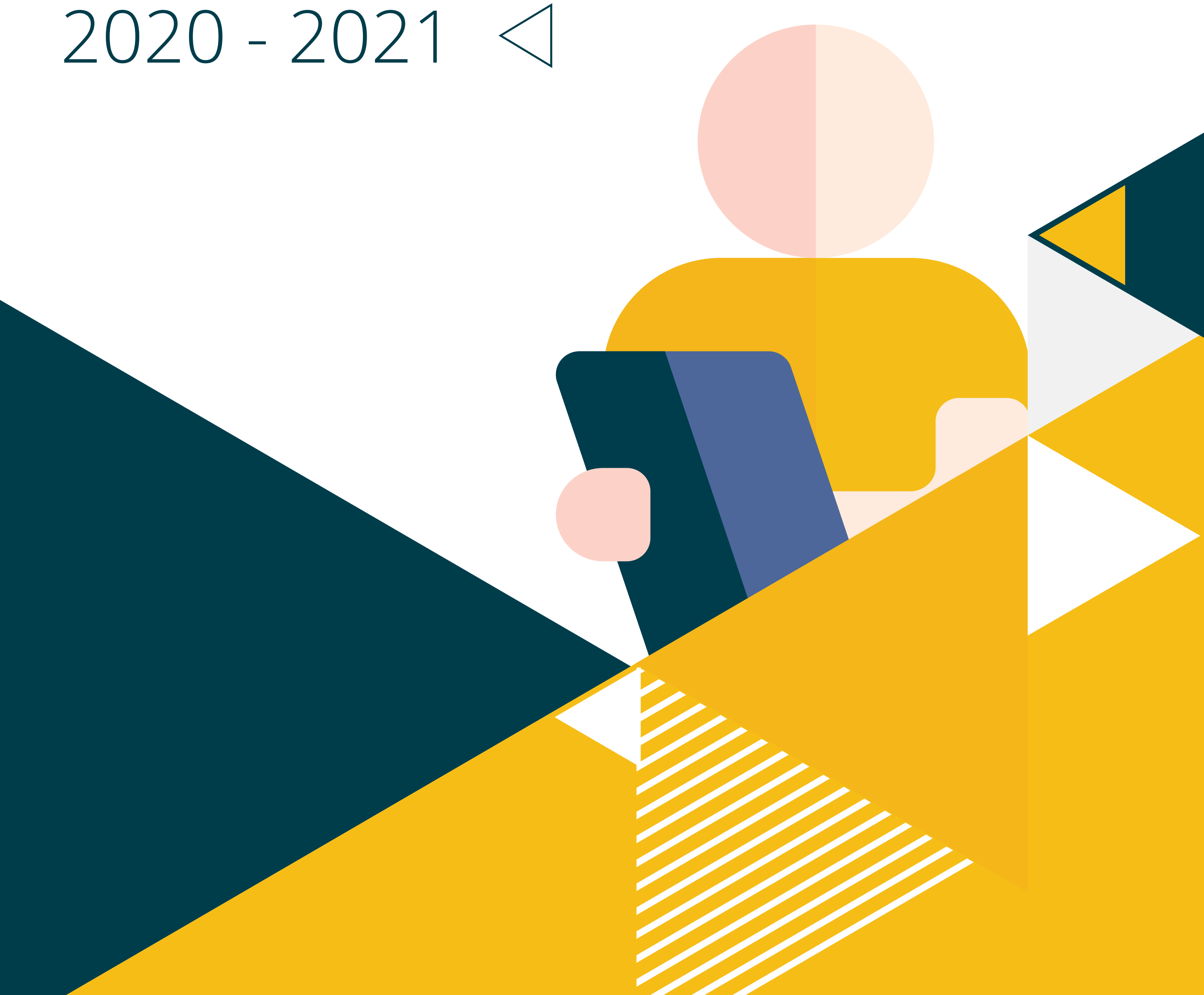
Health Information and Quality Authority
An tÚdarás Um Fhaisnéis agus Cáilíocht Sláinte

An Roinn Sláinte
Department of Health

Findings from the National Public Engagement on Health Information

2020 - 2021

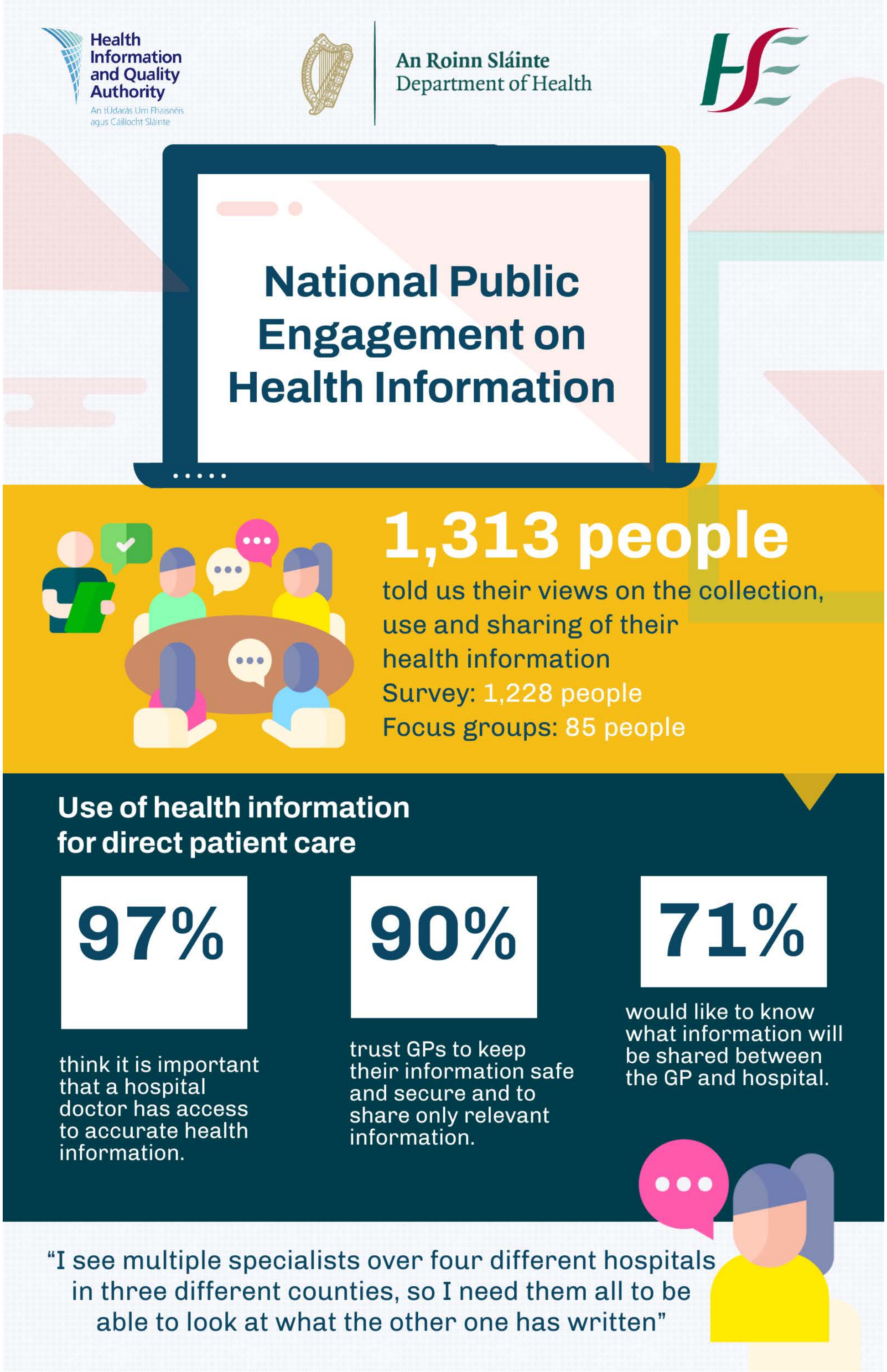


Thank you

Thank you to everyone who took the time to speak with us about how your health information is collected, used and shared in the survey and focus groups as part of the National Public Engagement on Health Information. Your input will be used to make improvements to how health information is used in Ireland. Without your support and participation we would not have been able to gather this important information to support safe and effective care. The National Public Engagement on Health Information ensures that your voice will be heard by the people who can change and improve how health information is shared in Ireland. By putting you at the centre of this process, we can work to ensure that the needs and wishes of everyone are taken into consideration and ultimately improve the quality of health and social care in Ireland.

Thank you to all the healthcare professionals who took part in our engagement meetings and focus groups in the initial phase 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 people working in representative organisations who helped to share information about 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 Advisory Group, Steering Group, and the Partnership Project Team. Your direction and guidance throughout is valued. Appendix 1 lists the members of these groups and the core project team.



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National Public Engagement on Health Information

1,313 people

told us their views on the collection, use and sharing of their health information

Survey: 1,228 people

Focus groups: 85 people

Use of health information for direct patient care

97% think it is important that a hospital doctor has access to accurate health information.

90% trust GPs to keep their information safe and secure and to share only relevant information.

71% would like to know what information will be shared between the GP and hospital.

"I see multiple specialists over four different hospitals in three different counties, so I need them all to be able to look at what the other one has written"

Use of health information for purposes beyond direct patient care

94% think it is important that health information is used to improve the quality of care provided to patients.

93% think it is important that health information is used to plan healthcare services.

77% want to know how their health information will be used beyond their direct care.

"if you are sharing somebody's information they [need to be] fully aware of where it's going, why it's going there, what it's being used for".

Digital records

86% think it is important that all healthcare professionals involved in their care have access to their digital record.

99% think a hospital doctor should be able to access their health information electronically, without their permission, when they are unconscious.

82% think it is important to know which healthcare professionals view their digital record.

"it would be great to know who has looked at [your record]...what information was accessed and how are they going to use it".

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Executive Summary

Background

The Health Information and Quality Authority (HIQA), in partnership with the Department of Health and the Health Service Executive (HSE), has conducted a National Public Engagement on Health Information to ask the public their views on how their health information should be collected, used and shared in Ireland. People were asked to share their views through a national survey and focus groups.

A major challenge for healthcare in Ireland today is achieving an appropriate balance between protecting personal health information, and the use and sharing of such information to improve care and provide a more seamless experience for patients receiving care across multiple healthcare settings.

The Sláintecare Report (2017) outlines a vision for the provision of integrated care in Ireland.(1) The Sláintecare Implementation Strategy and Action Plan 2021-2023 emphasises that the delivery of an integrated healthcare system needs to be underpinned by a robust eHealth programme, which is outlined as a key priority.(2)

It is important to engage with the public before introducing new eHealth and digital technologies, such as a national electronic health record. Involving people in important decisions about their health information will ensure that such technologies are implemented in a way that is acceptable to the public and that their rights in relation to health information are upheld. International evidence has shown that public engagement and involvement is extremely important for the successful introduction of new technologies.(3)

What is the current situation in Ireland?

The Department of Health has overall responsibility for leadership and policy decision-making in the Irish health sector, including for eHealth and health information policy. The HSE is responsible for implementing and providing public health services, strategic programmes in eHealth and a number of national data collections. HIQA is responsible for developing guidance, standards and recommendations in relation to health information.

Ireland’s current healthcare structures rely on many paper-based systems, making the use and sharing of patient records difficult, particularly between different health and social care settings. There are plans to introduce eHealth initiatives such as an individual health identifier, ePrescribing, summary care records, shared care records and electronic health records.(4) A modern health infrastructure in Ireland cannot be advanced without investment in eHealth and digital solutions.(5) The COVID-19 pandemic has further highlighted some of the challenges of managing and delivering an effective public health service in Ireland in the absence of fit-for-purpose, integrated health information systems. Recent cyber-attacks on the healthcare service highlight the urgency of progressing policy in relation to health information and digital health to support integrated care in a secure manner.

There is a pressing need for comprehensive national policy and legislation in relation to health information. There is also currently a lack of clarity around an appropriate consent model for the collection, use and sharing of personal health information. As new digital technologies for healthcare, such as electronic health records and patient portals, are introduced, it is essential that a robust consent model is in place to ensure good information management practices and to provide assurance that people's rights in relation to privacy and confidentiality will be upheld.

What is the National Public Engagement on Health Information?

A national telephone survey was conducted with 1,228 members of the public from October to December 2020. The survey asked the public for their feedback on how their personal health information is collected, used and shared by health and social care services in Ireland and their opinions on the use of digital technologies in this area. Participants were nationally representative of the Irish population which allows the findings to be generalised to the Irish population.

In addition to the national survey, 14 detailed focus groups were held between January and March 2021 with 85 people. Representatives of the public, patients, addiction service users, disability service users, homeless service users, mental health service users, migrant and asylum seeker communities, sexual health service users, members of the Traveller community, and young people aged 16 to 18 years old took part in the focus groups. The focus groups provided a deeper understanding of the survey findings and of some of the key issues and challenges faced by people who have specific health and social care needs.

What were the overall findings from the survey and focus groups?

The telephone survey and focus groups explored three key areas relating to health information; the use of health information for direct patient care, the use of health information beyond the direct care of the patient, and people's views in relation to digital health records. Six important findings emerged across these three key areas.

1. People want to be assured that safeguards are in place to keep their personal health information secure and that their right to privacy will be protected.

   People see the importance of using personal health information for their direct care and purposes beyond their direct care, but they want reassurance that appropriate safeguards are in place to keep their information secure and to protect their right to privacy. In the focus groups, people expressed concerns about data breaches, intentional or unintentional, and emphasised that the system must be secure and properly maintained in all healthcare settings. The survey findings show that 88% of people want to be informed about how their information would be kept safe and secure; this would make them more comfortable with sharing their health information.

The focus groups found that people were mostly concerned about the security of their sensitive information, such as information related to mental or sexual health. People spoke about the need for additional safeguards to keep this information secure and protect people's right to privacy. In the focus groups, people also said that all staff should receive training in relevant legislation, such as GDPR*, and they emphasised that confidentiality must underpin all actions within the health service.

2. People think it is important for health information to be collected, used and shared by healthcare professionals who are providing them with care. However, they would like to be more informed about who will use it and for what purpose.

   People think it is important that the healthcare professionals caring for them have access to their health information. The survey findings show that 97% of people think that it is important that a hospital doctor treating an individual should have access to accurate information about their medical history and medications. The focus groups found that some people are concerned that if healthcare professionals do not have the relevant health information available to them, it will have a negative impact on their health.

   People have high levels of trust that healthcare professionals will keep their health information safe and secure, and this trust is usually higher where a relationship has been built between the patient and the healthcare professional. The survey findings show that 90% of people trust their GP, 77% of people trust community healthcare services and 74% of people trust the hospital to keep their information safe and secure.

   People want to be informed about who their health information will be shared with and for what purpose. For example, 71% would like to know more about what information is shared between healthcare professionals who are treating them.

3. People think it is important for health information to be shared for purposes beyond their direct care, but they are more comfortable if identifiable information, such as their name and address, has been removed.

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* GDPR refers to the General Data Protection Regulation which is a regulation on data protection and privacy for all individuals within the European Union.

People see the importance of using health information for purposes beyond their direct care, such as for quality improvement, health service planning and research. The survey findings show that 94% of people think that it is important for health information to be used to improve the quality of care provided to patients, 93% think that it is important for health information to be used to plan healthcare services, and 94% think that it is important for health information to be used for research. However, 77% of people would like to be more informed about exactly how their information will be used for purposes beyond their direct care.

The focus groups found that people are generally happy for their information to be used for purposes beyond their direct care as long as it provides personal or public benefit. However, the survey indicates that people are more comfortable with their information being used if identifiable information, such as their name and address, have been removed. For example, 89% of people are comfortable with health information being used to improve the quality of services if identifiable information has been removed, whereas only 34% are comfortable if identifiable information is included.

People are more comfortable with public organisations using their information than private organisations. For example, 61% of people trust that their health information will be kept safe and secure if research is undertaken by a public organisation, whereas only 45% trust that their health information will be kept safe and secure if the research is undertaken by a private organisation.

4. People want to be able to access their own health information. They want to be actively involved in their own care and decisions that are made about their health information.

People have a right to access their own personal health information. The current system in Ireland makes it quite difficult for people to access this information. As a result, people want greater access to their own information to allow them to participate more in their own care. They believe that their health information belongs to them and that they should be able to view and access it. The survey findings show that people would like to have access to their own digital records, and many feel that this would empower them to play a more active role in their own care.

The focus groups highlighted that health information must be accessible to everyone, and there is a need to consider different formats for people with specific needs. People also want to be informed about the different ways that their health information is used — both for their direct care and for other purposes, such as quality improvement and research. The survey findings also show that 82% of people think that it is important to be able to see who has accessed their records.

5. People are comfortable with their health information being stored and shared electronically, and see the benefits of moving towards a more integrated digital healthcare system, once safeguards are in place to protect their privacy.

   People think that healthcare professionals should be able to access their health information electronically and they are happy for information to be shared electronically between healthcare professionals who are treating them. For example, the survey findings show that 99% of people think a hospital doctor should be able to access their health information electronically, without their permission, when they are unconscious. 89% of people think it is important that their prescription could be sent immediately from a hospital to a pharmacy. 86% of people would like to have access to their own digital records via a national patient portal.

   In the focus groups, people said that digital records would be valuable to provide a complete and up-to-date account of a person's health, which could contribute to timely and appropriate care. They also think that digital records would protect their privacy more than paper-based files, but only if the electronic system is safe and secure.

6. People consider certain types of information to be more sensitive than others and are more concerned about this information being shared without their consent.

   People consider certain types of information to be more sensitive than others. 24% of survey participants provided examples of some types of a person's medical information that they may not want healthcare professionals to access without their permission. While each person's opinion on this may differ, some examples of the more common types of sensitive information include information relating to mental health, sexual health, pregnancies or terminations, addiction issues and sexual orientation.

   The focus groups found that people who have these more sensitive types of information are less likely to want to share it, and they would like to have some control over who can access it. People are mostly concerned about being judged and discriminated against as a result of this information being viewed. People had concerns about this type of information being shared when it may not be relevant to the episode of care.

Where is change needed?

In relation to the use of health information for direct patient care, the findings indicate that people want health information to be more accessible to healthcare professionals when they are providing care to the patient. They also want to be able to access their own health information. People want to be informed about who their health information will be shared with and for what purpose, and they want assurance that they will not be discriminated against as a result of sensitive information contained in their health records.

In relation to the use of health information beyond the direct care of the patient, the findings indicate that people want to be informed about how their information will be used for purposes beyond their direct care. People would prefer if their identifiable information was removed before it was used for purposes beyond their direct care, and they would like to be asked for consent before private companies have access to their personal information.

In relation to digital records, people need assurances that appropriate safeguards are in place to keep their health information safe and secure and protect their right to privacy. People want to be able to access their own information via a patient portal, as they feel this would empower them to play a role in their own care. They would also like to know who has accessed their records and for what purpose. Many people would also like to be able to control who can see certain types of information that are considered more sensitive, for example information about mental health.

What happens next following this public engagement?

The findings from the public engagement will be used to make improvements to health information; ensuring it is kept safe, and that people's rights to privacy are upheld.

- HIQA will use the findings to develop recommendations in the area of health information, such as in relation to a consent model for health information in Ireland.
- The findings will be used by the Department of Health to inform the development of national policy and strategy in relation to health information.
- The HSE will use the findings to support the development and implementation of new technologies for health and social care that will support a more integrated care model in Ireland, as set out in Sláintecare.(5)

More information is available from www.hiqa.ie.

Chapter 1. About the National Public Engagement on Health Information

1.1 Background

Health information is information that is collected when you receive health or social care. Health information may include information about you, such as your name and address, and important medical information, such as your medical history or medications you take. A major challenge for healthcare in Ireland today is achieving an appropriate balance between protecting personal health information, and the using and sharing of such information to improve care and provide a more seamless experience for patients receiving care across multiple healthcare settings. Health information is an extremely valuable resource. Many advances in healthcare depend upon the increasing availability and application of high-quality health information. A robust health information environment will allow all stakeholders to make choices or decisions based on the best available information. This is a fundamental requirement to achieve a highly effective and reliable health and social care system in Ireland.

The Sláintecare Report (2017) outlines a vision for the provision of integrated care in Ireland. Sláintecare is a 10-year plan for health reform which aims to progress the health system 'towards integrated primary and community care, consistent with the highest quality of patient safety in as short a time-frame as possible'.(1) Delivering this ambitious goal needs sustained and progressive change across the Irish health system and requires continued political consensus, leadership and investment. The Sláintecare Implementation Strategy and Action Plan 2021-2023 emphasises that the delivery of an integrated healthcare system needs to be underpinned by a robust eHealth programme, which is outlined as a key priority.(2)

It is important to engage with the public before introducing new eHealth and digital technologies, such as a national electronic health record. Involving people in important decisions about their health information will ensure that such technologies are implemented in a way that is acceptable to the public and that their rights in relation to health information are upheld. International evidence has shown that public engagement and involvement is extremely important for the successful introduction of new technologies. In contrast, countries such as Australia and England have had attempts to introduce new eHealth technologies fail due to the lack of such public engagement.(3)

1.1.1 Summary of the current situation in Ireland

The Department of Health has overall responsibility for leadership and policy decision-making in the Irish health sector, including for eHealth and health information policy. The Health Service Executive (HSE) is responsible for implementing and providing public health services, strategic programmes in eHealth and a number of national data collections. The Health Information and Quality Authority (HIQA) is responsible for developing guidance, standards and recommendations in relation to health information.

Ireland's current healthcare structures still relies on many paper-based systems, making the use and sharing of patient records difficult, particularly across different health and social care settings. There are plans to introduce eHealth initiatives such as an individual health identifier, ePrescribing, summary care records, shared care records and electronic health records.(4) A modern health infrastructure in Ireland cannot be advanced without investment in eHealth and digital solutions.(5) The COVID-19 pandemic has further highlighted some of the challenges of managing and delivering an effective public health service in Ireland in the absence of fit-for-purpose, integrated health information systems.

There is a pressing need for comprehensive national policy and legislation in relation to health information. There is also currently a lack of clarity around an appropriate consent model for the collection, use and sharing of personal health information. As new digital technologies for healthcare, such as electronic health records and patient portals, are introduced, it is essential that a robust consent model is in place to ensure good information management practices and to provide assurance that people's rights in relation to privacy and confidentiality will be upheld. Furthermore, guidance is required to define the consent model for the various uses of health information.

The findings from the National Public Engagement on Health Information will be used by HIQA to inform the development of recommendations on a consent model for the collection, use and sharing of health information in Ireland. The findings will also be used by the Department of Health and the HSE to inform national policy and future developments in health technology.

As part of the recommendations development process, an advisory group has been set up with a broad range of membership, including patients and experts from across the health and social are system (Appendix 1). An international review on consent models in place in other countries found that public engagement and building a culture of trust in relation to the collection, use and sharing of health information is extremely important when developing a consent model. Internationally, the successful introduction of new eHealth initiatives and digital technologies in healthcare has been informed by public engagement.(3)

1.2. Partnership approach

The National Public Engagement on Health Information is of such importance that HIQA, the Department of Health and the HSE have worked in partnership to conduct it. The public engagement has enabled the public to voice their opinion on this topic and, in doing so, has provided a rich source of information that will allow each partner organisation to work towards improving how health information is collected, used and shared in Ireland.

A governance model was developed to support the National Public Engagement on Health Information. This governance model includes:

- **Steering Group for the National Public Engagement on Health Information:** This group is responsible for strategic oversight of the public engagement. The Steering Group comprises of members from HIQA, the Department of Health, the HSE and patient representatives.
- **Partnership Project Team:** This team is responsible for delivery of the project, developing the methodology and analysing and reporting on findings. While the core team will be based within HIQA, the team will also include a representative from the Department of Health and the HSE who will review documentation and join team meetings as required.

In addition, an advisory group was set up for the broader HIQA project to develop recommendations on a consent model for health and social care in Ireland. This group was consulted and asked for advice at various stages of the project. The membership of the governance groups can be found in Appendix 1.

The partnership is underpinned by a memorandum of understanding, clearly stating each partner's role and responsibilities. A copy of the memorandum of understanding can be found on www.hiqa.ie.

1.3 Aim of the National Public Engagement on Health Information

The National Public Engagement on Health Information aimed to understand the opinions and attitudes of the Irish public in relation to the collection, use and sharing of personal health information. The key objective was to listen to the voice of the public, understand the findings, and make measurable improvements to how personal health information is collected, used and shared in Ireland.

To engage with the public on this important topic:

- a National Public Engagement Survey on Health Information was carried out to ask over 1,200 members of the public for their feedback on how their personal health information is collected, used and shared by health and social care services in Ireland, and their opinions on the use of digital technologies in this area.
- 14 focus groups were held with the public, patients and representatives of different service user groups, such as people experiencing addiction and homelessness.

The findings from the public engagement will be used to:

- give the public a platform to voice their opinions on this topic and have a meaningful impact on how their health information will be collected, used and shared.
- inform HIQA's development of recommendations on a consent model for the collection, use and sharing of health information in Ireland.
- provide knowledge for the Department of Health and the HSE in relation to the public's opinions on health information to inform the Department of Health's forthcoming national health information strategy, and future developments in relation to national health information policy.

Chapter 2. Methodology for the National Public Engagement on Health Information

There were four phases to the national public engagement. The first two phases focused on developing and conducting the national telephone survey, and the third phase focused on undertaking focus groups with the public, patient representatives, and representatives of different service user groups. The fourth phase focused on the integration of findings from the survey and focus groups, analysing and reporting key findings, and the development of educational materials. A more detailed description of the methodology has been published in the *Technical report for the National Public Engagement on Health Information*, which can be found on www.hiqa.ie.

2.1 Engagement to inform the survey design

To inform the development of the survey questionnaire, a review of international evidence was undertaken, and focus groups and interviews were held with nine HIQA staff members and 21 healthcare professionals. This provided an understanding of the important issues that needed to be included in the questionnaire. Cognitive interviews were held with nine members of the public to assess the clarity and appropriateness of the proposed survey questions.

2.2 Telephone survey methodology

The telephone survey was conducted with a representative sample of 1,228 Irish people aged 18 and over between October and December 2020. A managed service was contracted to administer the survey and to process the responses received. The survey collected key demographic information about the participants and how often they use health and social care services. The final survey is included in Appendix 2. The survey addressed the following questions:

- How comfortable are the Irish population with the use and sharing of personal health information for direct patient care?
- How comfortable are the Irish population with the use and sharing of personal health information for purposes beyond their direct patient care, such as service planning, quality improvement and research?
- What level of comfort do people have in relation to new digital technologies in healthcare, such as electronic health records, electronic patient summaries and patient portals?
- What levels of trust do people have in healthcare professionals, organisations and government in relation to safeguarding their personal health information?

For numerical data, the number of responses for each question was calculated and compared by demographics and health questions. For open-ended questions, where people could provide longer answers, a coding framework was developed to categorise the answers into specific themes.

2.3 Focus groups methodology

Between January to March 2021, 14 focus groups were held with members of the public, patient representatives, and representatives of different service user groups. A total of 85 people took part in these groups. The focus groups aimed to develop a deeper understanding of the survey findings; 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 health information which may not have been fully captured in the survey. Specific representative organisations, from a range of locations across Ireland, were invited to ask individuals they represent to take part in these focus groups. Participants were sent information on the study and focus groups in advance, and were required to sign a consent form before taking part. In accordance with COVID-19 guidelines, focus groups were held online, using virtual conferencing technology, and followed the standard HIQA approach. Analysis was undertaken using the framework method.

Chapter 3. National Survey on Health Information

The following section describes the findings from the National Survey on Health Information. Further information on the methodology can be found in the technical report and additional survey data has also been made available on www.hiqa.ie.

3.1 Who took part in the survey?

A total of 1,228 people took part in the telephone survey. The demographics of the participants can be seen in Table 3.1 – for more detailed information on this, see Appendix 4.

Table 3.1 Characteristics of the survey sample

Demographic	n	%
Age category (years)		
18-24	115	9.36
25-34	176	14.33
35-49	419	34.12
50-64	299	24.35
65 or older	219	17.83
Gender		
Male	601	48.94
Female	623	50.73
Transgender	-	-
Gender fluid	1	0.08
Prefer not to say	2	0.16
Other	1	0.08
Regular user of health or social care services		
Yes	422	34.36
No	801	65.23
Pass	5	0.41
Long-term or chronic condition affecting your physical or mental health		
Yes	257	20.93
No	962	78.34
Pass	9	0.73
Disability		
Yes	69	5.62
No	1,153	93.89
Pass	6	0.49

3.2 What questions were asked in the survey?

The survey consisted of three scenarios based on the Irish healthcare system that guided participants through the survey questions (see Appendix 2 for the complete survey tool). The scenarios were read aloud to participants and, following this, participants were asked a series of questions relating to the scenario presented. The first scenario related to the use of health information for direct personal care. Participants answered eight questions based on Scenario 1. The second scenario explored attitudes to the use of health information beyond direct care (to improve quality of care, plan services and for research). Participants answered 10 questions based on Scenario 2. The third scenario explored attitudes in relation to electronic medical records and other digital technologies for health information. Participants responded to 11 questions based on Scenario 3.

The survey collected demographic information on:

- gender
- employment status
- occupation of the chief income earner in the household
- ethnicity
- whether respondents were regular health service users
- living with a long-term condition affecting their physical or mental health
- living with a disability
- family member or someone close to the respondent with a long-term condition or disability requiring regular use of health or social care services.

No significant differences were identified in these groups during the analysis of the survey responses.

3.3 Key findings

The survey explored health information under three key themes; the use of health information for direct patient care, the use of health information for purposes beyond direct patient care and digital health records. The key findings that emerged from the survey are listed below.

The use of health information for direct patient care

- 1,190 people (**97%**) think that it is important that a hospital doctor treating an individual should have access to accurate information about their medical history and medications.

- 1,127 people (**93%**) think that it is important that healthcare professionals involved in their direct care have access to relevant information.

- There are high levels of trust that healthcare professionals will keep their health information safe and secure. 1,095 people (**90%**) trust their GP, 920 people (**77%**) trust community healthcare services, and 894 people (**74%**) trust the hospital to keep their information safe.
- While most people (**76%**) have no concerns with their information being shared for their direct care, 62 people (**5%**) are concerned about information being shared that is not relevant to their care, and 64 people (**5%**) are concerned about information being shared that might be considered sensitive, such as information about mental health or sexual health.

The use of health information for purposes beyond direct patient care

- People think it is very important for health information to be used for purposes beyond their direct care. 1,151 people (**94%**) think that it is important for health information to be used for the purpose of improving the quality of care provided to patients, and 1,136 people (**93%**) think that it is important for health information to be used to help plan healthcare services.
- People have high levels of trust that their information will be kept safe and secure when it is used for these purposes. 961 people (**79%**) trust that their health information will be kept safe and secure if it is used for improving the quality of care. 941 people (**77%**) trust that their health information will be kept safe and secure if it is used to plan healthcare services.
- People are more comfortable if identifiable information, such as name and address, is removed before the health information is used for purposes beyond the direct care of the patient. 1,074 people (**89%**) are comfortable with health information being used to improve the quality of services if identifiable information has been removed. Only 407 people (**34%**) are comfortable with their health information being used to improve the quality of services if identifiable information is included.
- 1,025 people **(83%)** said they would be more comfortable if they were informed about possible future uses of the information.

Digital health records

- 1,051 people (**86%**) think that it is important or very important for all healthcare professionals involved in their care to have access to their electronic health record.
- 965 people (**79%**) said they could not think of any concerns they might have about healthcare professionals, who are treating them, having access to their electronic health record.

- 203 people (**16%**) worried that unnecessary information will be shared or that healthcare professionals not involved in their care will be able to access their record. 38 people (**3%**) were concerned about the security of the information.
- 292 people (**24%**) identified certain types of health information that they would consider more sensitive and that they would not like to be accessed without their permission. 107 people (**9%**) consider mental health information as sensitive and 64 people (**5%**) consider sexual health and reproductive information as sensitive.
- 1,058 people (**86%**) think that it is important or very important to be able to access and view their own medical records online.

"I don't mind healthcare professionals accessing my information but I would like to know who has access"

3.3.1 Scenario 1 – Use of health information for direct patient care

The first scenario presented to survey participants described a healthcare experience where health information was used to provide direct care to the patient. The use of health information for direct care means that health information about you is used by healthcare professionals who are treating you, to provide you with care. For example, every time you visit your general practitioner (GP) or go to a hospital for treatment, important health information about your health and care needs is recorded. This could be used and shared by healthcare professionals to ensure they have an understanding of all of the issues relating to your health.

Health and social care professionals must follow rules to ensure that your personal information is handled in the correct way. These include data protection laws, and codes of conduct and professional ethics.

Overall, people were very positive about the importance of healthcare professionals having access to their health information when they are providing care to them. There were high levels of trust that healthcare professionals would keep health information safe and secure. While the majority of people did not have any concerns about their information being used in this way, some were concerned about information being shared that was not relevant or the sharing of information that might be considered sensitive, such as information about mental health or sexual health. The majority of people would like more information about how their health information is used for direct patient care.

3.3.1.1 The importance of having access to information for direct patient care

The survey results show that 1,190 people (**97%**) believe that it is important or very important that a hospital doctor treating an individual should have access to accurate information about their medical history and medications. (Figure 1)

1,127 people (**93%**) think that it is important or very important that other healthcare professionals involved in direct care have access to relevant information about a hospital visit and any new medications prescribed for an individual. (Figure 2)

Figure 1: How important do you think it is that the hospital doctor treating you has access to accurate information about your medical history and medications?

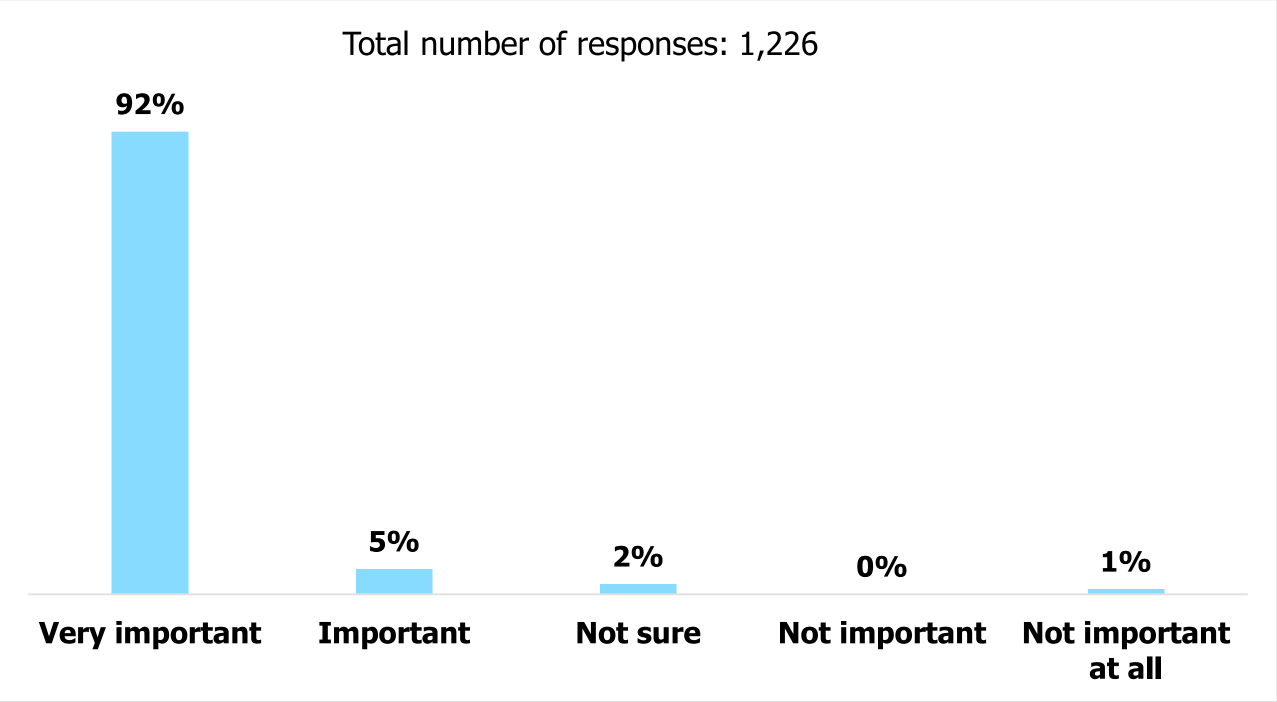
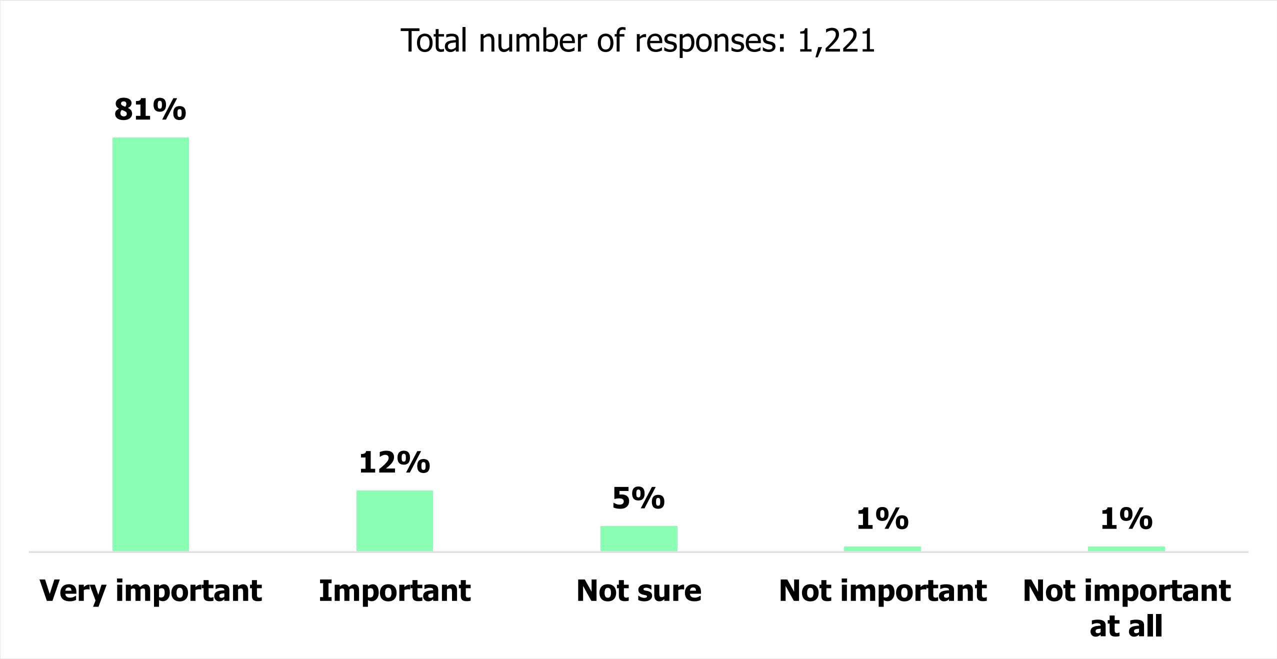


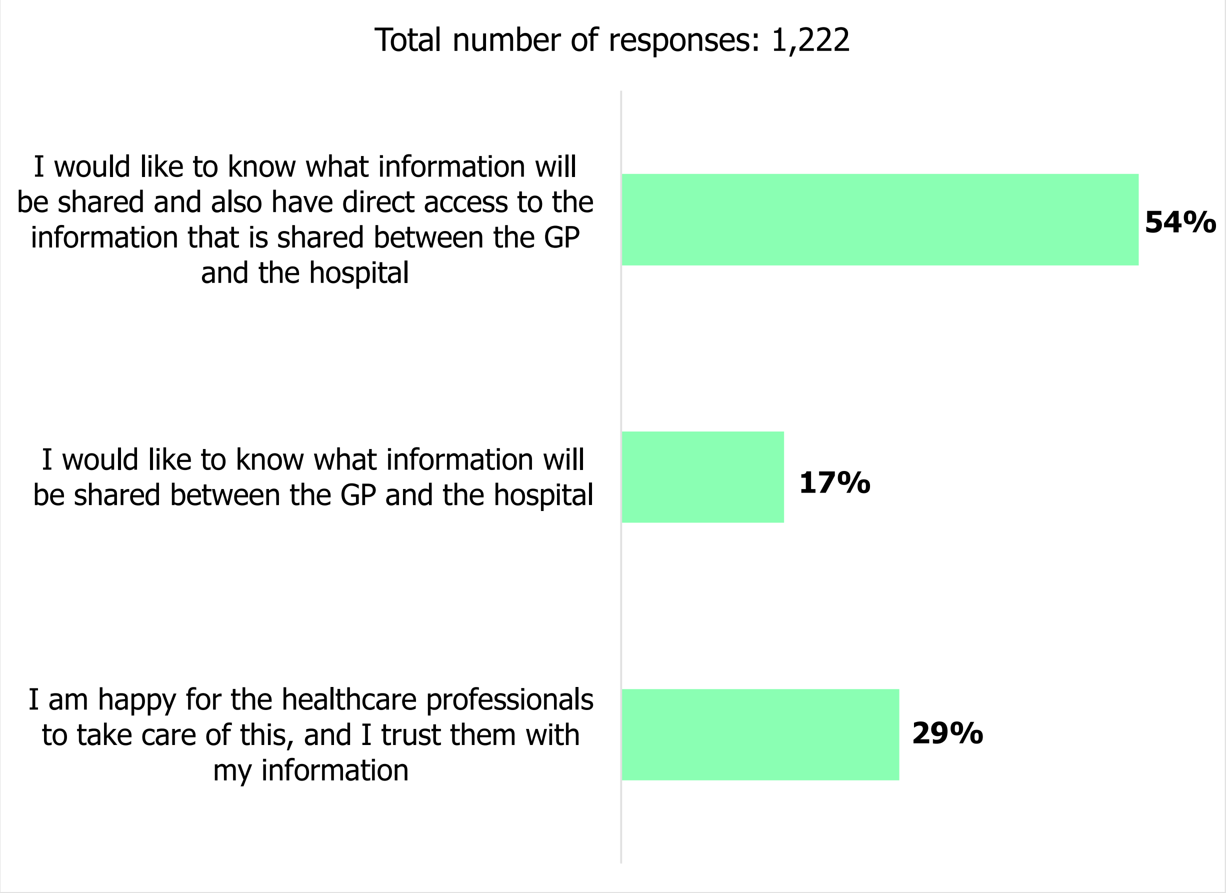
Figure 2: How important do you think it is that other healthcare professionals involved in your care (for example, your GP or public health nurse) have access to relevant information about your hospital visit and new medications?



In relation to the sharing of health information, the survey found that 358 people (**29%**) are happy for professionals to take care of it for them, and they trust them with their information. 205 people (**17%**) would like to know what information will be shared between the GP and the hospital. 659 people (**54%**) would like to know what information will be shared and they would also like to have direct access to the information that is shared between the GP and the hospital. (Figure 3)

When asked about confidence in answering questions about their own health, 1,085 people (**90%**) said they would feel confident or very confident in their ability to answer questions about their allergies. 1,078 (**89%**) said they would feel confident or very confident in their ability to answer questions about the medications they are taking, and 1,088 (**88%**) said they would feel confident or very confident in their ability to answer questions about their medical history. (Appendix 5)

Figure 3: Which of the following statements best describes your views about health information being shared between a GP and a specialist doctor in a hospital?



3.3.1.2 Public trust in relation to the use of health information for direct patient care

The survey results show that, when it comes to keeping their information safe and secure:

- 1,095 people (**90%**) trust or completely trust the GP
- 894 people (**74%**) trust or completely trust the hospital
- 920 people (**77%**) trust or completely community healthcare services such as the public health nurse.

For more information see Figure 4.

The survey results show that 1,119 people (**91%**) trust or trust completely that GPs will only share relevant information with the hospital. (Figure 5)

Figure 4: To what extent do you trust that your health information will be kept safe and secure by:

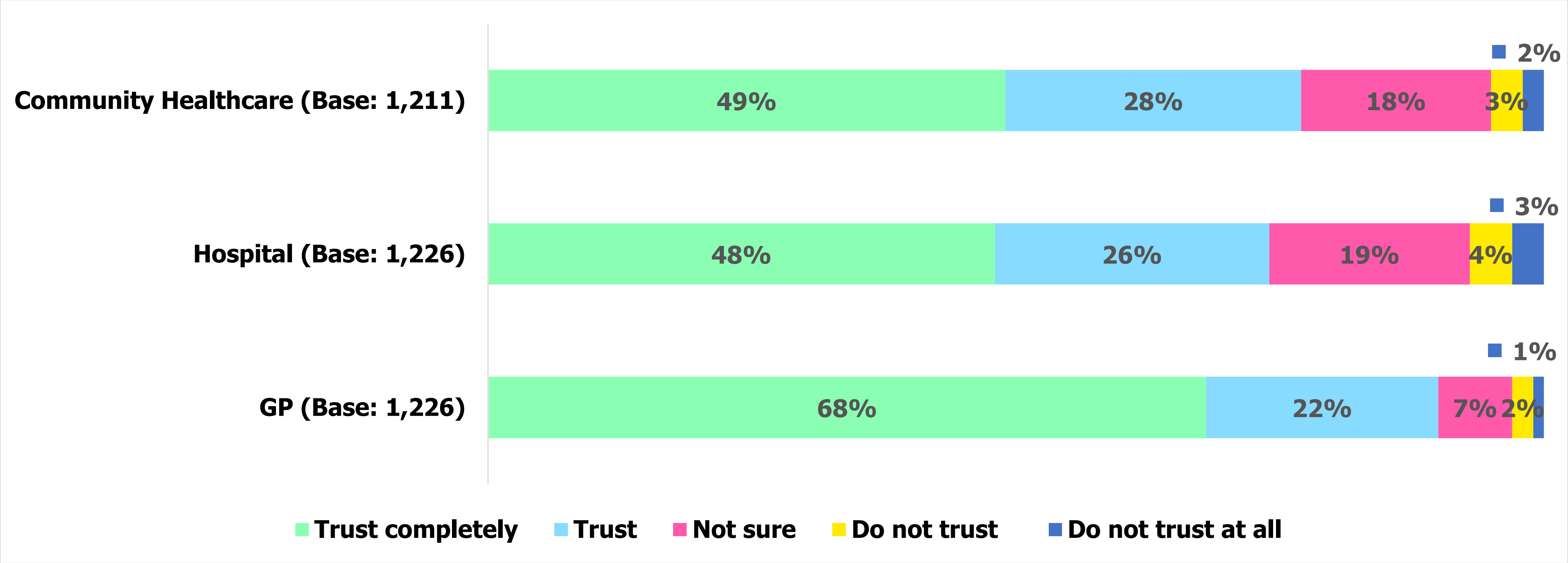
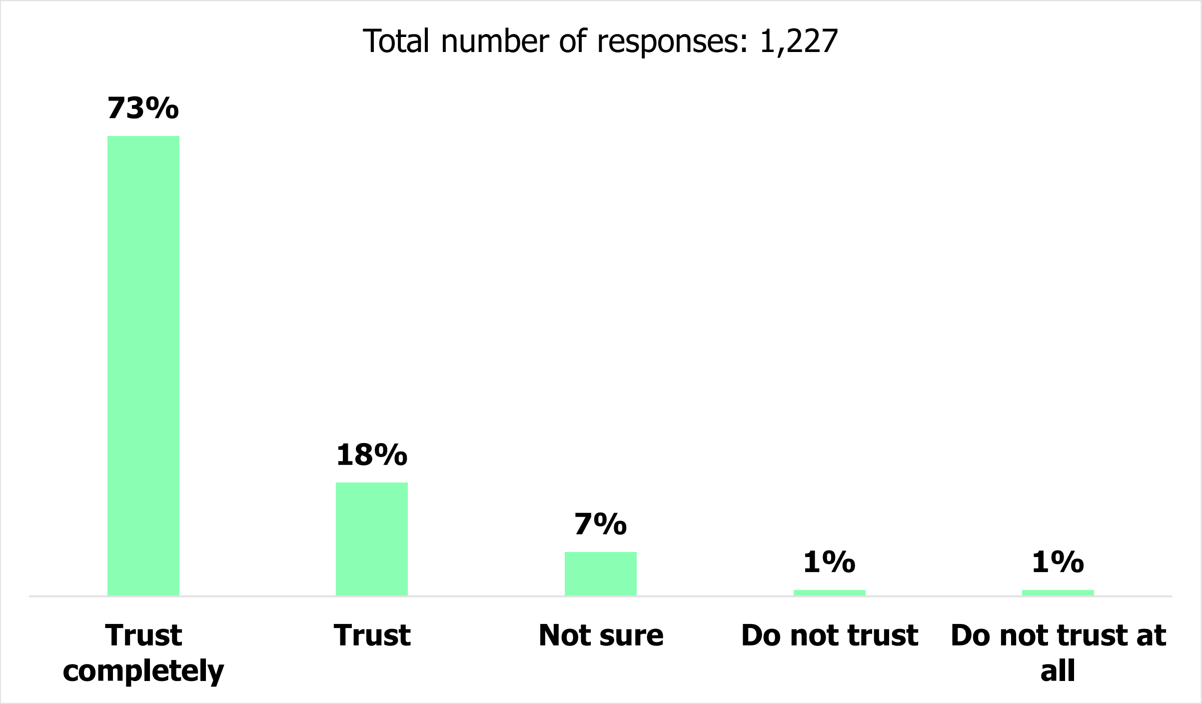


Figure 5: To what extent do you trust that the GP will only share the relevant health information with the hospital?



3.3.1.3 Concerns in relation to the sharing of health information for direct patient care

The survey identified some important concerns in relation to the sharing of health information for direct patient care.

928 people (**76%**) who completed the survey could not think of any situation where they would not want their health information to be shared with other healthcare professionals directly involved in their care.

300 people (**24%**) provided some details about situations where they would not want their health information to be shared with other healthcare professionals directly involved in their care.

The framework method was used to analyse and manage the wealth of information that was provided by the survey participants. For this question, an analytical framework consisting of 12 themes was developed.

Figure 6 shows the breakdown of participant comments by theme for this question.

Figure 7 gives examples of quotes that were given by the survey participants.

Figure 6: Can you think of any situation where you would not want your health information to be shared with other healthcare professionals directly involved in your care?

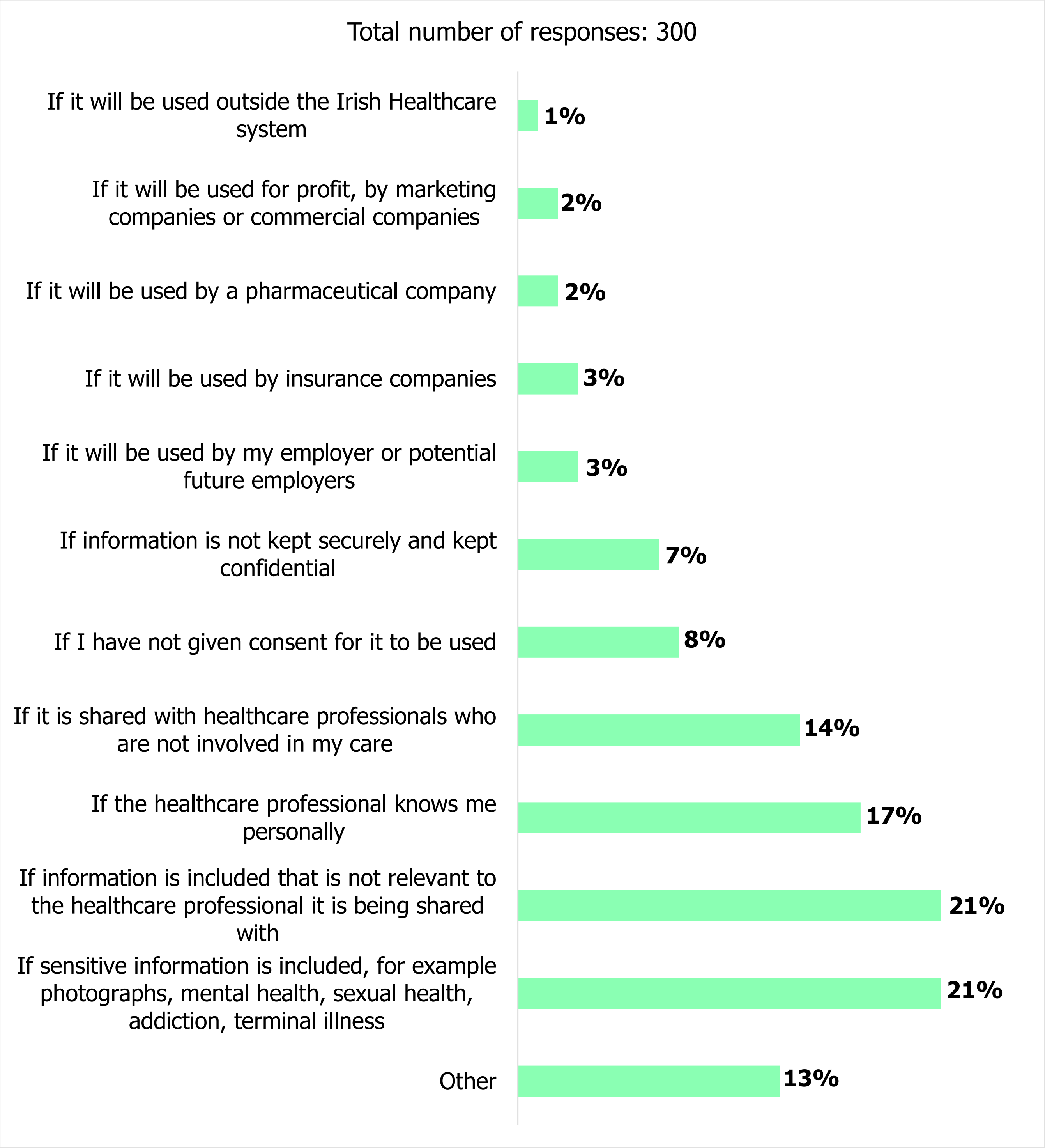


Figure 7: Can you think of any situation where you would not want your health information to be shared with other healthcare professionals directly involved in your care?

Was an ex-addict and after 12 years of being clean, this information is still being questioned

A neighbour who is known to you had access to this information

Certain people should have the info. Not all. Not as comfortable with nurse having info

I wouldn't want it to be shared without my consent

Couldn't be as confident that PHN would be as confidential as GP

If the pharmaceutical companies were involved, I wouldn't want my information going near them

Mental illness

Would not want all information shared. Information shared should be for the one problem I have, the problem that's relevant

3.3.2 Scenario 2 – Use of health information beyond the direct care of the patient

The second scenario that was presented to survey participants described a situation where health information, that was collected when receiving treatment, was used for purposes beyond the direct care of the patient.

Information that is collected when you receive healthcare can be combined with details of other people in Ireland and used for other purposes beyond your direct care. Examples of these purposes include:

- **Quality improvement** – Health information is used to help healthcare professionals improve the quality of care provided to patients by helping them to understand what treatments work best.
- **Health service planning** – Health information is used to help plan healthcare services around the country; to make sure that services are available, at the right time and place, for those who need them.
- **Research** – Health information is used by researchers to conduct health related research, such as research to improve population health or the research on the development of medications or medical devices.

The survey results show that people think it is very important for health information to be used for purposes beyond their direct care. People also have high levels of trust that their health information will be kept safe and secure when it is used for these purposes. However, people have more trust if the information is used by a public body rather than a private organisation. People are more comfortable if identifiable information, such as their name and address, is removed before the health information is used for purposes beyond the direct care of the patient. The majority of people would like to have more information about the different ways that health information is used for purposes beyond their direct care.

3.3.2.1 The importance of using health information for purposes beyond the direct care of the patient

The survey results show that people think it is important to use health information for purposes beyond direct patient care:

- 1,151 people (**94%**) think that it is important or very important for health information to be used for the purpose of improving the quality of care provided to patients. (Figure 8)
- 1,136 people (**93%**) think that it is important or very important for health information to be used to help plan healthcare services. (Figure 9)
- 1,148 people (**94%**) think that it is important or very important for health information to be used for research. (Figure 10)

Figure 8: How important is it that your health information can be used for the purpose of improving the quality of care provided to patients with heart problems?

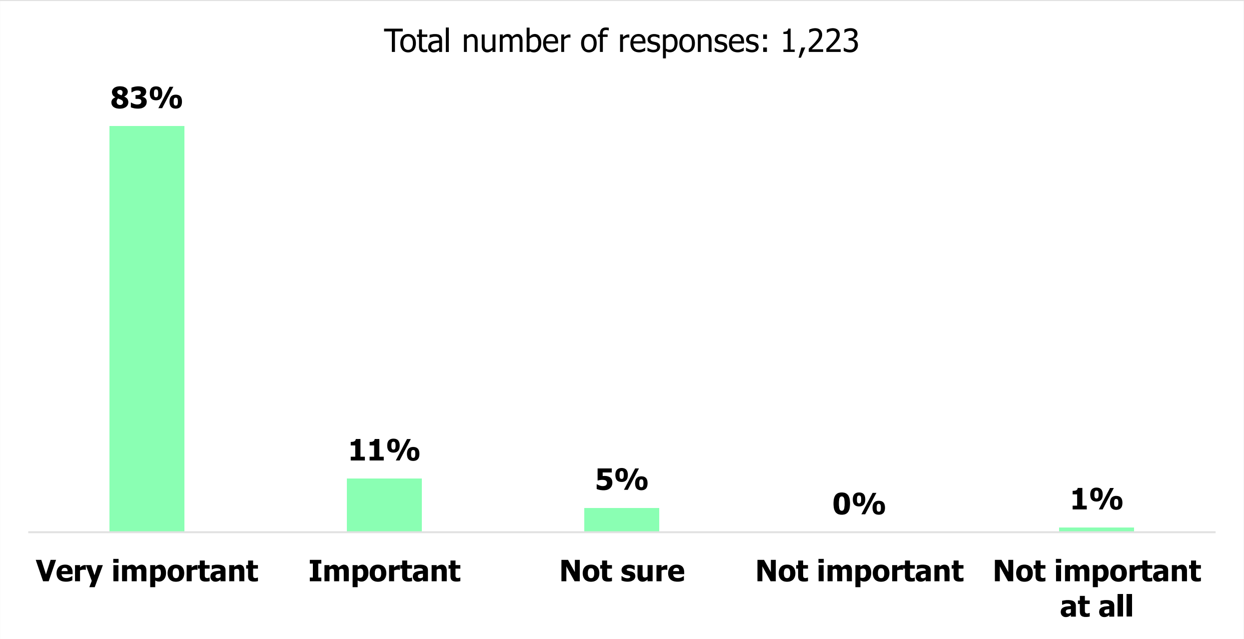


Figure 9: How important is it that your health information can be used to help plan healthcare services?

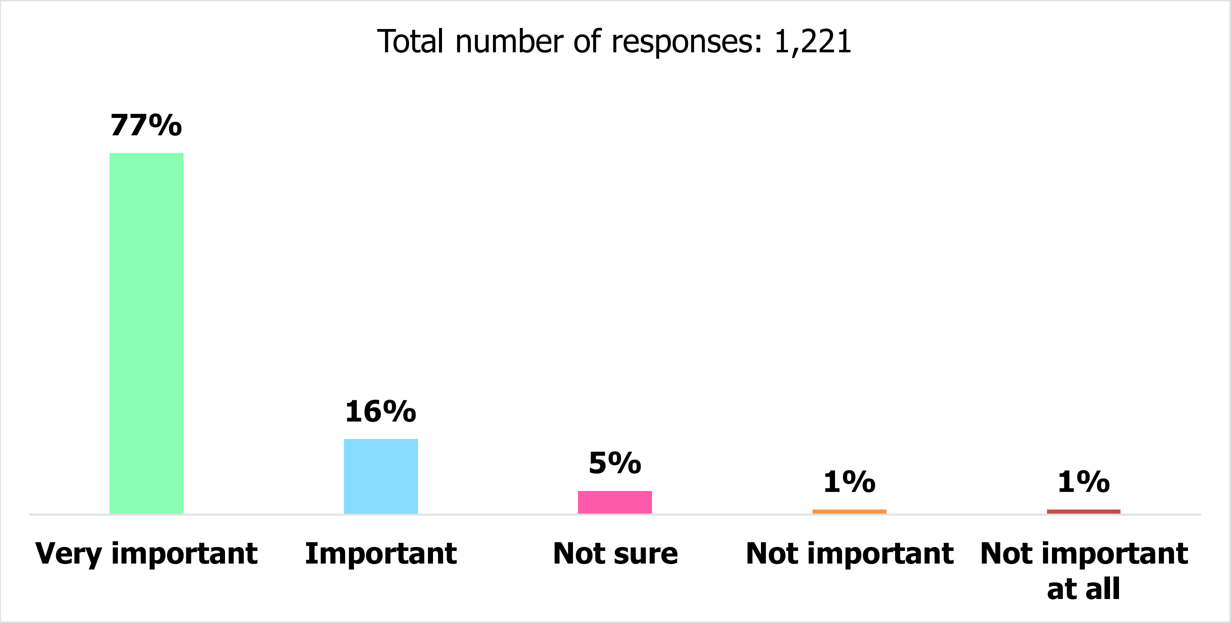
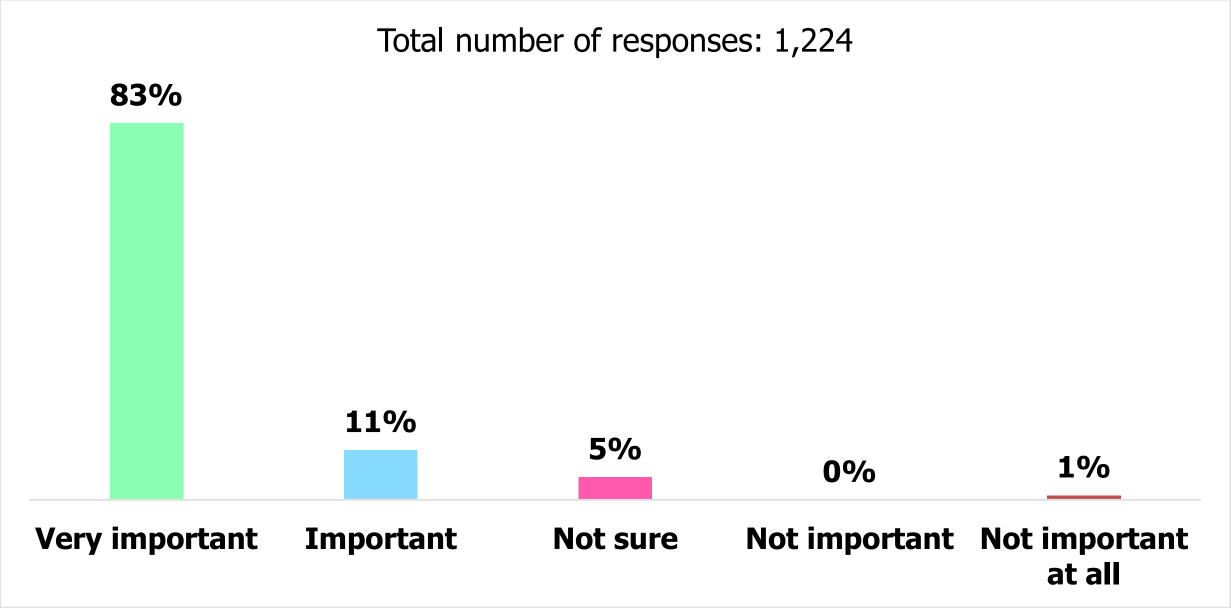
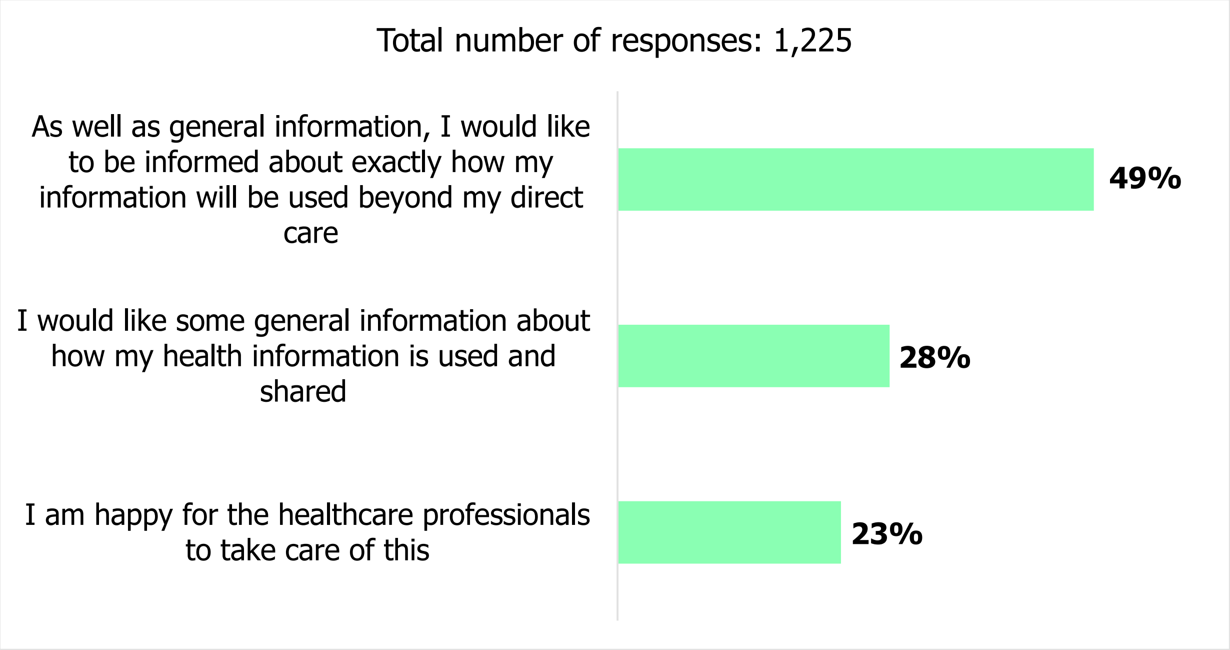


Figure 10: How important is it that the researchers can use this information about your heart problem to carry out health related research?



In relation to health information being used to improve the quality of care and to plan services, 595 people (**49%**) would like to be informed about exactly how their information will be used beyond their direct care, 347 people (**28%**) would like some general information about how their health information is used and shared, and 283 people (**23%**) are happy for healthcare professionals to take care of this. (Figure 11)

Figure 11: Which of the following statements best describes your views about health information being used to improve the quality of care and to plan services?

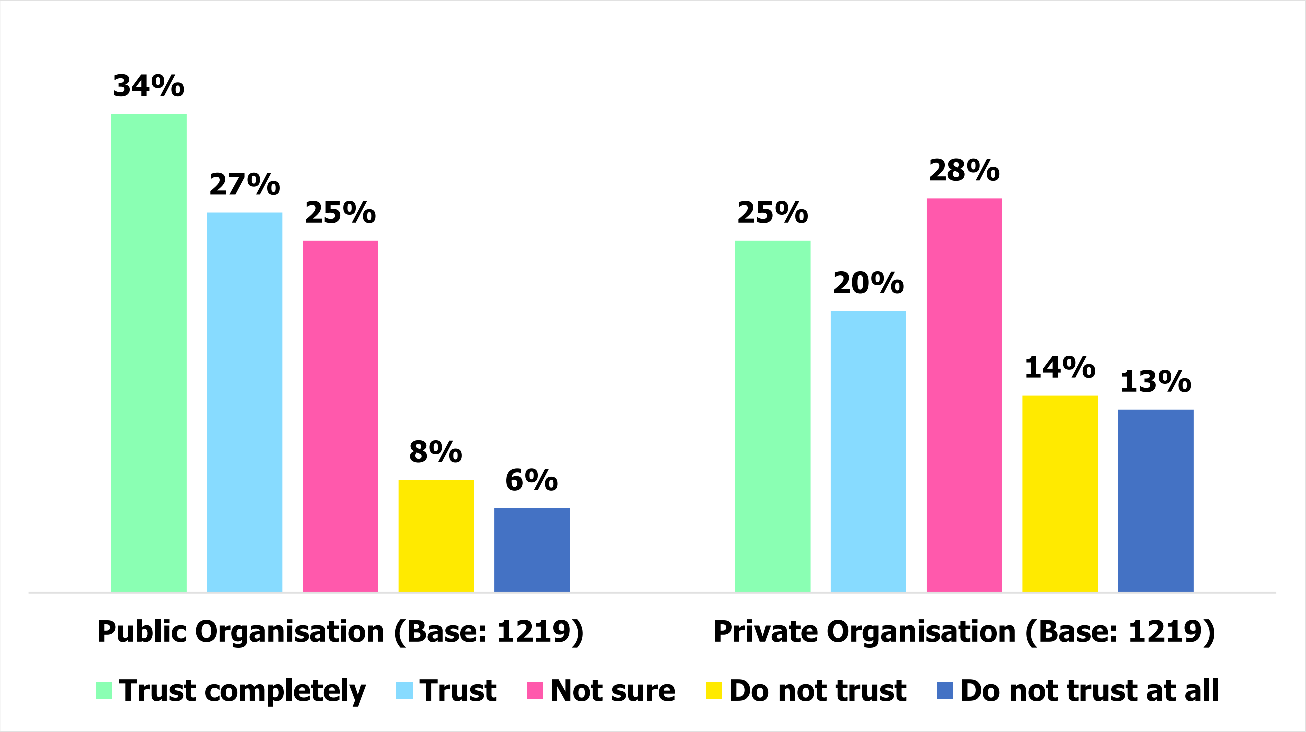


3.3.2.2 Public trust in relation to the use of health information for purposes beyond the direct care of the patient

Research

The survey results show that 755 people (**61%**) trust or trust completely that researchers will keep their health information safe and secure if research is funded and undertaken by a public organisation. 544 people (**45%**) trust or trust completely that researchers will keep their health information safe and secure if research is funded and undertaken by a private organisation. (Figure 12)

Figure 12: To what extent do you trust that the researchers will keep your health information safe in this situation, if the research is funded and carried out by a public or private organisation?



Quality improvement

The survey results show that 961 people (**79%**) trust or trust completely that their health information will be kept safe and secure if it is used for improving the quality of care. (Figure 13) 1,074 people (**89%**) are comfortable or very comfortable with health information being used to improve the quality of services if identifiable information, such as their name and address, has been removed. 407 people (**34%**) are comfortable or very comfortable with health information being used to improve the quality of services if identifiable information is included. (Figure 14)

Figure 13: To what extent do you trust that your health information will be kept safe and secure when it is used for the purpose of improving the quality of care provided to patients with heart problems?

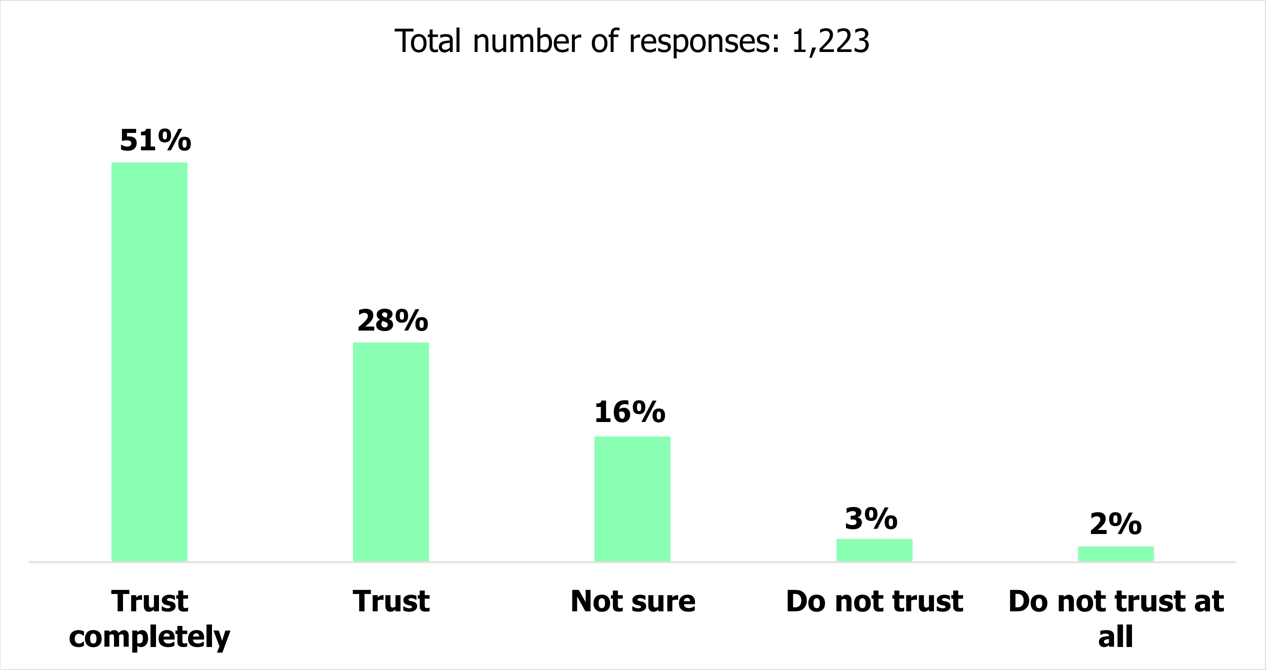
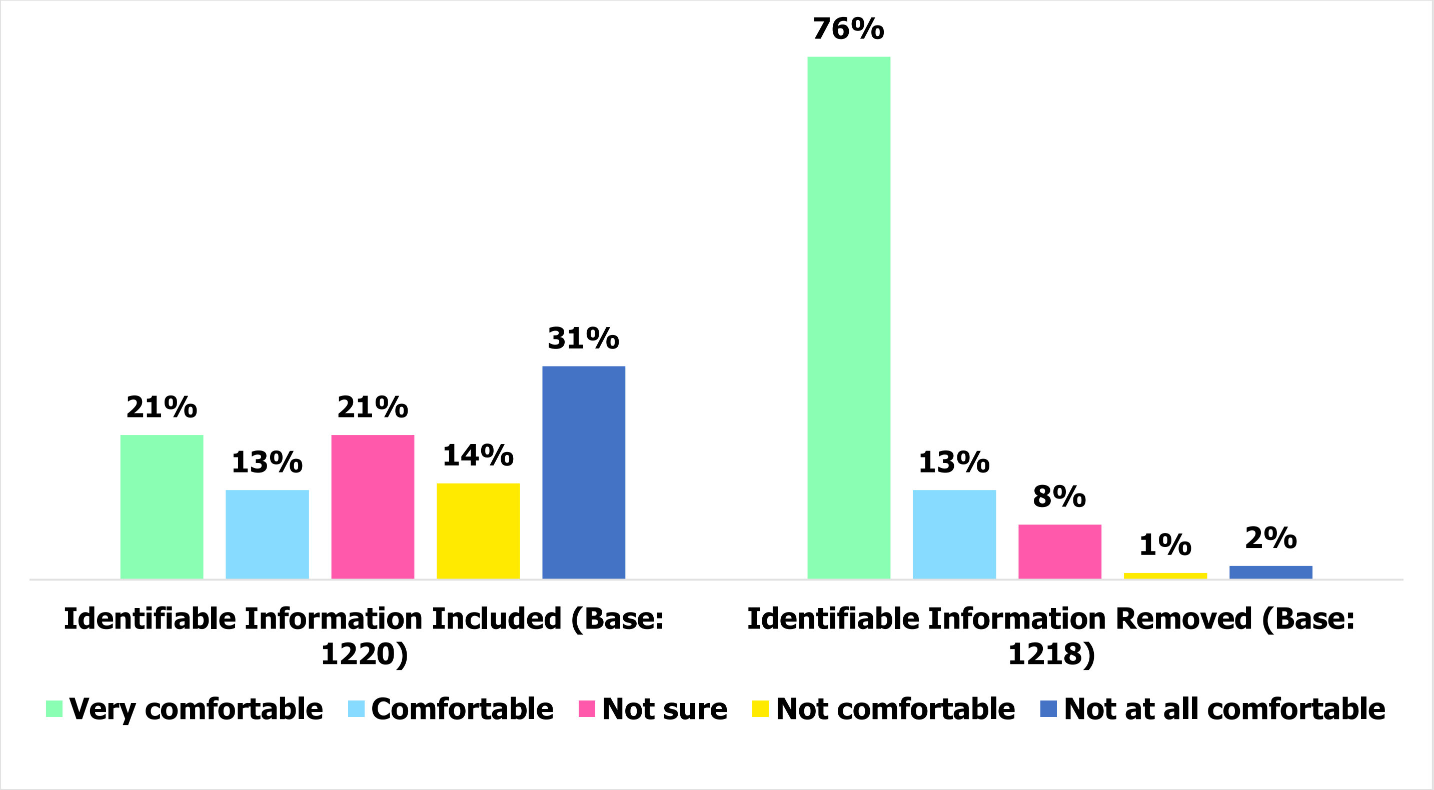


Figure 14: How comfortable would you be with this information being used to improve the quality of care if identifiable information included or removed?



Service planning

The survey results show that 941 people (**77%**) of people trust or trust completely that their health information will be kept safe and secure if it is used to plan healthcare services. (Figure 15) 1,095 people (**90%**) are comfortable or very comfortable with their health information being used to improve the quality of services if identifiable information, such as name and address, have been removed. 398 people (**33%**) are comfortable or very comfortable with health information being used for to improve the quality of services if identifiable information is included. (Figure 16)

Figure 15: To what extent do you trust that your health information will be kept safe and secure when it is used to plan healthcare services?

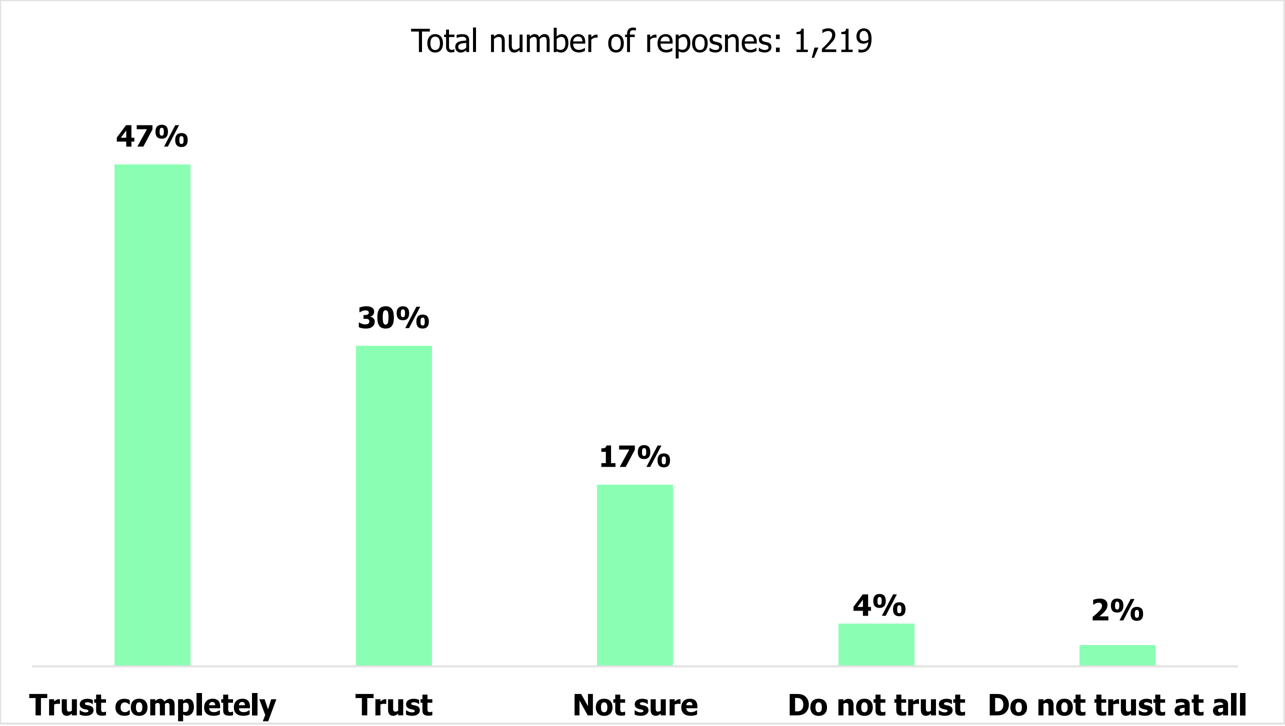
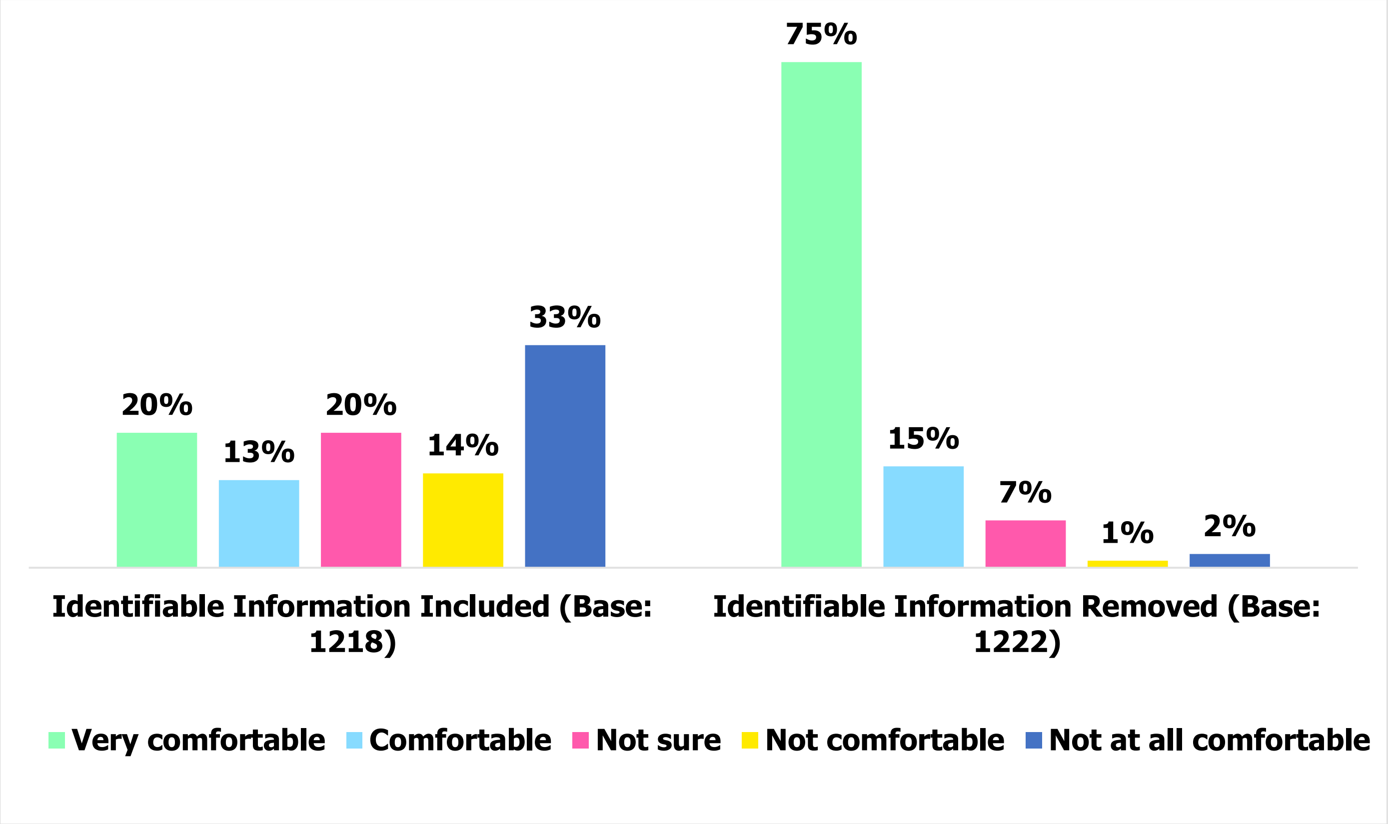


Figure 16: How comfortable would you be with this information being used to plan healthcare services if identifiable information included or remove



3.3.2.3 Concerns in relation to the sharing of health information for purposes beyond the direct care of the patient

The survey identified some important concerns in relation to the sharing of health information for purposes beyond the direct care of the patient.

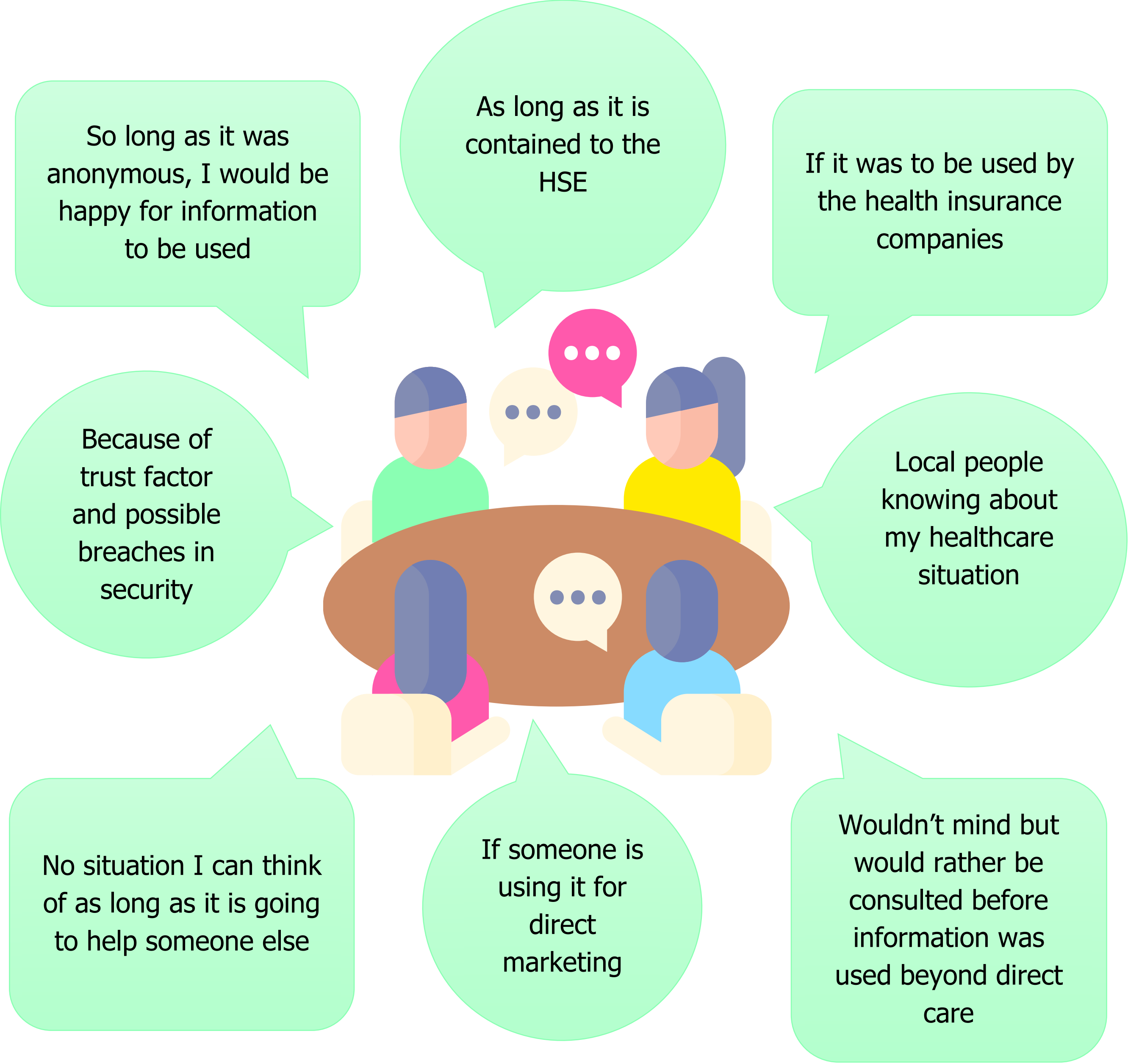
761 people (**63%**) of those who completed the survey could not think of any situation where they would not want their health information to be used for purposes beyond their direct care.

467 people (**37%**) provided some details about situations where they would not want their health information to be shared with other healthcare professionals directly involved in their care.

The framework method was used to analyse and manage the wealth of information that was provided by the survey participants. For this question, an analytical framework consisting of 13 themes was developed.

Figure 17 gives examples of quotes that were given by the survey participants. Figure 18 shows the breakdown of participant comments by theme for this question.

Figure 17: What, if any, situation can you think of that you would not want your health information to be used for purposes beyond your direct care, such as those described in this scenario?



So long as it was anonymous, I would be happy for information to be used

As long as it is contained to the HSE

If it was to be used by the health insurance companies

Because of trust factor and possible breaches in security

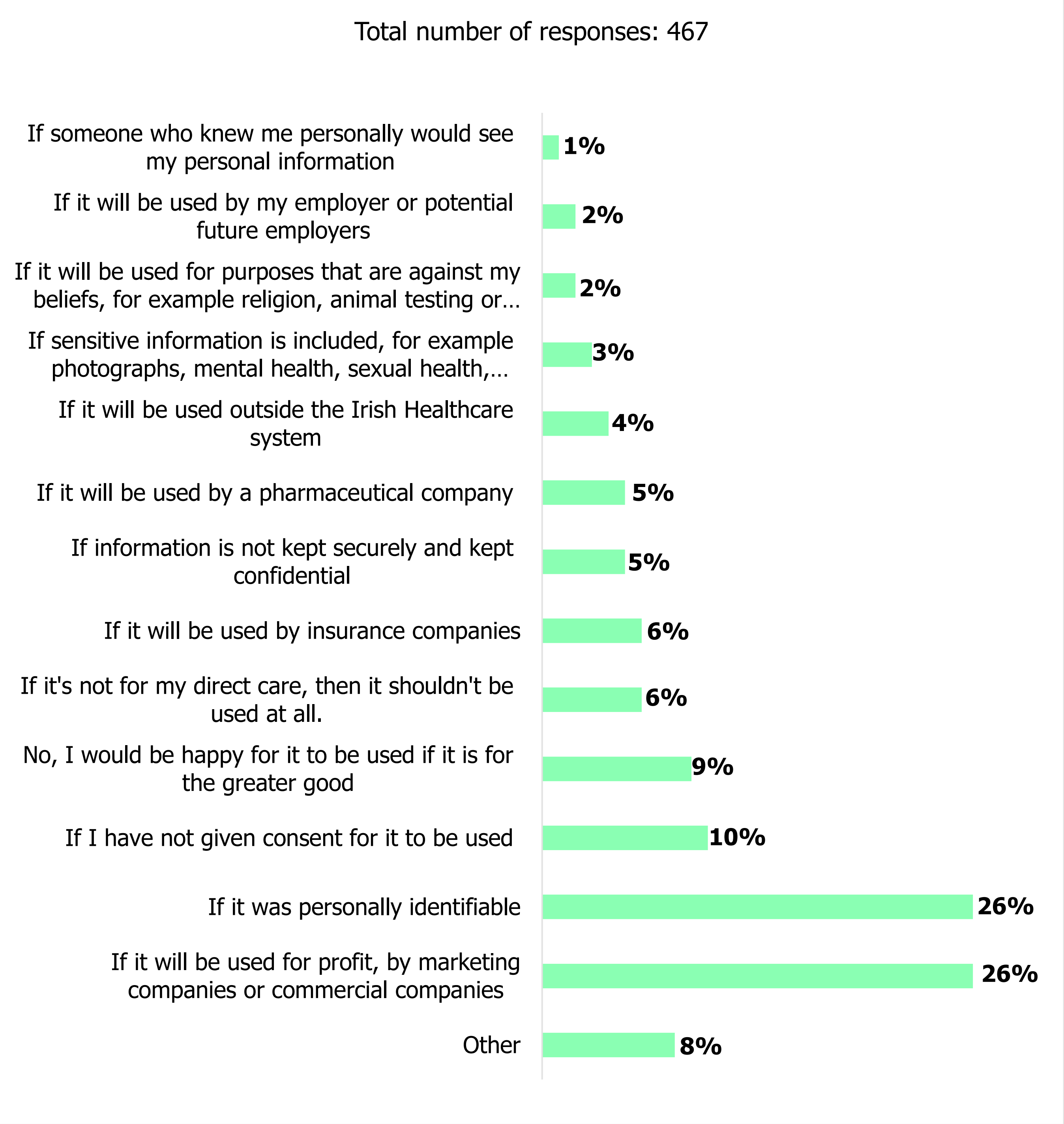
Local people knowing about my healthcare situation

No situation I can think of as long as it is going to help someone else

If someone is using it for direct marketing

Wouldn’t mind but would rather be consulted before information was used beyond direct care

Figure 18: What, if any, situation can you think of that you would not want your health information to be used for purposes beyond your direct care, such as those described in this scenario?



3.3.3 Scenario 3 – Digital health records

The third scenario that was presented to the survey participants described a situation where health information is accessed electronically by various healthcare professionals, such as a paramedic in an ambulance, healthcare professionals in a hospital, staff in a pharmacy, a community physiotherapist and a GP. The information could then be shared between these healthcare professionals using technology, such as electronic health records, electronic patient summaries and electronic prescribing. The scenario also describes a situation where the patient can access their own health information online, using a patient portal.

In Ireland, there is currently a mix of paper-based and electronic healthcare records in place. New technologies are being developed that will help move towards a digital healthcare system, including:

- **National electronic health record** – a national electronic health record (EHR) is a complete digital record of a patient's journey, throughout their life, across all health and social care settings, for every citizen.
- **National electronic patient summary** – a national electronic patient summary, (also known as a national summary care record) makes an electronic snapshot of the patient's essential clinical information available to healthcare professionals treating patients in situations such as attendance at an out-of-hours clinic or in an emergency situation.
- **Electronic prescribing** – Electronic prescribing or ePrescribing is defined as a prescriber's ability to electronically send an accurate, error-free and understandable prescription directly to a pharmacy from the point of care.
- **National patient portal** – a patient portal is specially created to allow online access for individuals to their own healthcare information through a website or apps on their smartphone or other devices.

The survey found that people see the value in digital health records and think it is very important for healthcare professionals to be able to access their medical records in a timely manner when they are receiving treatment. The majority of people did not have concerns about their health information being accessed electronically by healthcare professionals. Among those who did have concerns, the most common responses were in relation to unnecessary information being shared, the security of the information and the record being accessed by a professional who is not treating them. Some people identified certain types of health information that they would consider more sensitive and that they would not like to be accessed without their permission. This included information about mental health, sexual health and addiction, among others.

3.3.3.1 The importance of digital health records

The survey results show that people see the importance of digital health records and think it is very important for healthcare professionals to be able to access their medical records in a timely manner when they are receiving treatment:

- 1,188 people (**97%**) think it is important or very important that health information about them would be immediately available to a paramedic in an emergency.
- 1,213 people (**99%**) think it is important or very important that healthcare professionals in a hospital would be able to access health information about them.
- 1,211 people (**99%**) think that it is important or very important for the hospital doctor to be able to access their health information electronically, without their permission, when they are unconscious.
- 1,087 people (**89%**) think it is important or very important that their prescription could be sent immediately from the hospital to the pharmacy. (Figure 19)
- 1,051 people (**86%**) think that it is important or very important for all of the healthcare professionals involved in their care to have access to their electronic health record. (Figure 20)
- 1,058 people (**86%**) think that it is important or very important to be able to access and view their own medical records online. (Figure 21)
- 1,011 people (**82%**) think that it is important or very important to know which healthcare professionals have viewed their electronic health record. (Figure 22)

Figure 19: How important is it that your prescription is sent immediately to the pharmacy from the hospital?

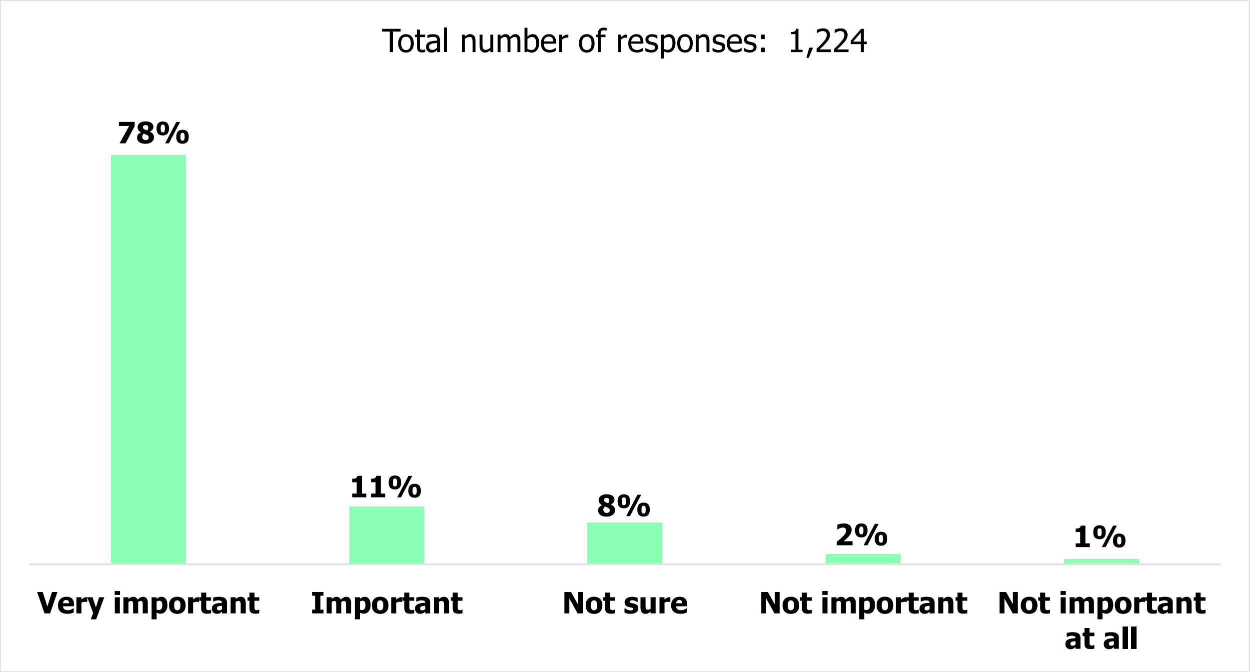


Figure 20: How important is it that all the healthcare professionals involved in your care have access to your electronic medical record?

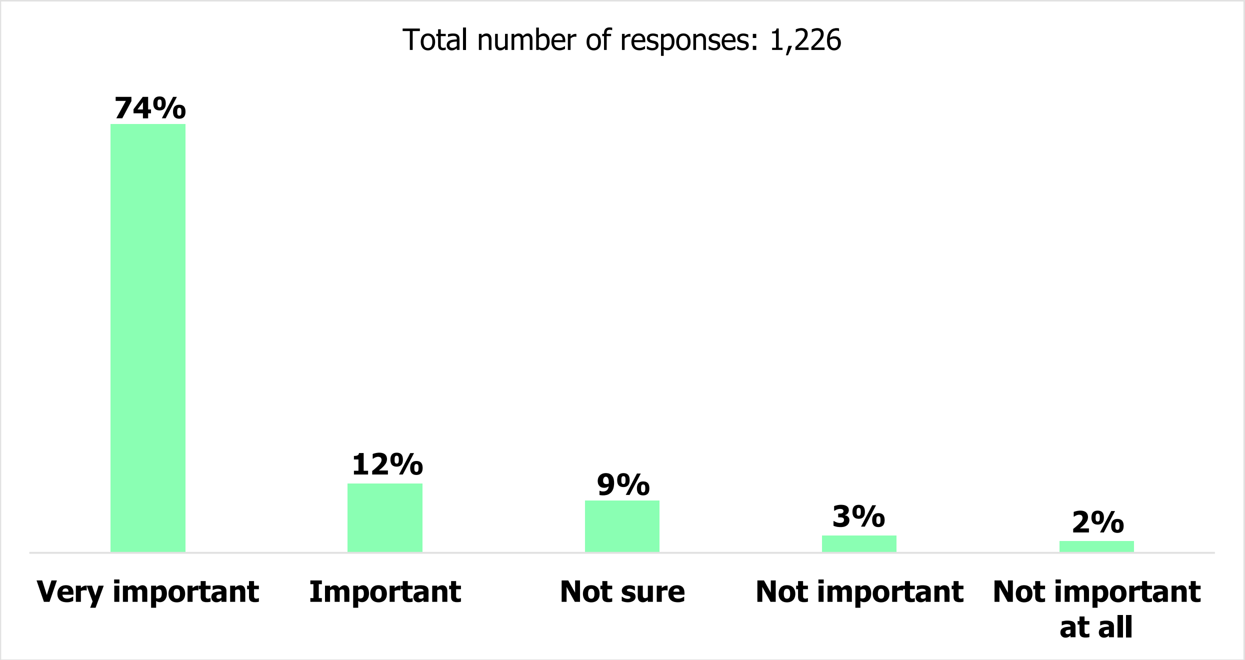


Figure 21: How important is it that you can access and view your own medical records online?

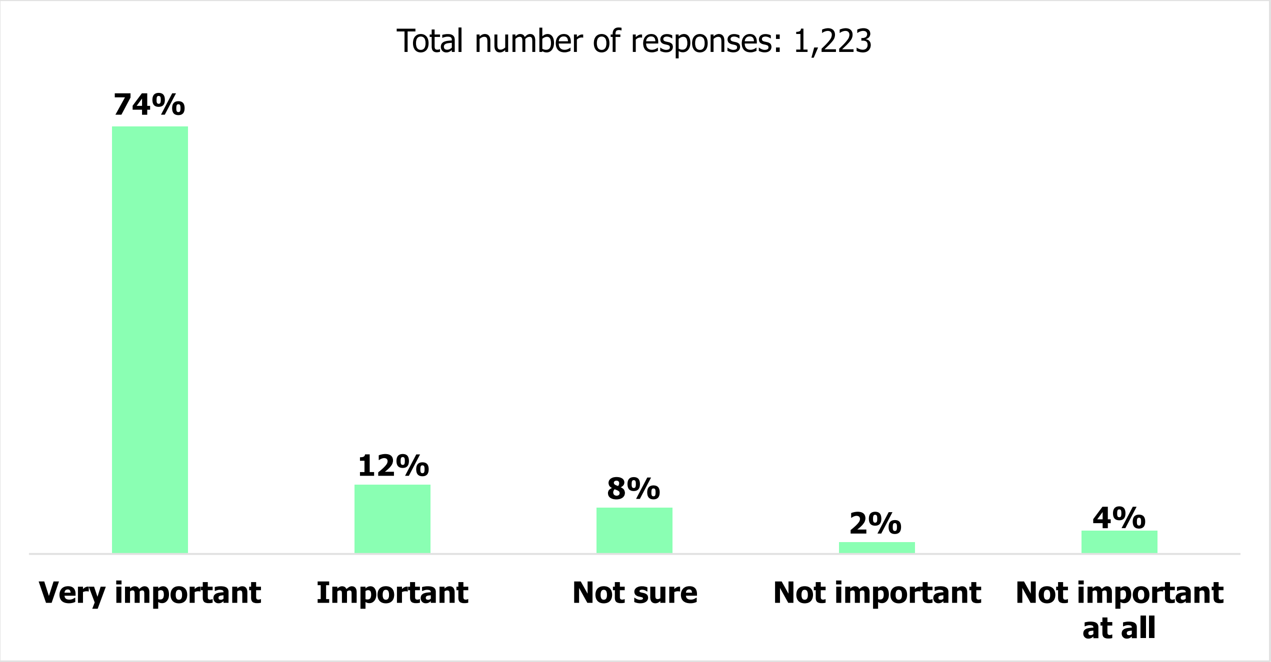
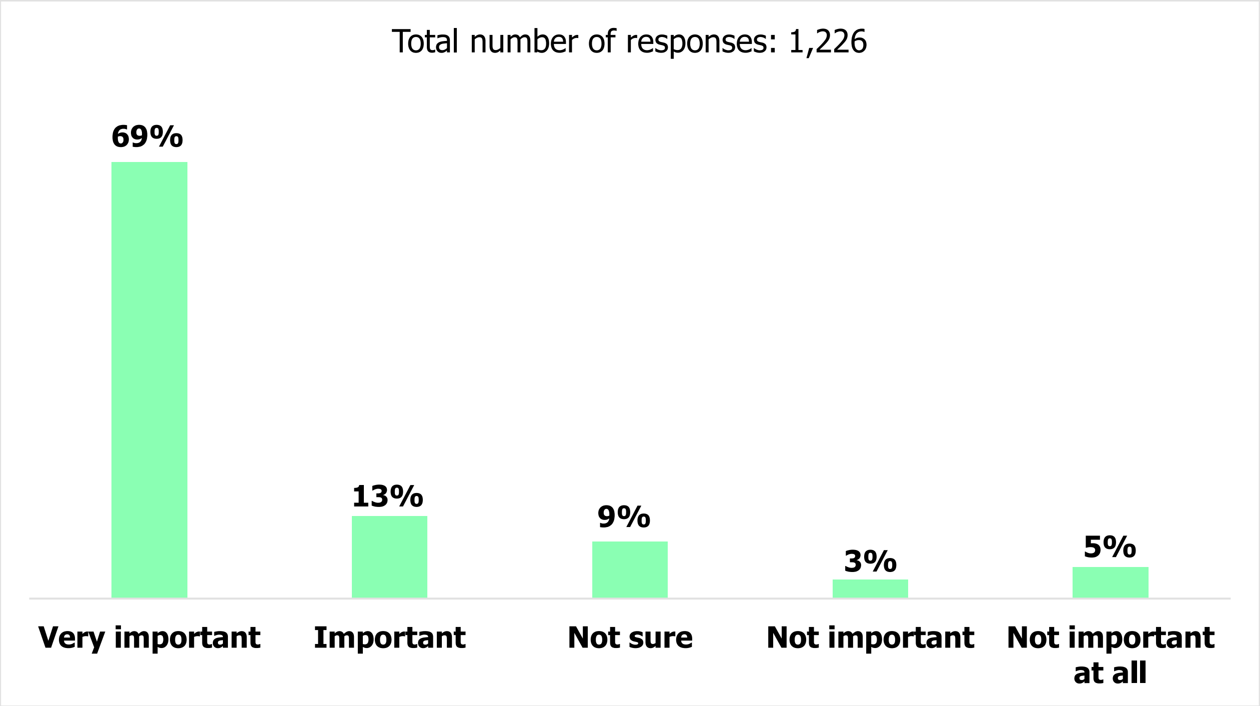


Figure 22: How important is it for you to know which healthcare professionals have viewed your electronic medical record?



3.3.3.2 Concerns in relation to digital health records

The survey identified some important concerns in relation to digital health records.

965 people (**79%**) could not think of any concerns they might have about healthcare professionals, who are treating them, having access to their electronic health record.

263 people (**21%**) provided some details about their concerns they might have about healthcare professionals, who are treating them, having access to their electronic health record.

The framework method was used to analyse and manage the wealth of information that was provided by the survey participants. For this question, an analytical framework consisting of 16 themes was developed.

Figure 23 gives examples of quotes that were given by the survey participants. Figure 24 shows the breakdown of participant comments by theme for this question.

Figure 23: Please tell us what concerns you would have about healthcare professionals treating you having access to your electronic medical record?

Access to your medical record should be curated depending on the healthcare professional looking at it as they do not need to know full history

A lot of them could be tied up with pharmaceutical companies

My concern would be that they could access my medical record at any time and not just when I am being treated

I would be wary about the safety of my information

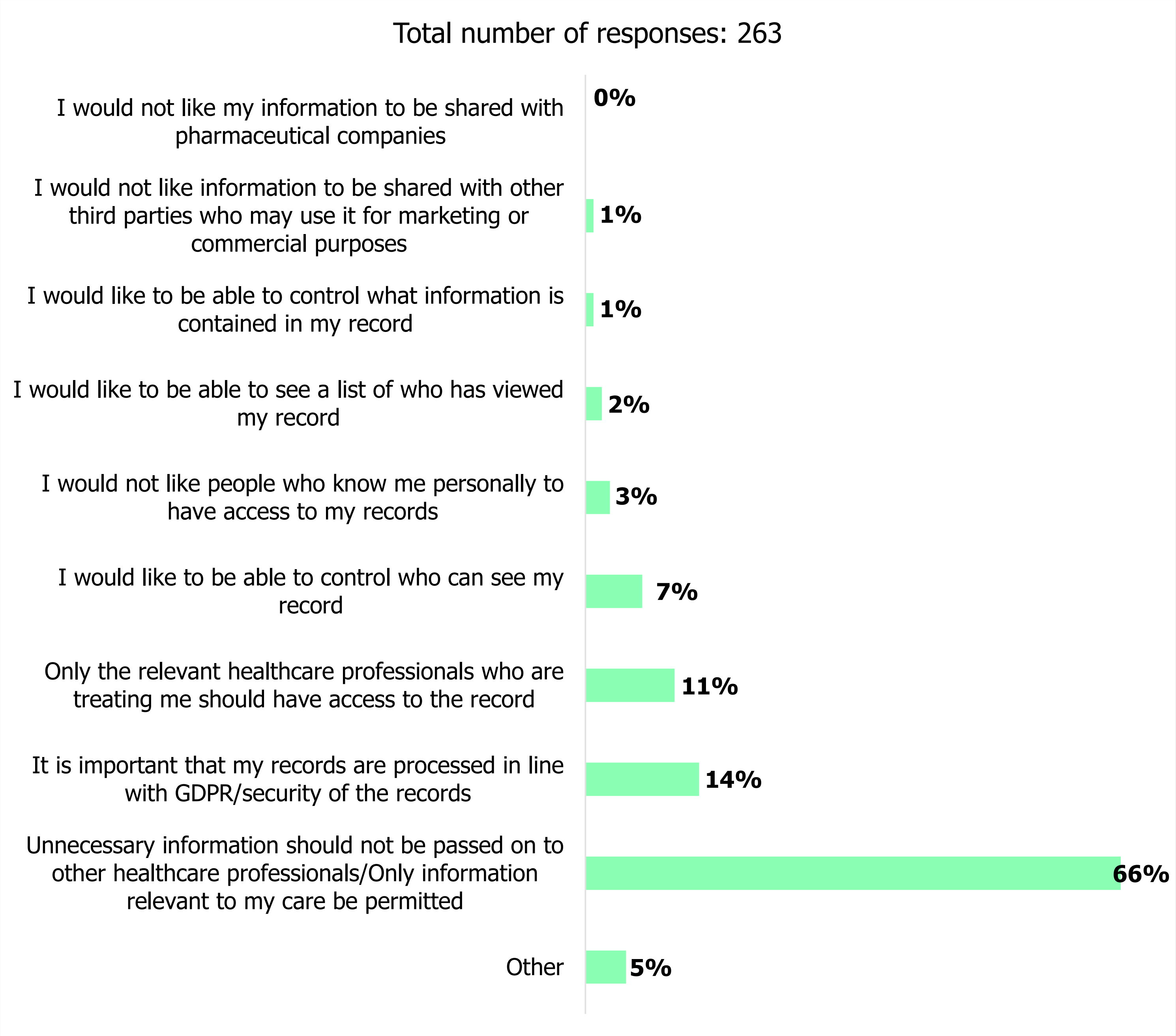
Afraid information would be used by a third party

The most important thing is that my information isn't available to any healthcare professionals rather only available to those treating me

It needs to be categorised in a certain way so that level of access is dependent on role

Sometimes could be other people in the practice that might be nosey and if you're from a place where you'd be well known, people can be conscious of that

Figure 24: Please tell us what concerns you would have about healthcare professionals treating you having access to your electronic medical record?



3.3.3.3 Types of information that may be considered more sensitive than others

The survey identified some common types of health information that people consider to be more sensitive than others.

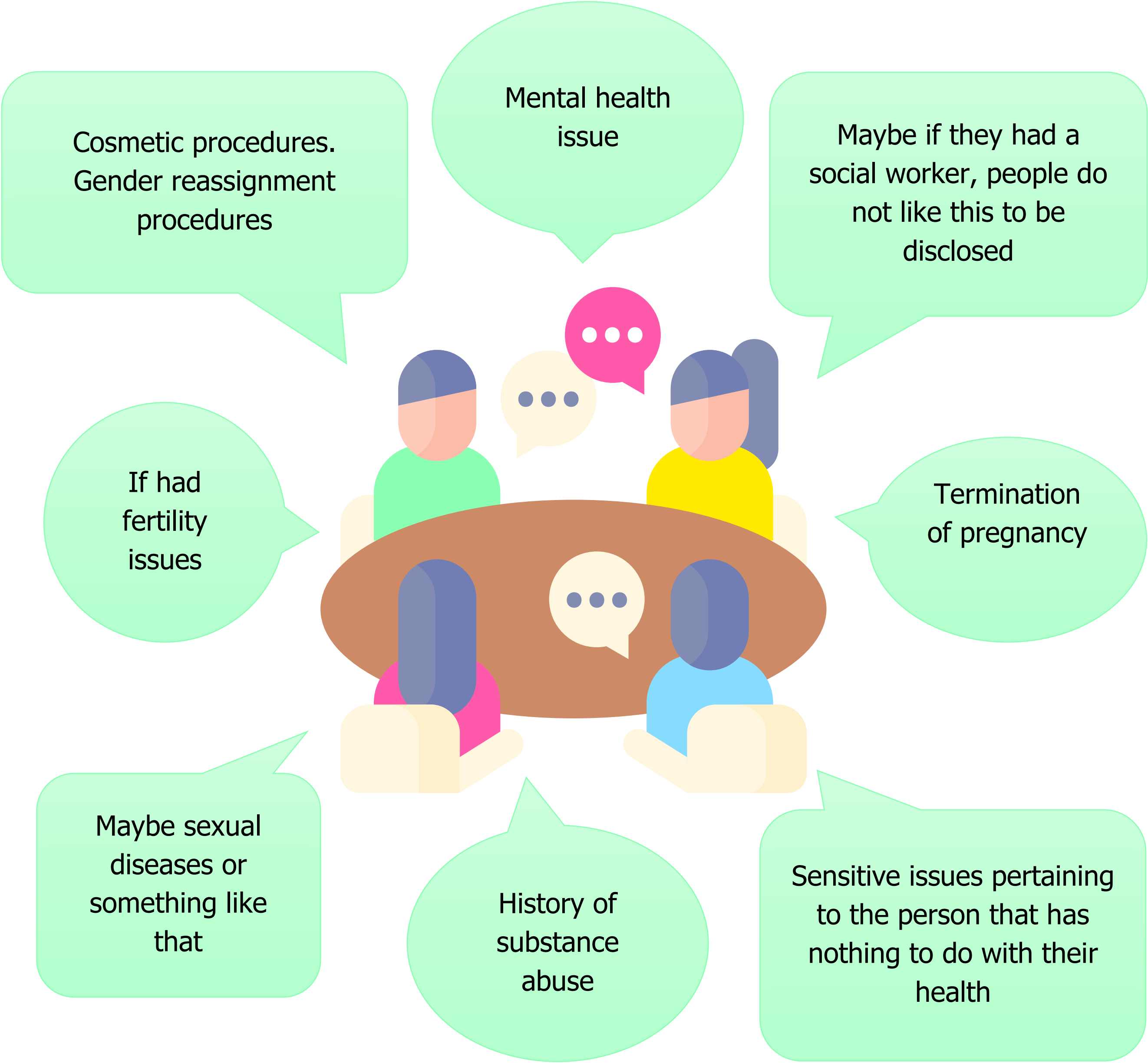
936 people (**76%**) who completed the survey could not think of any types of information that may be in a person's medical history that they might consider sensitive and not want healthcare professionals to access without their permission.

292 people (**24%**) provided examples of some types of information that may be in a person's medical history that they might consider sensitive and not want healthcare professionals to access without their permission.

The framework method was used to analyse and manage the wealth of information that was provided by the survey participants. For this question, an analytical framework consisting of 16 themes was developed – this framework helped organise and systematically reduce the thousands of comments into manageable chunks of information.

Figure 25 gives examples of quotes that were given by the survey participants. Figure 26 shows the breakdown of participant comments by theme for this question.

Figure 25: Please give us examples of such types of sensitive information that people might not want healthcare professionals to access without permission?



Cosmetic procedures. Gender reassignment procedures

Mental health issue

Maybe if they had a social worker, people do not like this to be disclosed

If had fertility issues

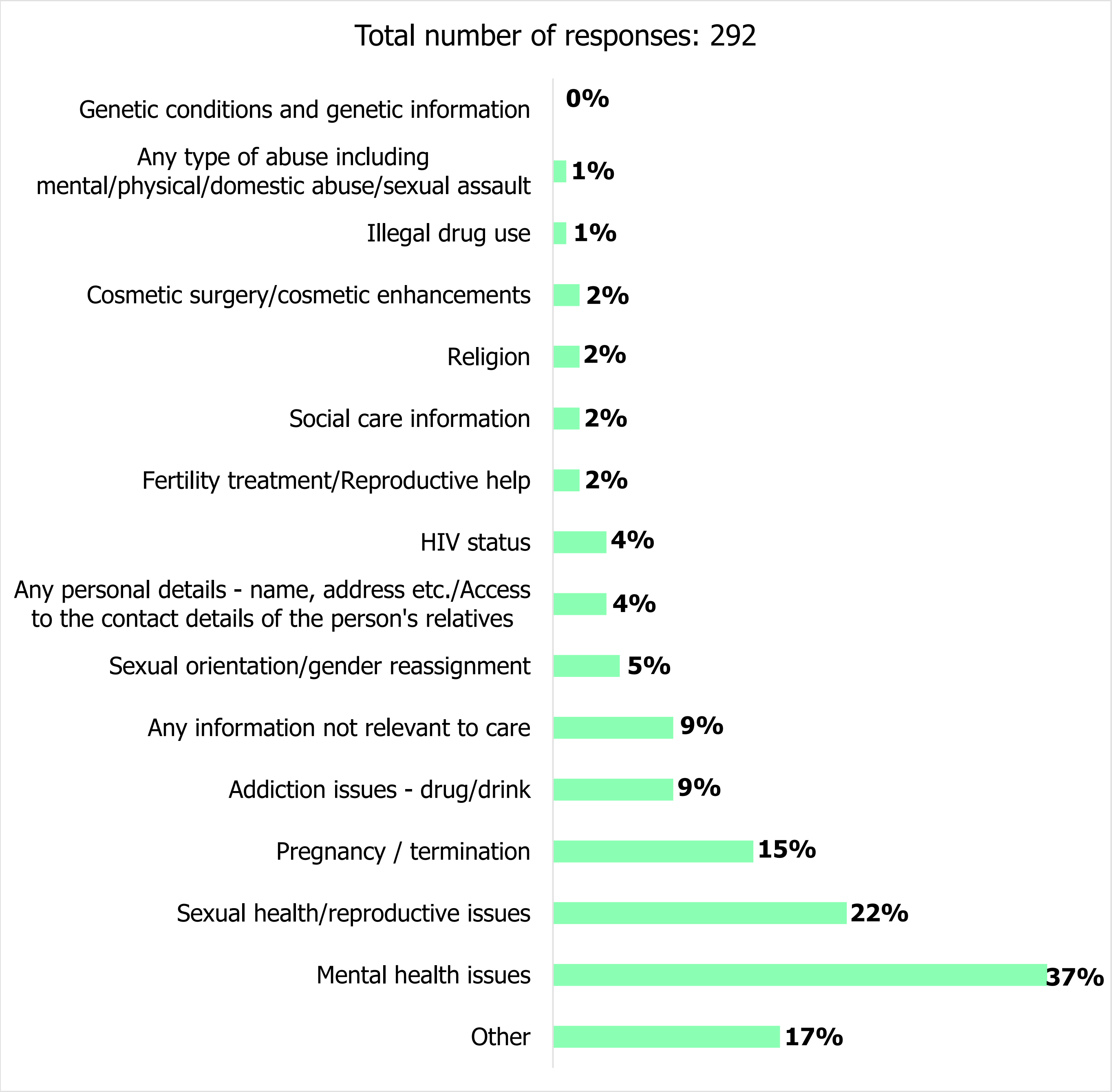
Termination of pregnancy

Maybe sexual diseases or something like that

History of substance abuse

Sensitive issues pertaining to the person that has nothing to do with their health

Figure 26: Please give us examples of such types of sensitive information that people might not want healthcare professionals to access without permission?



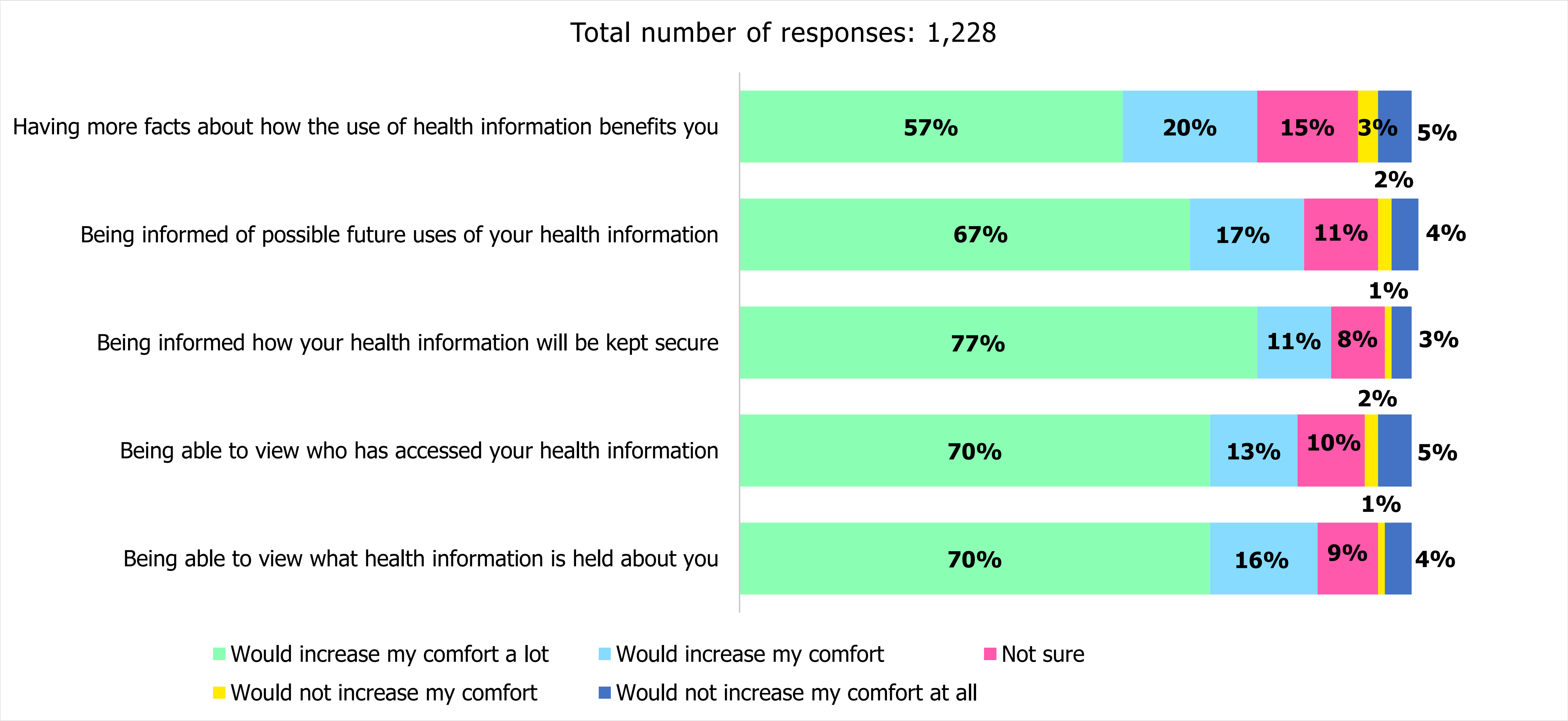
3.3.3.4 How to increase comfort in relation to the sharing of personal health information

The survey findings show that there are four important factors that would increase comfort in relation to the sharing of personal health information:

- 951 people (**77%**) said that they would be more comfortable if they were given more facts about how the use of health information benefits them.
- 1,025 people (**83%**) said they would be more comfortable if they were informed about possible future uses of the information.
- 1,082 people (**88%**) said they would be more comfortable if they were informed about how their information would be kept safe.
- 1,026 people (**83%**) said they would be more comfortable if they were able to view who had accessed their health information.
- 1,066 people (**86%**) said that they would be more comfortable if they could view what information is held about them.

For more information see Figure 27.

Figure 27: Thinking about the three scenarios that we have described, what would increase your comfort in relation to the use or sharing of your health information?

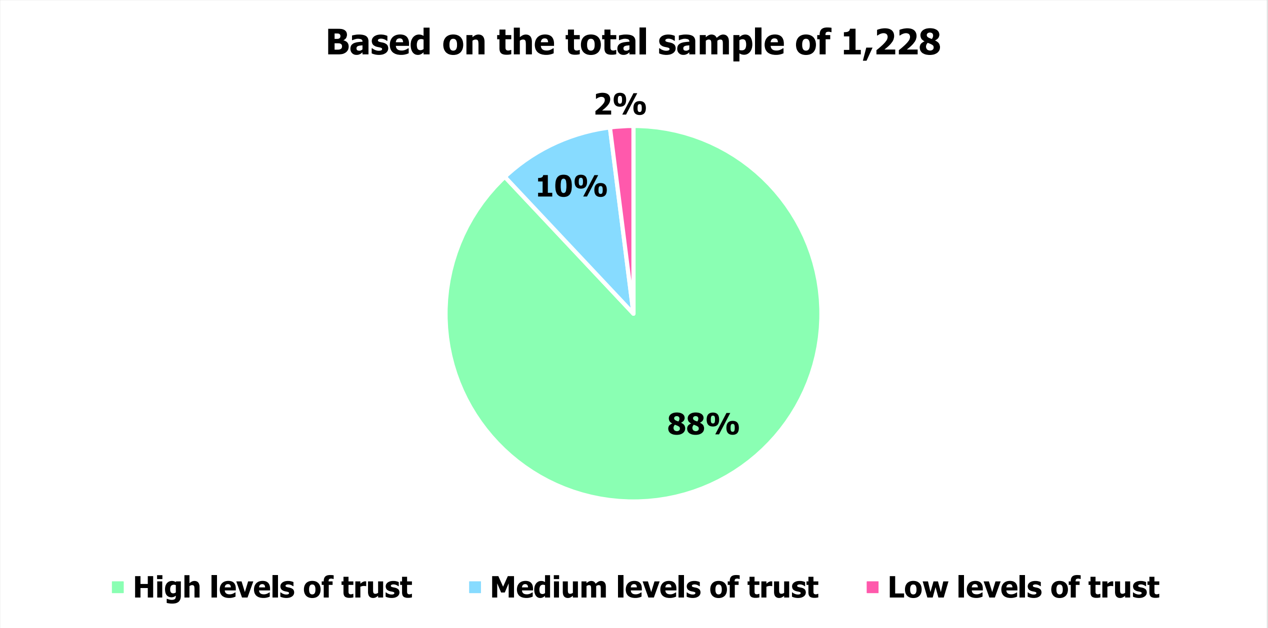


3.3.4 Factor analysis and segmentation

As part of the analysis of the survey findings a 'factor analysis'† was conducted which identified 'Trust' as the strongest factor. We then carried out a segmentation on the data related to the Trust factor and created three groups; those with high levels of trust (**88%**), those with medium levels of trust (**10%**) and those with low levels of trust (**2%**). (Figure 28)

This analysis provided additional insight into the characteristics of people with different levels of trust and what factors would increase the comfort levels of each group in relation to the use or sharing of their health information.

Figure 28: Proportion of the total sample that were in each group based on their level of trust.



A key finding from this analysis was that those with lower trust are more likely to want to be informed about the exact ways that their information is being used, and they are also more likely to want to be able to view access to their own health information. More information on this analysis can be found in Appendix 3.

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† **Factor analysis** is a statistical technique for identifying which underlying factors are measured by a (much larger) number of observed variables. Further details are provided in the Technical report.

Chapter 4. Focus groups on health information

4.1 Who took part in the focus groups?

Throughout January to March 2021, 85 people took part in 14 focus groups to provide a deeper understanding of the survey findings and some of the key issues and challenges faced by people who have specific health and social care needs. An overview of participants is presented in Table 4.1.

Table 4.1. Overview of focus group participants

	Participant group	Number of participants
1	Addiction service users	6
2	Disability service users	6
3	Homeless service users	4
4	Mental health service users	7
5	Migrant and asylum seeker communities	6
6	Patient representatives group 1	8
7	Patient representatives group 2	7
8	Public group negative[‡]	7
9	Public group neutral	5
10	Public group positive	6
11	Sexual health service users	4
12	Traveller communities	4
13	16 & 17 year olds group 1	8
14	16 & 17 year olds group 2	7

[‡] The survey identified three groups with differing attitudes towards information sharing, specific individuals were recruited to each public focus group. There was a group that was positive towards health information sharing, one group that was neutral towards information sharing, and one group that had negative attitudes towards the sharing of health information.

4.2 Key findings

An analysis of focus group discussions found that nine key findings were evident.

1. People believe that health information needs to be available to healthcare professionals and patients to facilitate high-quality care.
2. People want greater access to their health information to support personal empowerment and to participate in their own care.
3. It is essential that health information is accessible to all with a need to consider different formats and ways that it can be accessed.
4. There are mixed views on what is considered relevant data in the context of direct care.
5. Sharing information for purposes beyond the direct care of the patient is generally only acceptable if it provides personal or public benefit.
6. There are positive, yet cautious, views towards digital health records.
7. Building a positive relationship with healthcare professionals helps to create trust which positively influences willingness to share information.
8. There is a need to create a culture of confidentiality to build trust in the health service and support information sharing.
9. People want to be informed about how their health information is collected, used and shared, for both direct care and purposes beyond the direct care of the patient.

Each finding is discussed separately in this section with relevant extracts from the focus group discussions to illustrate the points being made.

"I see multiple specialists over four different hospitals in three different counties so I need them all to be able to look at what the other one has written [otherwise]…I have to go around telling everybody everything…and a lot of patients can't do that"

Finding 1

People believe that health information needs to be available to healthcare professionals and patients to facilitate high-quality care.

People want to be able to view their own health information so they can check it is correct before it is used to inform their direct care. Incorrect information is considered potentially dangerous as it may lead to errors in treatment or the wrong medication being prescribed. For migrants, language barriers and inadequate translation services at GP services may lead to wrong information being recorded. Most people agree that you should be able to view your own information, but there are mixed views on whether people should be able to change their information. People are concerned that important information might be deleted. They believe that some controls should be in place and any changes should be approved by a healthcare professional.

> *"I had two patient numbers, that's dangerous, they could give me the wrong blood because they've mixed me up with…another patient that has the same name as me" (Mental health service user)*
>
> *"if I don't necessarily understand English, speaking to my GP I probably do not explain exactly what it is I want to pass on and he interprets whatever I am saying in his own understanding" (Migrant community)*

There is general agreement across all groups that healthcare professionals should have access to relevant health information to inform your direct care. This is considered crucial for people with intellectual disabilities or people who cannot communicate verbally. Improved access for healthcare professionals may reduce the need for patients to repeat information to different healthcare professionals or to speak about distressing elements of their medical history, for example addiction issues or a miscarriage. Improved access may reduce the time that healthcare professionals spend gathering information from different services or duplicating clinical tests. It is believed that these changes would leave more time for direct patient care and contribute to increased efficiencies across the health service.

Finding 2

People want greater access to their health information to support personal empowerment and to participate in their own care.

People want easier access to their own health information. They believe that their health information belongs to them and that they should be able to easily view their own information. Currently, you have to complete a Freedom of Information (FOI) request to access your health information. This can be difficult for some people and can take a lot of time. People want greater access to their information to help them to participate in their direct care.

"[my daughter is] non-verbal so it's extremely important that information flows around her completely" *(Disability service user representative)*

"I see multiple specialists over four different hospitals in three different counties so I need them all to be able to look at what the other one has written if they feel they need to and whenever they feel the need to, [otherwise]…I have to go around telling everybody everything…and a lot of patients can't do that"
(Patient representative)

"some people might not like to constantly talk about their issues…the doctor might say…tell me about your life or your past life…and you could feel triggered…because you're now going back in to your life" *(Addiction service user)*

People who use certain services, such as addiction mental health services, often feel powerless in their interactions with the health service, and feel that healthcare professionals do not communicate openly with them. They want access to their own information to feel more involved and in greater control of their own care. Some people also need their health information when applying for housing or social welfare. Easier access to their own information would help speed up this process.

"it's your file and you should know what they're writing up on you, you should be told because it's your life and if you want to look at that file you should be allowed to look at it" *(Disability service user)*

"makes me feel more and more that I'm only a number to [my doctor], I'm only money to her at the end of the day" *(Addiction service user)*

"you don't know what's been said about you…they just write it down and that's the end of it, you're not participating in your care…I just find that very frustrating"
(Mental health service user)

However, there are concerns about particular groups, such as people with mental health issues or dementia, accessing their health information as it may have a negative impact. People are also concerned about accessing information before it is explained to them by a healthcare professional, such as a cancer diagnosis. People think that safeguards should be in place around accessing certain types of information and that support should be provided to people that need help to review and understand their information.

"there are certain illnesses will need a degree of oversight and...[there] needs to be supports in place to help people even…with the terminology"
(Patient representative)

Finding 3

It is essential that health information is accessible to all with a need to consider different formats and ways that it can be accessed.

People think it is important that everyone can access their own health information regardless of literacy level (health or digital literacy); presence of a disability; spoken language; and whether they have a mobile phone or computer. Different formats are required to meet the needs of particular groups, such as people with intellectual disabilities. People recognise that not everyone has access to, or are comfortable using, computers or smartphones. Access to health records via telephone and paper should also be available, and supports should be in place to help those that would have difficulty accessing a patient portal. They emphasise that many people do not understand the medical language used in current health records and that information should be presented in a way that everyone could understand.

"it needs to be easy for people with disabilities…easy passwords for them to understand and get in…if it's complicated…too many security questions…they'll get distressed" *(Disability service user)*

"the system really should be about the patient so the person writing the notes should be conscious that the patient may read this" (Patient representative)

Finding 4

There are mixed views on what is considered relevant data in the context of direct care.

When talking about sharing information between healthcare professionals who are providing care to a patient, many people think only relevant information should be shared. There is a difference of opinion on what people consider relevant information in the context of direct care. Some people believe that only information that is directly relevant should be shared with healthcare professionals. For example, if you go to a hospital with a broken arm, healthcare professionals do not need to access information related to your mental health. People are mostly concerned about healthcare professionals accessing sensitive information, such as information about their mental or sexual health, as they are worried about being judged and discriminated against in the care that they receive.

"if you went in with your arm, they don't need to know all the information about your leg or your brain, they just need to know information about the reason you're there and that's it" *(Addiction services user)*

"I would be very worried about having a physical illness and how I'd be treated…when they see I've got a psychiatric diagnosis and I'm on psychiatric medication" *(Mental health service user)*

Other people believe that all information is relevant and that only a healthcare professional can properly understand the information. There are some concerns that if a healthcare professional did not have access to all of the information, it could result in the wrong treatment which could be harmful. Younger adults believe that separating physical and mental health information might add to the stigma attached to mental health issues. Most people agree that certain healthcare professionals, such as your GP or emergency medicine doctors, should have access to all information as it may be important in a crisis. Essential information, such as name, age, blood type, allergies, could be accessed by all healthcare professionals. Hiding historical health information, rather than information related to ongoing health conditions, may be a potential solution.

"I would not consider myself competent to decide whether that is relevant or not…what we might think is not relevant could end up being relevant to diagnosing a future condition…we just don't realise it at the time"

(Patient representative)

"[the doctor] might not know you're taking [a certain drug]…mixed with another drug…which you're taking could cause a problem or maybe cause an overdose…it's good for a doctor to know what medication you're on"

(Addiction service user)

"if you had [the ability to hide based on] history of your medical records instead of something that's ongoing so if you did have mental health issues currently then…you shouldn't have a choice to hide that but if you did in the past then you should be able to hide that because…it's not really relevant anymore"

(16-18 year old)

Finding 5

Sharing information for purposes beyond the direct care of the patient is generally only acceptable if it provides personal or public benefit.

People generally agree that information could be shared for purposes beyond the direct care of the patient if it provided personal or public benefit, such as service planning. People are less willing to share information with private organisations if it is going to be used for marketing purposes or for financial gain with no benefit for the wider public. There is a greater willingness to share information if it is going to be used for research into new drugs as this is considered to be in the public's interest. For some, however, sharing information beyond the health service is a step too far as it requires trusting a greater number of people across different organisations.

"it's important the information is shared…the doctors and the hospitals can look into something new…they can experiment with different things to find out what works and what doesn't work" (Disability service user)

"I think that the greater good is definitely served by sharing a significant element of information…I don't think we should be giving information for cosmetic[s]"

(Patient representative)

"It's not just you have to trust your doctor and your health service, you have to trust the ones that give the permission to use that information…it spreads the trust too wide for me" (Patient representative)

There are concerns that information would be shared for non-healthcare purposes, such as with immigration agencies, insurance companies, and prospective employers. Migrants, especially undocumented migrants and asylum seekers, are specifically concerned about information being shared with other government organisations, such as the Department of Justice. These groups believe that information should not be shared for purposes beyond the direct care of the patient if it is going to have a negative personal impact.

"[I'm] 23 years away from addiction…living a completely different life but when you go to apply for…health insurance…the medical reports might show stuff that you don't really want to mention…then they might say you're not entitled to…medical cover" *(Addiction service user)*

There is a greater willingness to share information for purposes beyond the direct care of the patient if identifiable information is removed. This addresses people's concerns about the privacy of their information, but some people are still concerned about the motives of the organisations who receive their information. Some people said that anonymisation is not possible for smaller communities, such as homeless service users, which provides a barrier to sharing health information from these groups.

"all of the information should be de-identified so there shouldn't be anything that would link back to an individual…I think that…should be considered standard [practice]" *(Patient representative)*

"sometimes in small places [anonymisation] can be very difficult to do because the homeless population itself is quite small and the presentations…[are] quite unusual it's very hard to anonymise" *(Homeless service representative)*

Finding 6

There were positive, yet cautious, views towards electronic healthcare records.

The potential introduction of digital health records is welcomed as people believe that this would allow easier sharing and accessing of health information. This would ensure that an up-to-date and complete account of a person's health is available to the healthcare professional which would contribute to timely and appropriate care. People believe that digital records would make it easier to access your own health information. Many people have concerns about the privacy and confidentiality of digital records and people with low digital literacy tend to be more cautious about the introduction of digital health records. People are also concerned about computer systems failing and if it would effect a healthcare professional being able to provide direct care.

"I have been delayed in the clinic while they were waiting to find my chart [from] when I was in another clinic either that morning or yesterday…I'm delayed to see the consultant because he is waiting on the chart so I think electronic is the way to go" *(Sexual health service user)*

"to get [health] information I found [it] very hard…I had to ring up…they never get back onto you…you have to go ringing them again…they'll say your information…[is] in a part of the hospital that we're not at so we have to go and find it…if that was accessible electronically…the person…could go to a computer and click a button and have all the information" *(Addiction services user)*

"[I am worried about] a Monday morning coming in, turning on the computer and nothing works and you're trying to get on to somebody in IT then and try to get it fixed" *(Homeless service representative)*

Finding 7

Building a positive relationship with healthcare professionals helps to create trust which positively influences willingness to share information.

The focus group findings indicate that a person's trust in healthcare professionals and the health service influences their willingness to share information. Higher levels of trust in a healthcare professional is linked to a greater willingness to share for both direct care and purposes beyond their care. A person's level of trust is influenced by their previous experience with the health service and their relationships with healthcare professionals. GPs are viewed as the most trusted healthcare professional as most people have experience of visiting a GP and they say that it takes time and familiarity to build a trusted relationship. People who have regular contact with hospital or community health services have similar levels of trust with these professionals as with their GP. Some people also say that, due to the number of hospital staff, more people can access personal health information in a hospital setting which means you have to trust a greater number of people.

"more people are exposed to the [GP] on a more regular basis so I think that trust builds up… for people with more needs that are getting weekly visits or daily visits from the [public] health nurse…I think they do build up a much higher level of support" *(Patient representative)*

A minority spoke about their negative experiences which has led to a distrust in healthcare professionals and the health service as a whole. They spoke about healthcare professionals not listening to them, not being treated with dignity and respect, breaches of confidentiality, use of inappropriate language, miscommunication, and being discriminated against based on their health condition, addiction issues, or medical card ownership. Such negative experiences tended to be expressed by specific service user groups, such as migrants or users of addiction, sexual or mental health services.

"I do not trust many mental health services anymore, it takes a lot for me to trust even a GP… one psychiatrist just ignored a letter my GP had written…I wrote in a complaint to the manager…it was completely ignored"

(Mental health service user)

Finding 8

There is a need to create a culture of confidentiality to build trust in the health service and support information sharing.

Experiences of confidentiality breaches and inappropriate accessing or sharing of information contribute to a perceived lack of confidentiality across the health service. The accessing or sharing of sensitive information, such as addiction issues or sexual or mental health, is of particular concern. There are three elements that people consider important to achieve a culture of confidentiality: introduction of an electronic information system, individual control, and staff education.

Developing an electronic system for sharing health information is considered more private compared to paper files. There are concerns about data breaches, intentional or unintentional, and people emphasise that the system must be secure and properly maintained in all healthcare settings. Greater control over personal health information is also important. People want to control who can access their health information, particularly sensitive information, and to know who has accessed or attempted to access their health records. People think that this level of control would stop people from accessing health records inappropriately.

"I would agree with the electronic files…because sometimes the files they walk away from the desk and the file is open, someone leaves them behind"

(Traveller community)

"it would be great to know who has looked at [your record]…what day it was looked at, what information was accessed and how are they going to use it"

(Disability service user)

"[if there's] doctors in the family but they don't want to deal with them …what's to stop [them] from looking up the records" *(Public group)*

People think it is important that all staff adhere to relevant rules and procedures to create a confidential health service. Some people believe that there should be serious implications if staff break the confidentiality agreement. A focus on staff education is considered essential and must include all staff working in the health service; not just healthcare professionals who have direct contact with people. Unintended breaches of confidentiality, such as talking about a patient in public, appear to be of most concern and people emphasise that confidentiality must underpin all actions within the health service.

"[it's important] that personnel are actually trained in data protection, from the receptionists to the porter, from the ambulance…technology won't protect data"
(Public group)

"[healthcare professionals must be] careful that the screens are facing away from people so the only screen open when you're at a consultation is the screen relevant to your care and not the previous person" *(Patient representative)*

Finding 9

People want to be informed about how their health information is collected, used and shared, for both direct care and purposes beyond the direct care of the patient.

People want to be clearly informed of the information sharing process. They want to know what information will be shared, who it will be shared with, how long the information will be kept by different people or organisations, and how the information will be shared, such as on paper or through an electronic system. Knowing how the information is used appears to increase a person's willingness to share their information. People believe that healthcare professionals must make sure that people have a clear understanding of the information sharing process. If digital health records are going to be used, people want an independent organisation to oversee and govern the management of information. This organisation would be responsible for checking that people do not access or share information inappropriately and that any information breaches are dealt with in an open and transparent way.

"if you are sharing somebody's information they [need to be] fully aware of where it's going, why it's going there, what it's being used for"
(Patient representative)

"you'd need to have a credible auditing system to process all of that…an independent auditor" *(Public group)*

> *"if they don't have it in easy to read [format] they have to explain it to them what's going to happen…it's very important to have it in easy to read [format] so people with intellectual disabilities could understand what's happening"*
>
> *(Disability service user)*

A number of people want to be asked for their consent for the use of their information. This appeared to be of greater concern for people from particular service user groups, such as users of addiction services and undocumented migrants, as they fear discrimination either from healthcare professionals or other groups that use their information. They are less concerned about being asked for their consent if they think that the information sharing process is clearly explained.

Chapter 5. Overall findings

This section looks at the key findings from both the survey and focus groups and what they tell us about people's views on the use of health information for direct patient care, for purposes beyond the direct care of the patient, and for digital health records.

5.1 Findings in relation to the use of health information for direct patient care

Overall, people have high levels of trust in healthcare professionals to keep their information safe and secure, and this increases their willingness to share information for their direct care. GPs are the most trusted healthcare professional as people are more familiar with their GP than other healthcare professionals. People that have regular contact with hospital and community health services generally have high levels of trust in these healthcare professionals also. The findings suggest that some people, such as users of mental health services, have limited trust in healthcare professionals due to negative experiences of the health service where they felt discriminated against and not treated with dignity and respect. People believe that all staff working in the health service, and not just healthcare professionals who have direct contact with patients, need to have appropriate training to ensure that information is managed correctly and that each person's confidentiality is maintained.

The findings show that most people think it is important that healthcare professionals have access to their health information to inform appropriate and timely direct patient care, and to contribute to a more efficient health service for all patients. It is important for healthcare professionals to have access to accurate and up-to-date health information, particularly for people that may have intellectual disabilities or are unable to communicate verbally. Most people want to know what information is being shared with other healthcare professionals for their direct care. They also want to be able to access this information as many worry that some information might be wrong which could lead to inappropriate treatment or medications being prescribed.

Some people want greater access to their information so that they can be more involved in their own care. If people can view their own health information, they believe that there should be safeguards in place so people do not see information before it has been explained to them by a healthcare professional, such as a cancer diagnosis. It is also important that information is accessible to everyone. It must be available in different formats to meet the needs of different groups, such as people with intellectual difficulties or people who do not have access to a computer.

Most people have no concerns with their information being shared for their direct care, while some people are concerned that information could be shared that was not relevant to the care episode. However, others think that only a healthcare professional can decide what information is relevant. A healthcare professional may be unable to make a diagnosis if all of the information has not been shared with them. Some people are worried about sensitive information being shared, such as information on mental or sexual health. They are worried that they might be discriminated against in their care if the healthcare professional can see this information.

Some people are also concerned that information could be shared with healthcare professionals that know them personally or are not involved in their direct care. People agree that certain healthcare professionals, such as your GP or doctors working in the emergency department, should be able to see all of your health information. Essential information, such as allergies, could be made available to all healthcare professionals. People want to be able to see who has accessed their information as they think this might stop healthcare professionals from looking at information inappropriately.

5.2 Findings in relation to uses of health information beyond the direct care of the patient

People think it is important that health information is used for purposes beyond the direct care of the patient, such as quality improvement, service planning, and health-related research, as long as it provides personal or public benefit. Overall, most people have no concerns with health information being used for purposes beyond the direct care of the patient and have high levels of trust that health information will be kept safe and secure if it is used for these purposes.

There is more trust in public organisations than private organisations as people are concerned about the motives of private organisations. People are happy if private organisations use their information to provide public benefit, such as developing new vaccines. They do not want their information to be used for direct selling of products or for financial gain with no public benefit. Some people do not want to share their information with private organisations as they believe that more people will have access to their information and they do not know if they can trust them. People from certain service user groups, such as mental health or sexual health service users, believe that their information should not be shared for purposes beyond their direct care if it is going to have a negative personal impact. For example, undocumented migrants are worried that their information will be shared with immigration agencies, and users of addiction services are worried that their information will be shared with insurance companies.

People are more comfortable with sharing their information for purposes beyond their direct care if identifiable information is removed, such as their name and address. Removing identifiable information addresses people’s concerns about their privacy, although some people are still concerned about the motives of private organisations. Anonymisation is not always possible in smaller communities which can act as a barrier to sharing information from these groups.

Most people want to be informed about how their information is shared for purposes beyond their direct care. They would like to know what information is shared, who it is shared with, and how the information is used. People think that healthcare professionals must make sure that people understand how the information is used for purposes beyond direct patient care. Some people want to be asked for their consent for the use of their information. This is more important for people who consider their health information more sensitive or people from minority communities, as they fear discrimination. They are less concerned about being asked for their consent if they feel that the information sharing process is clearly explained.

5.3 Findings in relation to the use of digital health records

Digital records are viewed as valuable, as people think that they allow easier sharing of health information between healthcare professionals. They would give a complete and up-to-date account of a person’s health which could contribute to timely and appropriate care. People also think that digital records would make it easier for people to access their own health information. People see digital health records as more private than paper files as passwords are generally needed to access electronic systems, but only if appropriate safeguards are in place.

Most people have no concerns about their health information being accessed electronically. Some people are concerned about the security of their information on a digital record and want to know that appropriate systems and checks are in place to make sure their information is safe and secure. People are worried that unnecessary information will be shared with healthcare professionals or that healthcare professionals not involved in their care will be able to access their record. They want to see what information is available on their digital record and to know who views their digital record and their reason for accessing the information.

Some people are worried about sharing their sensitive information on a digital record and want to be asked for their permission to share this information with healthcare professionals. Some types of information that people consider sensitive include mental health, sexual health, pregnancies or terminations, addiction issues, and sexual orientation.

Chapter 6. Conclusion and next steps

6.1 What were people's views on the collection, sharing and use of health information in Ireland?

Overall, people think it is important that healthcare professionals have access to their health information for their direct care, and that health information is used to improve the quality of care and to plan health and social care services. People have high levels of trust in healthcare professionals to keep their information safe and secure, and this trust is built up over time as people have positive experiences of the health service. People are generally more comfortable with sharing their information for purposes beyond their direct care if identifiable information is removed, such as their name and address.

People want to be better informed about what information is shared for their direct care, and the different ways that health information is used beyond their direct care. People want to be able to see their own health information, and they also want to know which healthcare professionals have looked at their information, and for what purpose.

People welcome the move towards a more digital healthcare system as they see the value of sharing health information electronically and that healthcare professionals having quicker access to their health information. There are some concerns about the security of digital health records and people want to know that appropriate systems are in place to make sure their information is safe.

"[It is important] that patients would be well informed about this before it was brought in. There would need to be assurances that systems were highly secure"

6.2 What happens next?

The findings from the public engagement will be used to make improvements to health information; ensuring it is kept safe, and that people's rights to privacy are upheld.

- HIQA will use the findings to develop recommendations in the area of health information, such as in relation to a consent model for health information in Ireland.
- The findings will be used by the Department of Health to inform the development of national policy and strategy in relation to health information.
- The HSE will use the findings to support the development and implementation of new technologies for health and social care that will support a more secure and integrated care model in Ireland, as set out in Sláintecare.(5)

More information is available from www.hiqa.ie.

Appendices

Appendix 1 - Membership of governance groups

Steering Group for the public engagement on the collection, use and sharing of personal health information

Name	Organisation Title
Rachel Flynn (Chair)	Health Information and Quality Authority (HIQA) *Director of Health Information and Standards*
Barbara Foley	Health Information and Quality Authority (HIQA) *Health Information Quality Manager*
Alan Cahill	Department of Health *Senior Statistician, Statistics and Analytics Unit*
Niall Sinnott	Department of Health *Head of eHealth and Information Policy*
Fran Thompson	Health Service Executive (HSE) *Interim Chief Information Officer*
Noreen Noonan	Health Service Executive (HSE) *ICT Programme Manager for the National EHR Programme & Lighthouse Projects*
Jacinta Hastings	National Patient Forum *Patient representative*
Nuala Ryan	Irish Platform for Patient Organisations, Science & Industry *Patient representative*

Partnership Project Team for the public engagement on the collection, use and sharing of personal health information

Name	Organisation Title
Barbara Foley (Chair)	Health Information and Quality Authority (HIQA) *Health Information Quality Manager*
Cathy Duggan	Health Information and Quality Authority (HIQA) *Health Information Programme Lead*
Orla Bruton	Health Information and Quality Authority (HIQA) *Health Information Research Officer*
Sarah Jane Flaherty	Health Information and Quality Authority (HIQA) *Health Information Research Officer*
Cathal Collier	Health Service Executive (HSE) *Senior Project Manager*
Mark Brady	Health Service Executive (HSE) *Project Manager*
Pauline White	Department of Health *Statistician*

Advisory group on recommendations for the collection, use and sharing of health information

Name	Nominated Representative
Collette Tully	Royal College of Surgeons Ireland *Executive Director, National Office of Clinical Audit (NOCA)*
John Sweeney	Irish College of General Practitioners *National ICT Project Manager*
Suzanne Browne	Health Informatics Society of Ireland (HISI) Nurses and Midwives *CNIO Chief Nursing Informatics Officer*
Anne Lynott	Institute of Community Health Nursing *Director Public Health Nursing*
Colm Lawlor	Nursing and Midwifery Board of Ireland (NMBI) *Data Protection Officer*
Zetti Azvee	The College of Psychiatrists of Ireland *College of Psychiatrists Ireland (CPSYCHI) representative*
Fergus Ó'Cuanacháin	Child and Family Agency (Tusla) *Director of ICT*
Alan Reilly	Irish Pharmacy Union *Head of Information and Technology*
Derick Mitchell	Irish Platform for Patients' Organisations Science & Industry, IPPOSI *Chief Executive Officer*
Eileen O'Sullivan	Irish Platform for Patients' Organisations Science & Industry, IPPOSI *Patient Representative*
Sheila Fitzgerald	Irish Platform for Patients' Organisations Science & Industry, IPPOSI *Patient Representative*
Jacinta Hastings	National Patient Forum *Patient Representative*
Kieran Culhane	Central Statistics Office *Senior Statistician, Statistical System Coordination Unit*
Peter Connolly	Health Service Executive *Information Governance Lead*
David Hanlon	Health Service Executive *Clinical advisor to HSE/Summary Care Record team*
Yvonne Goff	Health Service Executive *Chief Clinical Information Officer of the Health Service Executive*
Roisin Doherty	Health Service Executive *Director Access to Information (A2I) and HIDs*
Noreen Noonan	Health Service Executive *ICT Programme Manager for the National EHR Programme & Lighthouse Projects*

Joe Ryan	Health Service Executive *National Director of National Services*
Niall Sinnott	Department of Health *Head of eHealth and Information Policy*
Alan Cahill	Department of Health *Senior Statistician, Statistics and Analytics Unit*
Sarah Craig	Health Research Board *Head of NHIS - National Health Information Systems*
Simon Woodworth	Health Information Systems Research Centre UCC *Director, Health Information Systems Research Centre*

Appendix 2 - Survey tool

1. What age are you?

Please specify ______________________________

2. What county are you currently living in?

Please specify ______________________________

And do you reside in a…

- City, (like) Dublin, Cork, Limerick, Waterford, Galway
- A large town 5000+population
- A small town 1500 to 4999
- A rural area

Scenario intro text

Every time you visit your GP or go to a hospital for treatment, important health information about your health and care needs is recorded. Healthcare organisations hold basic personal information about you, such as your name, address and date of birth. Health and social care professionals must follow rules to ensure that your personal information is handled in the correct way. These include Data Protection laws, and codes of conduct and professional ethics. I will now describe three scenarios (or situations) involving the collection, use and sharing of health information and then I will ask you a series of questions after each one.

Scenario 1 – Circle of care

You have been feeling unwell recently and you go to see your GP. The GP is concerned and refers you to a specialist doctor in a local hospital. The GP sends a referral to the hospital that includes information about you (such as your name and date of birth) and your health (such as any medication you take, or your medical history).

Q1. Using a scale of 1-5, where 1 is not at all important, and 5 is very important, how important do you think it is that the hospital doctor treating you has access to accurate information about your medical history and medications?

Not at all important				Very important
1	2	3	4	5

Q2. Using a scale of 1 to 5, where 1 is do not trust at all, and 5 is trust completely, to what extent do you trust that your health information will be kept safe and secure by:

ROTATE ORDER ↓	Do not trust at all				Trust completely
The GP	1	2	3	4	5
The hospital	1	2	3	4	5

Q3. Using a scale of 1 to 5, where 1 is do not trust at all, and 5 is trust completely, to what extent do you trust that the GP will only share the relevant health information with the hospital?

Do not trust at all				Trust completely
1	2	3	4	5

Q4. Which of the following statements best describes your views about health information being shared between a GP and a specialist doctor in a hospital?

a) I am happy for the healthcare professionals to take care of this, and I trust them with my information
b) I would like to know what information will be shared between the GP and the hospital
c) I would like to know what information will be shared and also have direct access to the information that is shared between the GP and the hospital

You attend the hospital for your appointment. To get an understanding of your full medical history the specialist doctor asks you a series of questions about your health. She/he asks questions about the type of medication you take, about any previous illness and about the symptoms you are experiencing.

Q5. Using a scale of 1-5, where 1 is not at all confident, and 5 is very confident, how confident would you be in accurately answering questions about:

ROTATE ORDER ↓	Not at all confident				Very confident
Your medical history	1	2	3	4	5
The medications you take	1	2	3	4	5
Your allergies	1	2	3	4	5

The specialist doctor prescribes new medication. You will need follow- up care so the doctor sends a referral to the public health nurse, this includes details about you and your health. The public health nurse then visits you at home and gives you the follow-up care requested by the doctor.

Q6. Using a scale of 1-5, where 1 is not at all important, and 5 is very important, how important do you think it is that other healthcare professionals involved in your care (for example your GP or public health nurse) have access to relevant information about your hospital visit and new medications?

Not at all important				Very important
1	2	3	4	5

Q7. Using a scale of 1 to 5, where 1 is do not trust at all, and 5 is trust completely, to what extent do you trust that community healthcare services, like the public health nurse, will keep your health information safe in this situation?

Do not trust at all				Trust completely
1	2	3	4	5

Q8. Can you think of any situation where you would **not** want your health information to be shared with other healthcare professionals directly involved in your care? Any other comments?

Scenario 2 – Use of information beyond your direct care

Now let us move on to the second scenario.
Information that is collected when you receive healthcare is also used for other purposes **beyond your direct care**. In this scenario we will discuss three ways your health information can be used:

1. To improve the quality of care
2. To plan healthcare services
3. For research

You have recently spent time in hospital and you have been diagnosed with a minor heart problem. Information that is collected when you are being treated is combined with details of other people with heart problems in Ireland. This information helps healthcare professionals **improve the quality of care** provided to patients by helping them to understand what treatments work best for people with heart problems.

Q1. Using a scale of 1-5, where 1 is not at all important, and 5 is very important, how important is it that your health information can be used for the purpose of improving the quality of care provided to patients with heart problems?

Not at all important				Very important
1	2	3	4	5

Q2. Using a scale of 1 to 5, where 1 is do not trust at all and 5 is trust completely, to what extent do you trust that your health information will be kept safe and secure when it is used for the purpose of improving the quality of care provided to patients with heart problems?

Do not trust at all				Trust completely
1	2	3	4	5

Q3. On a scale of 1-5, where 1 is not at all comfortable, and 5 is very comfortable, how comfortable would you be with this information being used to improve the quality of care if Or if (second option)

ROTATE ORDER	Not at all comfortable				Very comfortable
identifiable information was included, such as your name and address?	1	2	3	4	5
Non-identifiable information was included, so personal information, such as your name and address had been removed.	1	2	3	4	5

When you leave hospital, the information about your hospital visit is recorded in a national database. This information is used **to help plan healthcare services** around the country; to make sure that services are available, at the right time and place, for those who have heart problems.

Q4. Using a scale of 1-5, where 1 is not at all important, and 5 is very important, how important is it that your health information can be used to help plan healthcare services?

Not at all important				Very important
1	2	3	4	5

Q5. Using a scale of 1 to 5, where 1 is do not trust at all, and 5 is trust completely, to what extent do you trust that your health information will be kept safe and secure when it is used to plan healthcare services?

Do not trust at all				Trust completely
1	2	3	4	5

Q6. On a scale of 1-5, where 1 is not at all comfortable, and 5 is very comfortable, how comfortable would you be with this information being used to plan healthcare services if

Or if (second option)

ROTATE ORDER	Not at all comfortable				Very comfortable
identifiable information was included, such as your name and address?	1	2	3	4	5
Non-identifiable information was included, so personal information, such as your name and address had been removed.	1	2	3	4	5

Q7. Which of the following statements best describes your views about health information being used to improve the quality of care and to plan services?

a) I am happy for the healthcare professionals to take care of this
b) I would like some general information about how my health information is used and shared
c) As well as general information, I would like to be informed about exactly how my information will be used beyond my direct care.

Information that is collected when you are being treated for your heart problem may be used by researchers to carry out health-related research. The information used by the researchers will not include identifiable information such as your name and address.

Q8. Using a scale of 1-5, where 1 is not at all important, and 5 is very important, how important is it that the researchers can use this information about your heart problem to carry out health related research?

Not at all important				Very important
1	2	3	4	5

Q9. Using a scale of 1 to 5, where 1 is do not trust at all, and 5 is trust completely, to what extent do you trust that the researchers will keep your health information safe in this situation, if:

ROTATE ORDER ↓	Do not trust at all				Trust completely
The research was funded and undertaken by a public organisations, such as a university	1	2	3	4	5
The research was funded and undertaken by a private organisation such as a pharmaceutical company	1	2	3	4	5

Q10. Can you think of any situation where you would **not** want your health information to be used for purposes beyond your direct care?? Any other comments?

Scenario 3 – Digital records

Now let us move on to the final scenario. In Ireland, there is currently a mix of paper-based and electronic healthcare records in place. New technologies are being developed that will help us to move towards a digital healthcare system.

Imagine you have been in an accident. You have injured your head and leg. In the ambulance, you lose consciousness. The paramedic knows your name and address, so is quickly and easily able to find your electronic medical record containing a summary of important information about you and your health. This includes information about your medical history, medications and allergies.

Q1. Using a scale of 1-5, where 1 is not at all important, and 5 is very important, how important is it that information about you and your health is immediately available to the paramedic?

Not at all important				Very important
1	2	3	4	5

In the hospital, the healthcare professionals treating you have access to your full electronic medical record. They can see information about your recent hospital admission and your heart problem. They can also see that you have an allergy to a type of antibiotic and that you are taking a specific medication.

Q2. Using a scale of 1 to 5, where 1 is not at all important and 5 is very important, how important is it that the healthcare professionals in the hospital can view this information about you and your health?

Not at all important				Very important
1	2	3	4	5

Q3. Using a scale of 1 to 5, where 1 is not at all important, and 5 is very important, how important is it that the hospital doctor can access your electronic medical record at a time like this, when you have lost consciousness and are unable to give your permission?

Not at all important				Very important
1	2	3	4	5

Q4. Can you think of any types of information that may be in a person's medical history that they might consider sensitive and not want healthcare professionals to access without permission?

Yes	1
No	2

IF YES AT Q.4 – ASK Q.4a

Q.4a Please give us examples of such types of sensitive information that people might not want healthcare professionals to access without permission? Any other examples?

ASK ALL

A week later, you have made a good recovery and you are ready to be discharged. The hospital doctor has prescribed a new medication and this is sent electronically to the pharmacy, where you can pick it up immediately.

Q5. Using a scale of 1 to 5, where 1 is not at all important, and 5 is very important, how important is it that your prescription is sent immediately to the pharmacy from the hospital?

Not at all important				Very important
1	2	3	4	5

The hospital doctor refers you to a community physiotherapist. At your appointment, the physiotherapist has access to your electronic medical record and can see the details of your recent visits to the hospital. You attend your GP later that day. The GP also has access to your electronic medical record and can see all the information from the hospital and the physiotherapist.

Q6. Using a scale of 1 to 5, where 1 is not at all important and 5 is very important, how important is it that all the healthcare professionals involved in your care have access to your electronic medical record?

Not at all important				Very important
1	2	3	4	5

Q7. Would you have any concerns about the healthcare professionals who are treating you, having access to your electronic medical record?

Yes	1
No	2

IF YES AT Q.7 ASK Q.7a

Q.7a Please tell us what concerns you would have about healthcare professionals treating you having access to your electronic medical record? Any other comments?

ASK ALL

When you go home, you are able to access your electronic medical record online; it will have been updated with the details of your hospital visits, your new medications and information from the physiotherapist and GP. You can check the record to see that all information recorded about you is correct.

Q8. Using a scale of 1 to 5, where 1 is not at all important and 5 is very important, how important is it that you can access and view your own medical records online?

Not at all important				Very important
1	2	3	4	5

Q9. Using a scale of 1 to 5, where 1 is not at all important and 5 is very important, how important is it for you to know which healthcare professionals have viewed your electronic medical record?

Not at all important				Very important
1	2	3	4	5

Q10. Do you have any additional comments in relation to electronic medical records? Any other comments?

Q11. Thinking about the 3 scenarios that we have described, what would increase your comfort in relation to the use or sharing of your health information? For each answer please use a scale of 1 to 5, where one is "would not increase my comfort" and 5 is "would increase my comfort a lot"

ROTATE ORDER ↓	Would not increase my comfort				Would increase my comfort a lot
Being able to view what health information is held about you.	1	2	3	4	5
Being able to view who has accessed your health information.	1	2	3	4	5
Being told how your health information will be kept secure.	1	2	3	4	5
Having more facts about how the use of health information benefits you.	1	2	3	4	5

Being informed of possible future uses of your health information.	1	2	3	4	5

Demographic Questions Part 2

And finally I would like to ask you a couple 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**".

1. What is your gender? (open question)

Then code:

- Male
- Female
- Transgender
- Gender fluid
- Prefer not to say.
- Other (record exact wording) ___________________________

What is your current working status?

- At work
- Unemployed
- Student
- Home duties
- Retired
- Other – Please specify ____________________________________
- Pass (do not read out)

2. What is the occupation of the Chief Income Earner in the household?

Please specify _______________________________

Pass (Do not read out)

3. The next question we will ask is in relation to ethnicity. It is asked solely in order to ensure we a have spoken to a representative sample of the population. May I ask what your ethnic or cultural background is? Is it…

White

- Irish
- Irish Traveller
- Roma
- Any other White background (specifically) _________________

Black or Black Irish:

- African
- Any other Black background (specifically) _________________

Asian or Asian Irish:

- Chinese
- Indian
- Pakistani
- Bangladeshi
- Any other Asian background (specifically) ________________

Other, including mixed group/background:

- Arabic
- Mixed, *please specify*
- Other, *please specify:*
- *Pass (Do not read out)*

4. Please select which of these applies most closely to you:

I **am not** a regular user of health or social care services IF NEEDED, PROMPT: I visit my GP or emergency department if situation arises)

a) I **am, or have been,** a regular user of health or social care services IF NEEDED, PROMPT: I have had to regularly visit my GP or receive care in my home or a hospital)

5. Do you have a long-term or chronic condition affecting your physical or mental health? (by chronic or long-term condition we mean something like a rare disease, Diabetes or depression)

- Yes
- No

6. Do you have a disability?

- Yes
- No

7. Does a family member or someone close to you, that you care for, have a chronic disease or disability that requires regular check-ups and use of health or social care services?

- Yes
- No

Appendix 3 - Factor analysis

A factor analysis was conducted. Eight factors were identified; the relevant factor score is included in brackets:

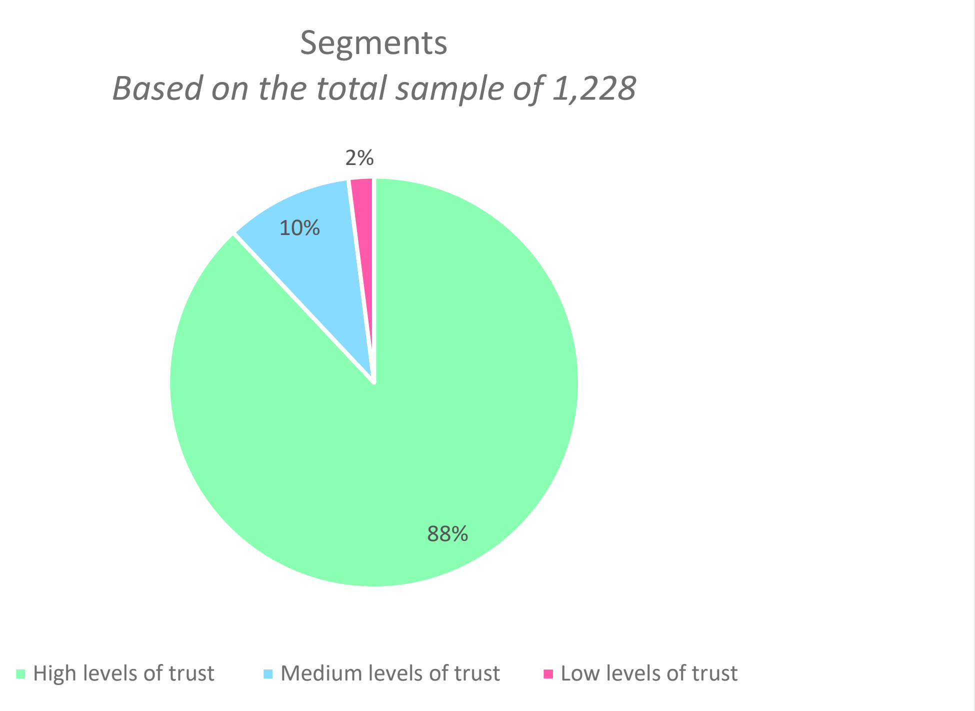
- Trust (0.868)
- Transparency (0.830)
- Identity (0.761)
- Non-Identity (0.750)
- Access (0.747)
- History (0.707)
- Prescription/records (0.528)
- Other healthcare professionals (0.432).

Trust was the strongest factor and was created by combining the responses to the following questions:

- To what extent do you trust that your health information will be kept safe and secure by the GP?
- To what extent do you trust that your health information will be kept safe and secure by the hospital?
- To what extent do you trust that community healthcare services will keep your health information safe in this situation?
- To what extent do you trust that the GP will only share the relevant health information with the hospital?
- To what extent do you trust that your health information will be kept safe and secure when it is used for the purpose of improving the quality of care provided to patients with heart problems?
- To what extent do you trust that your health information will be kept safe and secure when it is used to plan healthcare services?

As trust was the strongest factor, a segmentation was carried out on the data from the "Trust Factor" and three groups were created:

1. Those with high levels of trust (average score of 3.5 or higher)
2. Those with medium levels of trust (average score of 2.5 – 3.5)
3. Those with low levels of trust (average score of 2.5 or lower)



How to increase comfort in relation to the use or sharing of your health information

The three groups were created to enable us to identify what would increase the comfort levels of each group in relation to the use or sharing of your health information

The findings from the factor analysis and segmentation show that 88% of people have high levels of trust. People in this group:

- were less likely to want to know what information is shared between healthcare professionals who are treating them and to have direct access to this information, with 51% wanting this information compared with 54% of total respondents (Table 1)
- were less likely to want to know exactly how their information is used beyond their direct care – 46% compared with 49% of total respondents (Table 2)

The findings from the factor analysis and segmentation show that 10% of people have medium levels of trust. People in this group:

- were more likely to want to know what information is shared between healthcare professionals who are treating them and to have direct access to this information, with 75% wanting this information compared with 54% of total respondents. (Table 1)
- were more likely to want to know exactly how their information is used beyond their direct care, with 66% wanting this information compared with 49% of total respondents. (Table 2)

The findings from the factor analysis and segmentation show that 2% of people have low levels of trust. People in this group:

- were more likely to want to know what information is shared between healthcare professionals who are treating them and to have direct access to this information, with 77% wanting this information compared with 54% of total respondents. (Table 1)
- were more likely to want to know exactly how their information is used beyond their direct care, with 85% wanting this information compared with 49% of total respondents. (Table 2)
- were more likely to have increased comfort if they could view the health information that is held about them. With 82% saying their comfort would be increased a lot compared with 70% of total respondents. (Table 3)

Table 1: Which of the following statements best describes your views about health information being shared between a GP and a specialist doctor in a hospital?

	TOTAL	**Trust Level**		
		Low	Medium	High
Base (unweighted):	*1225*	*30*	*118*	*1077*
I am happy for the healthcare professionals to take care of this	29% *358*	**10%** *3*	**12%** *15*	**32%** *340*
I would like to know what information will be shared between the GP and hospital	17% *205*	**13%** *4*	**13%** *15*	**17%** *186*
I would like to know what information will be shared and also have direct access to the information that is shared between the GP and the hospital	54% *662*	**77%** *23*	**75%** *88*	**51%** *551*

Table 2: Which of the following statements best describes your views about health information being used to improve the quality of care and to plan services?

	TOTAL	**Trust Level**		
		Low	Medium	High
Base (unweighted):	*1225*	*27*	*118*	*1080*
I am happy for the healthcare professionals to take care of this	23% *283*	**4%** *1*	**9%** *10*	**25%** *272*
I would like some general information about how my health information is used and shared	28% *347*	**11%** *3*	**25%** *30*	**29%** *314*
As well as general information, I would like to be informed about exactly how my information will be used beyond my direct care	49% *595*	**85%** *23*	**66%** *78*	**46%** *494*

Table 3: Would being able to view what information is held about you increase your comfort in relation to the use or sharing of your health information?

	TOTAL	**Trust Level**		
		Low	Medium	High
Base (unweighted):	*1228*	*27*	*118*	*1083*
5 – Would increase my comfort a lot	70% *874*	**82%** *22*	**64%** *75*	**71%** *777*
4 – Would increase my comfort	16% *192*	**7%** *2*	**22%** *26*	**15%** *164*
3 – Not sure	9% *106*	**-** -	**9%** *10*	**9%** *96*

2 – Would not increase my comfort	1% *14*	**-** *-*	**1%** *1*	**1%** *13*
1 – Would not increase my comfort	3% *42*	**11%** *3*	**4%** *6*	**3%** *33*

Appendix 4 - Demographics of survey respondents

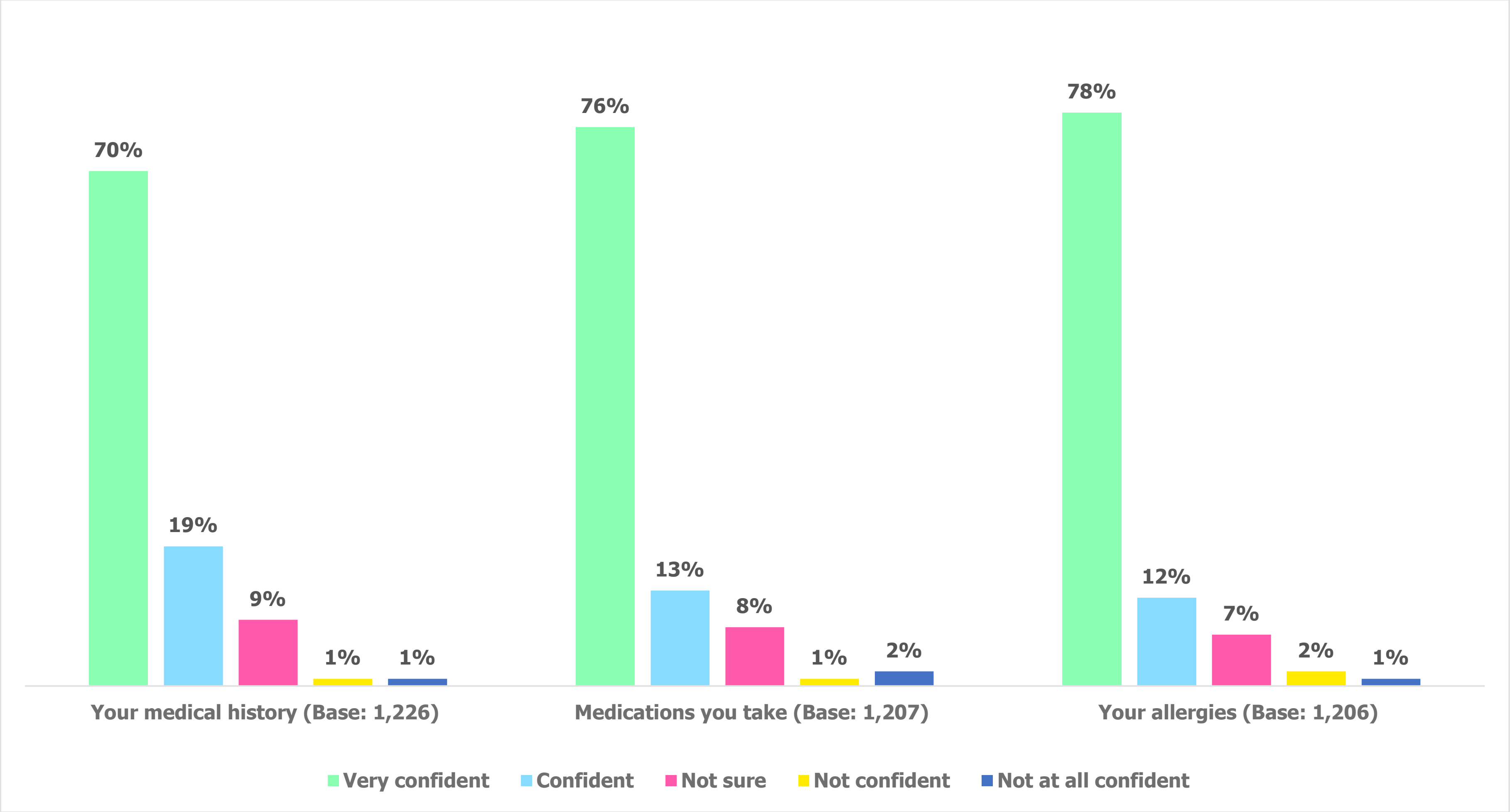
Demographic	n	%
Age category (years)		
18-24	115	9.36
25-34	176	14.33
35-49	419	34.12
50-64	299	24.35
65 or older	219	17.83
Geographical location		
Carlow	8	0.65
Cavan	16	1.30
Clare	31	2.52
Cork - City	52	4.23
Cork – Rest of county	79	6.43
Donegal	44	3.58
Dublin – City	264	21.50
Dublin – Rest of county	132	10.75
Galway – City	27	2.20
Galway – Rest of county	37	3.01
Kerry	30	2.44
Kildare	50	4.07
Kilkenny	26	2.12
Laois	18	1.47
Leitrim	10	0.81
Limerick – City	30	2.44
Limerick – Rest of county	33	2.69
Longford	3	0.24
Louth	36	2.93
Mayo	29	2.36
Meath	61	4.97
Monaghan	11	0.90
Offaly	24	1.95
Roscommon	11	0.90
Sligo	19	1.55
Tipperary	34	2.77

Demographic	**n**	**%**
Waterford – City	6	0.49
Waterford – Rest of county	19	1.5
Westmeath	18	1.47
Wexford	35	2.85
Wicklow	31	2.52
Pass	4	0.33
Gender		
Male	601	48.94
Female	623	50.73
Transgender	-	-
Gender fluid	1	0.08
Prefer not to say	2	0.16
Other	1	0.08
Ethnic group		
White Irish	1050	85.50
Irish Traveller	1	0.08
Roma	3	0.24
Any other white background	71	5.78
Black African	13	1.06
Any other black background	3	0.24
Chinese	5	0.41
Indian/Pakistani/Bangladeshi	22	0.81
Any other Asian background	15	0.73
Arabic	1	0.24
Mixed	3	1.22
Other	28	0.08
Pass	13	0.24
Regular user of health or social care services		
Yes	422	34.36
No	801	65.23
Pass	5	0.41
Long-term or chronic condition affecting your physical or mental health		
Yes	257	20.93
No	962	78.34
Pass	9	0.73
Disability		
Yes	69	5.62
No	1,153	93.89

Demographic	**n**	**%**
Pass	6	0.49
Family member with chronic disease or disability		
Yes	411	33.47
No	807	65.72
Pass	10	0.81

Appendix 5 - Confidence in answering questions about own health

How confident would you be in accurately answering questions about:



References

1. The Committee on the Future of Healthcare. *The Slaintecare Report*. 2016. Available from: https://www.gov.ie/en/publication/0d2d60-slaintecare-publications/#the-slaintecare-report. Accessed on: 29/04/2021.
2. Government of Ireland. *Sláintecare Implementation Strategy and Action Plan 2021-2023*. 2021. Available from: https://www.gov.ie/en/publication/6996b-slaintecare-implementation-strategy-and-action-plan-2021-2023/. Accessed on: 17/05/2021.
3. Health Information and Quality Authority (HIQA). *International review of consent models for the collection, use and sharing of health information*. 2020. Available from: https://www.hiqa.ie/sites/default/files/2020-02/International-Review–consent-models-for-health-information.pdf. Accessed on: 21/04/2021.
4. Health Information and Quality Authority (HIQA). *eHealth in Ireland Frequently Asked Questions*. 2021. Available from: https://www.hiqa.ie/reports-and-publications/health-information/ehealth-ireland-frequently-asked-questions. Accessed on: 23/03/2021.
5. Department of Health. *Slaintecare Implementation Strategy*. 2018. Available from: https://www.gov.ie/en/publication/6011cf-slaintecare-implementation-strategy/. Accessed on: 21/04/2021.

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