No ☐ (*Survey ends. A page appears telling the participant that the survey has ended.**)

B. Are you currently in paid employment in health and social care in the Republic of Ireland?

Yes ☐ *(Survey continues.)*

No ☐ *(Survey ends. A page appears telling the participant that the survey has ended.*)*

C. Are you registered with or a member of:

- CORU ☐
- The Dental Council of Ireland ☐
- The Medical Council ☐
- The Nursing and Midwifery Board of Ireland ☐
- The Pharmaceutical Society of Ireland ☐
- The Pre-Hospital Emergency Care Council ☐
- The Psychological Society of Ireland? ☐

(If the respondent selects any of these, the survey continues.)

No ☐ *(Survey ends. A page appears telling the participant that the survey has ended.*)*

SECTION ONE (1/4) – SHARING HEALTH AND SOCIAL CARE INFORMATION WITH THE PUBLIC

How comfortable you are using technology

Q.1 Please rate how comfortable you are using technology in general, where 1 is very uncomfortable and 5 is very comfortable.

	Very uncomfortable				Very comfortable
	1	2	3	4	5
Using websites like Google					
Using social media like Facebook or TikTok					
Using personal digital devices related to health, for example, step counters, pedometers, smart watches, fitness bracelets					
Using personal health apps on your mobile phone, for example, to monitor sleep or calorie intake or to support medication intake					
Interacting with online services, for example, online banking, renewing your passport online, or Revenue Online Service					

SECTION ONE (1/4) – SHARING HEALTH AND SOCIAL CARE INFORMATION WITH THE PUBLIC

The public having digital access to their own health information

Q.2a-l The EU has targets for the public to have digital access to their medical records by 2030. Please rate each of the following, where 1 is you would be very uncomfortable and 5 is you would be very comfortable with the people you treat or care for having digital access to the following types of information recorded about them.

	Very uncomfortable				Very comfortable	Not relevant to my role
	1	2	3	4	5	
Health conditions or diagnoses						

Medications prescribed by healthcare practitioners						
Allergies						
Vaccinations						
Details of surgeries						
Results of blood or screening tests						
Reports on x-rays and other scans						
Referrals you have made (for example, from you to another professional or service)						
Discharge information						
A list of future medical or other health or social care appointments						
Plans of care (for example, information on services or supports required)						
Notes (for example, notes you write during or after an appointment)						

Q.2m Please specify other types of information you would be comfortable or uncomfortable with the people you treat or care for having digital access to. (Optional question)

I would be comfortable with:

I would be uncomfortable with:

SECTION ONE (1/4) – SHARING HEALTH AND SOCIAL CARE INFORMATION WITH THE PUBLIC

Access to backdated information/records or new information/records from a given date

Q.3 Please select the option that best describes your opinion.

The people you treat or care for should:

have digital access to backdated information/records and new information/records about them.
have digital access to new information/records about them only.
not have digital access to information/records about them.
Not relevant to my role

SECTION ONE (1/4) – SHARING HEALTH AND SOCIAL CARE INFORMATION WITH THE PUBLIC

Radiology Reports and Laboratory Tests

Q.4 There can be different approaches around the timeframe when radiology reports and results of laboratory tests are made available online to the people you treat or care for. Which of the following best describes your opinion as to when they should be made available? Select the one which best applies to you.

People should have access to their radiology reports and results of laboratory tests <u>as soon as</u> they are available, which could be <u>before</u> they are reviewed by a health or social care professional.
People should be able to view their radiology reports and results of laboratory tests <u>after</u> they are reviewed and made available on the system by a professional. The professional has to release them on the system to the person.
People should have access to their radiology reports and results of laboratory tests only <u>after</u> consultation (either in-person or by telephone or video) with a professional. The professional then makes them available on the system.
The timeframe I would prefer would depend on the reports or results.
The reports or results should not be made available digitally.

Not relevant to my role

SECTION ONE (1/4) – SHARING HEALTH AND SOCIAL CARE INFORMATION WITH THE PUBLIC

Changes to your recording behaviour

Q.5 When a system is in place where the public have digital access to their health and social care information, do you think this will affect how and what you record about the interactions you have with people you treat or care for? Please choose the answers that best apply to you.

Q.5a Amount of Information

I will record less information.
I will record the same amount of information.
I will record more information.
Not relevant to my role

Q.5b Language Used

I will change the language I use.
I will not change the language I use.
Not relevant to my role

Q.5c Content of Records

I will change the type of content I record.
I will not change type of content I record.
Not relevant to my role

Q.5d When a system is in place where the public have digital access to their health and social care information, please specify any other ways you think this may affect how and what information you record about the people you treat or care for. (Optional question)

SECTION ONE (1/4) – SHARING HEALTH AND SOCIAL CARE INFORMATION WITH THE PUBLIC

Q.6a-j There are potential benefits for the people you treat or care for having access to their health and social care information in an online health record. Please rate each of the following, where 1 is you strongly disagree, and 5 is you strongly agree. People will:

Benefits	Strongly disagree				Strongly agree	Not relevant to my role
	1	2	3	4	5	
Be better informed about their health.						
Have a better understanding of their health.						
Have a greater ability to manage their health.						
Have a greater ability to prepare questions to ask during appointments.						
Have a greater ability to prepare information to share during appointments.						
Have greater confidence to talk to you about their health.						
Have greater ownership of their health.						
Have greater trust in you because they would have access to the records being written about them and their care.						
Have the ability to identify errors or omissions in their information.						
Experience no benefits.						

Q.6k Please specify other benefits or challenges the people you treat or care for will experience by having access to their health and social care information in an online health record. (Optional question)

Benefits

Challenges:

SECTION ONE (1/4) – SHARING HEALTH AND SOCIAL CARE INFORMATION WITH THE PUBLIC

Q.7 When a system is in place where the public have digital access to their health records, what do you think will be the benefits for you, if any? (Optional question)

SECTION TWO (2/4) – THE PUBLIC PROVIDING INFORMATION

The public adding information to their own online health record

Q.8a-g Would it be useful to you if the people you treat or care for could add their own information to their online health record? Please rate each of the following where 1 is not very useful and 5 is very useful.

	Not very useful				Very useful	Not relevant to my role
	1	2	3	4	5	
Personal details (name, address, phone number, etc.)						
Details of the person to contact in case of emergency						
Details of Medical Cards or other medical schemes						
Details of over-the-counter medicines and supplements						

regularly used like cough medicine, pain killers, vitamins						
Lifestyle information like food diaries or number of hours sleep						
Information on conditions which have not been formally diagnosed by a health professional, for example, food intolerances, allergies, a fear of needles						
Data from personal health devices or apps on smart phones that track physical activity, promote smoking cessation, help with weight management, support mental health, and so on						

Q.8h Please specify any other types of information recorded by the people you treat or care for which you may find useful. (Optional question)

SECTION TWO (2/4) – THE PUBLIC PROVIDING INFORMATION

The public identifying errors or omissions

Q.9 If the people you treat or care for had a way of identifying errors or omissions in their online health records, would you find this:

helpful
not helpful
not relevant to your role

SECTION THREE (3/4) – PROVIDING SERVICES AND COMMUNICATING DIGITALLY WITH THE PUBLIC

Public readiness to interact digitally

Q.10 Generally speaking, do you think the people you treat or care for are ready to interact digitally with you, for example through telehealth, email,

text message etc.? Please rate how ready you think they are where 1 is they are not at all ready and 5 is they are very ready.

Not at all ready				Very ready
1	2	3	4	5

SECTION THREE (3/4) – PROVIDING SERVICES AND COMMUNICATING DIGITALLY WITH THE PUBLIC

We are now going to ask you some questions about telephone and video consultations. Initially, only think about telephone consultations.

Q.11 Have you ever had telephone consultations with the people you treat or care for rather than seeing them in-person?

Yes
No

SECTION THREE (3/4) – PROVIDING SERVICES AND COMMUNICATING DIGITALLY WITH THE PUBLIC

Telephone consultations

Q.11a Did you start carrying out these telephone consultations:

Pre the onset of the COVID-19 pandemic	
Post the onset of the pandemic	

SECTION THREE (3/4) – PROVIDING SERVICES AND COMMUNICATING DIGITALLY WITH THE PUBLIC

Telephone consultations

Q.11b Please rate how comfortable you are as a professional having telephone consultations rather than in-person consultations, where 1 is very uncomfortable and 5 is very comfortable.

Very uncomfortable				Very comfortable
1	2	3	4	5

SECTION THREE (3/4) – PROVIDING SERVICES AND COMMUNICATING DIGITALLY WITH THE PUBLIC

Telephone consultations

11c Since the easing of COVID-19 restrictions, has the frequency of telephone consultations:

increased
decreased
remained the same

SECTION THREE (3/4) – PROVIDING SERVICES AND COMMUNICATING DIGITALLY WITH THE PUBLIC

We are now going to ask you some questions about video consultations.

Q.12 Have you ever had video consultations with the people you treat or care for rather than seeing them in-person?

Yes
No

SECTION THREE (3/4) – PROVIDING SERVICES AND COMMUNICATING DIGITALLY WITH THE PUBLIC

Video consultations

Q.12a Did you start carrying out these video consultations:

Pre the onset of the COVID-19 pandemic?	
Post the onset of the pandemic?	

SECTION THREE (3/4) – PROVIDING SERVICES AND COMMUNICATING DIGITALLY WITH THE PUBLIC

Video consultations

Q.12b Please rate how comfortable you are as a professional having video consultations rather than in-person consultations, where 1 is very uncomfortable and 5 is very comfortable.

Very uncomfortable				Very comfortable
1	2	3	4	5

SECTION THREE (3/4) – PROVIDING SERVICES AND COMMUNICATING DIGITALLY WITH THE PUBLIC

Video consultations

Q.12c Since the easing of COVID-19 restrictions, has the frequency of video consultations:

increased
decreased
remained the same?

SECTION THREE (3/4) – PROVIDING SERVICES AND COMMUNICATING DIGITALLY WITH THE PUBLIC

Digital interactions with the public

Q.13a-g What digital interactions enable you to provide clinically effective care to the people you treat or care for? Please rate each option where 1 is very ineffective and 5 is very effective.

	Very ineffective				Very effective	Not relevant to my role
	1	2	3	4	5	
Text messages for administration tasks (for example appointment management)						
Emails for administration tasks (for example appointment management)						
Telephone consultations						
Video consultations						
Remote monitoring (for example of vital signs using pulse oximeters or heart rate monitors; activity sensors; security alarms)						
Virtual wards[‡‡]						
Chatbots[§§]						

Q.13h What other digital interactions enable you to provide clinically effective care to the people you treat or care for? (Optional question)

[‡‡] Virtual wards allow patients to be safely and conveniently cared for at home rather than in hospital. Support can include remote monitoring using apps and wearable and medical devices such as heart rate monitors and pulse oximeters. Multi-disciplinary teams based in the community may also provide face-to-face care of patients. See https://www.england.nhs.uk/virtual-wards/what-is-a-virtual-ward/

[§§] A chatbot is a computer programme that understands questions and creates automatic responses to them, simulating human conversation. Chatbots respond to written or spoken questions, or a combination, without the need for human intervention. See https://www.ibm.com/topics/chatbots. They can be used to provide information to patients, people who use services, and care givers. They can help with health related tasks for example appointment booking. In a health context, chatbots are sometimes referred to as healthbots.

SECTION THREE (3/4) – PROVIDING SERVICES AND COMMUNICATING DIGITALLY WITH THE PUBLIC

Attitudes to digital technologies

Q.14 We would next like to see if professionals' attitudes to digital technologies in health and social care have changed since the onset of the COVID-19 pandemic and after the cyber-attack in the HSE. Please select the option which best describes your attitude.

	I have a more positive attitude to digital technologies.	I have a less positive attitude to digital technologies.	My attitude hasn't changed.
Since the onset of the COVID-19 pandemic			
Since the cyber-attack in the HSE			

SECTION THREE (3/4) – PROVIDING SERVICES AND COMMUNICATING DIGITALLY WITH THE PUBLIC

Increase comfort levels

Q.15a-e What would make you more comfortable providing services or information digitally? Please rate each option where 1 is would not increase my comfort and 5 is would increase my comfort a lot.

	Would not increase my comfort				Would increase my comfort a lot	Not relevant to my role
	1	2	3	4	5	
Having protocols in place which identify when, as part of a care pathway, it is						

appropriate or inappropriate to provide services or information digitally						
Training in digital tools provided to you						
Knowing what measures are in place to keep services and information secure from cyber-attacks						
Knowing what measures are in place to keep services and information private						
Being clear on who to contact for technical support						

Q.15f What else would make you feel more comfortable providing services digitally or sharing information digitally with people you treat or care for? (Optional question)

SECTION THREE (3/4) – PROVIDING SERVICES AND COMMUNICATING DIGITALLY WITH THE PUBLIC

Q.16 There can be challenges to providing services and communicating digitally with the people you treat or care for. Please select what you think might be the three main potential challenges.

IT challenges for professionals, for example, broadband speeds, computer access problems etc.
Working location challenges for professionals, for example, access to appropriate locations for online consultations
Governance challenges for professionals, for example, codes of practice, guidance on use in care pathways
IT skills of professionals
IT skills of the people you treat and care for
Increase in workload for professionals

The potential of creating or widening a digital divide among the people you treat or care for
IT challenges among the people you treat or care for, for example, broadband speeds, computer access etc.
Lack of suitable locations for the people you treat or care for to attend virtual appointments
Changes to reimbursements for professionals
Lack of standardised ways of capturing and sharing information
Other (Please specify any other potential barriers to implementing digital health and social care.)

SECTION THREE (3/4) – PROVIDING SERVICES AND COMMUNICATING DIGITALLY WITH THE PUBLIC

Your relationship with the public

Q.17a&b We would next like to see if you think your relationship with the people you treat or care for will change when information is shared digitally and care is provided digitally. Please select the option which best describes your opinion.

Question 17a&b	Improve	Disimprove	Remain the same
When information is shared digitally, relationships will			
When care is provided digitally, relationships will			

Q.17c Please comment on your answer. (Optional question)

SECTION THREE (3/4) – PROVIDING SERVICES AND COMMUNICATING DIGITALLY WITH THE PUBLIC

The public knowing who had accessed their record

Q.18 How comfortable or uncomfortable would you be with the public knowing which professionals had accessed their digital records? Please rate where 1 is you would be very uncomfortable and 5 is you would be very comfortable.

Very uncomfortable				Very comfortable
1	2	3	4	5

SECTION THREE (3/4) – PROVIDING SERVICES AND COMMUNICATING DIGITALLY WITH THE PUBLIC

Additional comments

Q.19 Do you have any additional comments in relation to sharing information digitally and providing care digitally to the people you treat or care for? (Optional question)

SECTION FOUR (4/4) – ABOUT YOU

Q.20 Which of these <u>best</u> describes your speciality in your current role?

Nursing and Midwifery Board of Ireland	**CORU**	**Pharmaceutical Society of Ireland**
Nurse ☐	Dietitian ☐	Community Pharmacist ☐
Midwife ☐	Dispensing Optician ☐	Hospital Pharmacist ☐
Medical Council	Medical Scientist ☐	Pharmaceutical Assistant ☐

General practitioner ☐	Occupational Therapist ☐	**Psychological Society of Ireland**
Non-consultant hospital doctor (NCHD) ☐	Optometrist ☐	Psychologist ☐
Consultant or Specialist (with drop-down to choose from) ▪ Anaesthesia ☐ ▪ Emergency Medicine ☐ ▪ Medicine ☐ ▪ Obstetrics and Gynaecology ☐ ▪ Occupational Medicine ☐ ▪ Ophthalmology ☐ ▪ Paediatrics ☐ ▪ Pathology ☐ ▪ Psychiatry ☐ ▪ Public Health Medicine ☐ ▪ Radiology ☐ ▪ Sports and Exercise Medicine ☐ ▪ Surgery ☐	Physical Therapist ☐	Psychotherapist ☐
	Physiotherapist ☐	**Dental Council of Ireland**
	Podiatrist ☐	Clinical Dental Technician ☐
	Radiographer ☐	Dental Hygienist ☐
	Radiation Therapist ☐	Dental Nurse ☐
	Social Worker ☐	Dental Specialist ☐
	Speech and Language Therapist ☐	Dentist ☐
	Pre-Hospital Emergency Care Council	
	Advanced Paramedic ☐	
	Emergency Medical Technician ☐	
	Paramedic ☐	

Q.21 Which of the following best describes the area you primarily work in?

Please select one from:

- Acute ☐

- Community ☐
- Primary Care ☐
- Not relevant to my role ☒

Q.22 Which of the following best describes the sector you primarily work in?

Please select one from:

- Public sector ☐
- Private sector ☐
- Voluntary sector ☐

Q.23 Which of the following best describes your current employment status?

Please select one from:

- Permanent employee ☐
- Contract employee ☐
- Agency contract employee ☐
- Self-employed ☐

Q.24 Is your role primarily in management/administration or in direct care?

Select the option that best applies.

- Management/administration ☐
- Direct care ☐
- Other ☐

Q.25 Please indicate the age group to which you belong:

- Between 18 and 24 ☐
- Between 25 and 34 ☐
- Between 35 and 49 ☐

- Between 50 and 64 ☐
- 65 or older ☐

Q26: Are you?

Please select one.

- Male ☐
- Female ☐
- Other ☐

Appendix 5: Public focus groups - schedule of questions

Question one

Managing health by viewing and interacting with online health records

Every time you go to a GP or if you go to hospital, details about your appointment are recorded in your medical record. We know from the public survey that generally speaking, people would like to read this information about themselves and also manage their health by interacting with their record. For example, they'd like to be able to view details of blood tests or X-rays. They'd like to be able to renew prescriptions or contact professionals about information that's missing or incorrect in a record. What does the group think about this, about managing your health in an online health record?

Prompts (if necessary)

- What kinds of information would you like to be able to read?
- What would you like to do in an online record to help manage your health?
- Do you think it would be beneficial for you to use an online health record to manage your health?
  - Why? Why not?
- Do you think it would be beneficial to be able to read your own health and social care information? Why/Why not?
- Why would you not want to have online access to your health and social care information?

Question two

Sharing your online record with trusted family member or friend

Another thing you could do with an online health record is share your information with someone else, for example a trusted family member. This could be in a situation where you have to go to hospital. How would people feel about that?

Prompts (if necessary)

- Would you be comfortable with all your information being shared?
- What would you share/not share?
- How would you feel about sharing more sensitive information about yourself?

- What would make you feel more in control or comfortable about sharing your information?
- Do you think being older or younger would make you feel more or less comfortable sharing information?

Question three

Digital care

Next, we'll look at aspects of digital care. Traditionally, you would have face-to-face appointments with a GP but digital care can mean having appointments by phone or online video. Digital care can also mean things like doctors giving you devices and technology to use at home to help monitor or manage conditions. We know from the public survey that generally speaking people would be comfortable with different types of digital care such as receiving text messages about upcoming appointments or saying test results are available; using devices at home that a professional would give you e.g. to monitor blood pressure; or tracking or recording symptoms in an online system. If these types of digital care were offered to you, how would you feel about using them?

Prompts (if necessary)

- If you were offered a telephone or video consultation, how do you think you would feel about it? Would you be comfortable with it? Why/why not?
- Do you think you would be comfortable using devices a doctor would give you to use at home?

Final thoughts

Looking at the survey, we can see that people are, generally speaking, very engaged and enthusiastic about the idea of digital health and social care. What do members of the group think about this?

Prompts (if necessary)

- When we think of other aspects of our lives like banking, leisure, or government services like renewing passports or applying for driving licences, a lot of those are digital for example on our phones. Or they are becoming more digital. What do people think of health and social care becoming more digital?

Appendix 6: Professional focus groups - schedule of questions

Question one

Professionals sharing information with the public

A note at the beginning that I'm using the term the public meaning anyone you may treat or care for or provide services to, be it a patient, service user, resident etc.

Every time you see a member of the public, you record information about that interaction. We know from the survey results that generally speaking professionals are (very) comfortable sharing most types of health and social care information with the public in a digital record. Most items are in the 80% or 70% comfortable/very comfortable range (allergies, lists of appointments, vaccinations, plans of care, medications, referrals, diagnoses/health conditions etc.). However, one area that was lower was sharing notes written during or after an appointment (66% (very) comfortable). Overall, what does the group think of sharing information digitally with the public?

Prompts (if necessary)

- What challenges, if any, would you see in sharing information?

  For yourself? For the public?

- What benefits, if any, would you see?

  For yourself? For the public?

- We also asked about sharing radiology and lab test results and if a consultation needs to take place before results are shared digitally. What does the group think of this?
- At what point should results be made available, if they should be?
- Is there any information you would not make available digitally?
- If a system was in place where historical information was made available to the public, how would you feel about sharing that?

Question two

The public providing information

In the survey, we found that 86% of professionals felt it would be helpful if the public had a way of identifying errors or omissions in their online health records. What does the group think of this?

Prompts (if necessary)

- What benefits, if any, would you see to people identifying errors/omissions? For yourself? For the public?
- What challenges would you see? For yourself? For the public?
- If we compare this to the public survey, the 86% rating tallies with the public where 90% thought it would be (very) important to be able to use their digital record to contact professionals about errors or omissions. What do you think of this?
- Would it be useful if the public could add other information to their online health record? If so, what information?

Question three

Digital care and changing relationships

Next, we'll look at digital care and the effects it may have on relationships between professionals and the public. We know from the survey that nearly half of respondents think that sharing information digitally will mean improved relationships. However, there is some concern over the impact of care being provided digitally, e.g. through telemedicine, with 36% thinking relationships will disimprove.

What does the group think of this? The impact of digital information and services on your relationship with the public?

Prompts (if necessary)

- While there is some concern that digital care will negatively affect relationships (36%), a small majority of professionals feel that telephone consultations are an effective way to provide clinical care (53%). 37% think video consultations are effective. What do you think of this?
- Concerns over potential loss of in-person services came up a lot in our public focus groups. What do you think of this?
- Would you be concerned about the loss of face-to-face interactions?
- Would you be concerned about equity and exclusion from services?
- Do you think digital will mean you will have more interactions with the public? E.g. dealing with more queries or clarifications?

Final thoughts

Looking at the survey, we can see that professionals are, generally speaking, positive about digital technologies in health and social care and that COVID had a positive impact on opinions (60% more positive since COVID). Only 29% of respondents said the cyberattack* had negatively affected their opinions. What do members of the group think about this?

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