



# Technical report for the National Public Engagement on Health Information

2020 - 2021 ◀





## **About the National Public Engagement on Health Information**

A major challenge for healthcare in Ireland today is achieving an appropriate balance between the protection of personal health information, and the use and sharing of such information to improve care. The National Public Engagement on Health Information was completed in partnership by the Health Information and Quality Authority (HIQA), the Department of Health and the Health Service Executive (HSE). The aim of this project was to undertake a public engagement on opinions and attitudes relating 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 in the way that personal health information is collected, used and shared in Ireland.

### **Purpose of this technical report**

This report provides a technical description of the methodology, methods and procedures implemented during the National Public Engagement on Health Information. This report has been designed to provide sufficient detail for repetition, replication and review. This document does not report in detail on the results from the public engagement. A report on the findings can be downloaded from [www.hiqa.ie](http://www.hiqa.ie).

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## 1. Overview

### 1.1 The National Public Engagement on Health Information

A major challenge for healthcare in Ireland today is achieving an appropriate balance between the protection of personal health information, and the use and sharing of such information to improve care. To inform and influence key decisions on these matters, it is essential to engage with the public to ensure their views and opinions are understood. Ireland currently has a mix of paper-based and electronic health records. As outlined in *Sláintecare*, Ireland aims to move towards a more integrated, digital healthcare system. Internationally, the successful introduction of new eHealth initiatives and digital technologies in healthcare has been informed by public engagement. Countries that failed to engage with the public have seen vast amounts of resources wasted due to the failure of new eHealth initiatives that were not accepted by the public.<sup>(1)</sup>

HIQA, in partnership with the Department of Health and the HSE, aimed to engage with, listen to and understand the experiences of people that use Ireland's health and social care services by conducting a national public engagement, in the form of a national survey and focus groups. This feedback provided a rich source of evidence and valuable insight to inform national policy, future developments in health technology and recommendations on how personal health information is collected, used and shared in Ireland.

To engage with the public on this important topic, the partner organisations

- Completed a national public engagement survey on health information which asked 1,228 members of the public for their feedback on how their personal health information is collected, used and shared by health and social care services and their opinions on the use of digital technologies in this area.
- Held 14 focus groups 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 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; this knowledge will inform the Department of Health's forthcoming national health information strategy and future developments in relation to national health information policy.

## 1.2 Management of the National Public Engagement on Health Information

The National Public Engagement on Health Information is of such importance that the Health Information and Quality Authority (HIQA), the Department of Health (DoH) and the Health Service Executive (HSE) have worked in partnership to ensure its completion. The National 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 all of the partner organisations 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 Survey on Health Information:** The steering group is responsible for strategic oversight of the public engagement. The Steering Group comprises members from HIQA, the Department of Health, the HSE and patient representatives.
- **Partnership Project Team:** This team is responsible for the operational aspects of the project, developing the methodology and analysing and reporting on findings. While the core team is based within HIQA, the team also includes representatives 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 information in Ireland. This group was consulted and asked for advice at various stages of the project.

The membership of these 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](http://www.hiqa.ie).

HIQA contracted a managed service (Behaviour and Attitudes) to administer the survey and to process the responses received. The managed service also conducted three public focus groups, in line with HIQA's focus group methodology. A further 11 focus groups were conducted by the HIQA team.

## 1.3 Stakeholder engagement and communication plan

A communications plan was developed for this project. This ensured clear and consistent engagement with stakeholders throughout the project. The plan focused on ensuring that the findings of the public engagement are used to the maximum



potential, both within the partner organisations and across Ireland's health and social care system.

#### **1.4 Ethical approval**

Ethical approval for the National Public Engagement Study on the Collection, Use and Sharing of Personal Health Information in Ireland was obtained from the Royal College of Physicians of Ireland (RCPI).

#### **1.5 Information governance**

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

## 2. Survey design

### 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 engagement meetings were conducted to gain an understanding of what is important to people in relation to how their health information is collected, used and shared. Focus groups were held internally with HIQA staff. Engagement meetings were held with healthcare professionals to understand potential barriers to sharing information and to ensure that the survey questionnaire reflected the Irish healthcare system. A list of the organisations represented in the engagement meetings is presented in Appendix 2. An overview of the key themes identified is presented in Appendix 3. Following a review of international evidence, it was agreed that a scenario-based survey would be most appropriate as it guided the survey participants through a complex topic using relatable stories based on the Irish health system. Cognitive interviews were held with members of the public to assess the clarity and appropriateness of the proposed survey scenarios and questions.

The engagement activities that informed the survey design were as follows:

- two focus groups with nine people
- 21 engagement meetings with healthcare professionals
- nine cognitive interviews to assess the clarity and appropriateness of the proposed survey scenarios and questions.

### 2.2 The National Public Engagement Survey on Health Information

The telephone survey was conducted with a representative sample of the Irish public aged 18 and over. The survey collected key demographic information about the participants and how often they use health and social care services. The survey consisted of three scenarios based on the Irish healthcare system that guided participants through the survey questions. The final survey is included in Appendix 4. 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?

## **2.3 Telephone survey methodology**

### **2.3.1 Computer-assisted telephone interviewing (CATI) methodology**

A computer-assisted telephone interviewing (CATI) approach was used for both the pilot and the main survey. CATI interviewers, working with the managed service, conducted interviews with members of the public over the phone and are guided by a questionnaire that is displayed on their computer screens. They are then able to record and input the survey participant answers into the questionnaire. Once an interviewer completes the survey, they can no longer access the survey or the answers.

### **2.3.2 Pilot survey**

A pilot of 10 interviews was carried out on 19 and 20 October 2020. The purpose of this pilot study was to test the survey tool and ensure that participants understood all the questions. Two experienced CATI interviewers worked on the pilot. There were 202 connected calls during the pilot and the interview completion rate was 0.77 interviews an hour. The average length of the survey was 24 minutes and 25 seconds. Following the pilot, changes were made to the survey tool to reduce the interview length to 20 minutes. The results from these pilot interviews were only used to inform the content of the survey and were not included in the final survey results. Please see the final Survey Tool in Appendix 4.

### **2.3.3 Interviewer training**

Twenty-nine members of the CATI team (including two supervisors) were trained and briefed on the Public Engagement Survey project by the CATI Manager. The training covered:

- overall aim of the survey and survey topic
- sensitive data and consent
- vulnerable groups
- FAQs from respondents (see Appendix 5)
- open ended questions
- leaflets and further information from HIQA (see Appendix 5 and Appendix 6)

- briefing the survey (going through each question)
- anonymisation criteria (see Appendix 7).

### **2.3.4 Consent**

Participant consent was obtained at the beginning of the survey tool (see Appendix 4 for full Survey Tool). Participants were asked to confirm that they understood the purpose of the survey and that it was voluntary, and whether they consented to taking part.

For those that gave their consent, it was recorded by the interviewer and the interviewer either proceeded with the interview at that time or an appointment was made to conduct the interview later at a time that suited them. Survey participants were also informed that their participation was voluntary and that they had the right to withdraw from the survey at any time. If consent was not given by a participant, this was processed as a 'refusal' and the survey was closed. It was not counted as an interview and the participant was thanked for their time.

### **2.3.5 The survey**

Once participants consented to participate in the survey, they were asked demographic questions and presented with scenario-based questions in relation to the collection, use and sharing of health information (see Appendix 4 for the full Survey Tool). The scenarios were first read 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 patient 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 demographic information that was collected included:

- 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
- living with a disability

- if the participant has a family member or someone close to the respondent with a long-term condition or disability requiring regular use of health or social care services.

### **2.3.6 Data retention and destruction**

Anonymised responses from the pilot survey will be retained for a period of five years following the close of the survey. The file containing phone numbers and first names of responders to the telephone survey was deleted four weeks after the close of the survey.

### 3. National Public Engagement on Health Information: Survey fieldwork

#### 3.1 Sampling

A sample of 1,200 people aged over 18 years was chosen for this study to achieve a nationally representative sample. A sample of 1,200 is statistically robust, with a plus or minus margin of error of 2.83 at a 95% confidence interval. The sample was quota controlled by gender, age and region and then subsequently weighted to match the profile of the Irish population as defined by the Central Statistics Office (CSO)<sup>1</sup>; this ensures that the findings can be generalised to the Irish population. Please see Table 3.1 below for the final demographic quotas achieved.

**Table 3.1 Demographic quotas achieved**

Demographics	Target	Total Completes	% Completed
<b>Totals</b>	1200	1228	102%
<b>Male</b>	586	602	103%
Refused Age	0	0	
18 to 24-year-olds	82	54	66%
25 to 34-year-olds	94	94	100%
35 to 49-year-olds	182	199	109%
50 to 64-year-olds	123	150	122%
65 + year olds	105	105	100%
<b>Female</b>	614	620	101%
Refused Age	0	1	
18 to 24-year-olds	85	61	72%
25 to 34-year-olds	98	82	84%
35 to 49-year-olds	191	220	115%
50 to 64-year-olds	128	150	117%
65 + year olds	112	112	100%
<b>Region</b>	1200	1228	102%
DK/NA/Invalid	0	0	
Dublin	348	396	114%
Rest of Leinster	324	310	96%
Munster	324	314	97%
Connaught/Ulster	204	204	100%
Refused	0	4	

<sup>1</sup> Population estimates based on the CSO Labour Force Survey (2018/Q4 – 2019/Q3) were used for weighting of the sample.

### 3.1.1 Random digit dialling

Survey participants were recruited using a random digit dial sample to ensure all households, including ex-directory, were covered. 80% of this sample was accessed through mobile phone numbers and 20% was accessed through landline phone numbers. Numbers were manually dialled. Mobile numbers were randomly generated for all mobile providers in Ireland: 083, 085, 086, 087 and 089 numbers. A three digit randomly generated number was appended onto an existing real number. Once mobile numbers were generated, a Home Location Register check via Hlrlookup.com on the number was completed to ensure it was a 'live' number. For the remaining 20% of landline numbers, a list was used of all area codes for counties in Ireland. The proportion was checked against CSO Census 2016 population statistics to ensure that the area codes selected provided a representative sample of the public. For example, if one third of the population live in a particular area code, one third of the survey participants contacted on landlines were selected from that area code. Numbers were generated by appending a randomly generated number to an existing real block of digits. The latest CSO population statistics for counties in Ireland is set out in Table 3.2. This was used for the landline selection procedures.

**Table 3.2 CSO population statistics for counties in Ireland**

County	Population 2016
Carlow	1.20%
Dublin	28.30%
Kildare	4.70%
Kilkenny	2.10%
Laois	1.80%
Longford	0.90%
Louth	2.70%
Meath	4.10%
Offaly	1.60%
Westmeath	1.90%
Wexford	3.10%
Wicklow	3.00%
Clare	2.50%
Cork	11.40%
Kerry	3.10%
Limerick	4.10%
Tipperary	3.40%
Waterford	2.40%
Galway	5.40%
Leitrim	0.70%
Mayo	2.70%
Roscommon	1.40%

Sligo	1.40%
Cavan	1.60%
Donegal	3.30%
Monaghan	1.30%

### 3.1.2 Response rate

There were 16,718 attempted calls and a sample size of 1,228 was achieved. The resulting sample (n=1,228) by age, geographic spread and representatives of different service user groups is set out in the table below in Table 3.3.

**Table 3.3 Overview of sample characteristics**

Demographic	n	%
<b>Age category (years)</b>		
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
<b>Geographical location</b>		
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
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
<b>Gender</b>		
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
<b>Ethnic group</b>		
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
<b>Regular user of health or social care services</b>		
Yes	422	34.36
No	801	65.23
Pass	5	0.41
<b>Long-term or chronic condition affecting your physical or mental health</b>		
Yes	257	20.93
No	962	78.34

Pass	9	0.73
<b>Disability</b>		
Yes	69	5.62
No	1,153	93.89
Pass	6	0.49
<b>Family member with chronic disease or disability</b>		
Yes	411	33.47
No	807	65.72
Pass	10	0.81

## 4. Data processing, analysis and reporting: Survey

### 4.1 Data processing steps

Completed questionnaires were entered directly into a customised data entry form using ASKIA software. ASKIA software was also used to create tables of the responses. The data were then exported into SPSS Version 25 for further analysis. Missing data were not taken into account during analysis. As such, it was excluded from the tables and any further analyses. For the factor analysis (described in section 4.2.2), missing data were managed by setting it to 'missing' in SPSS, thus excluding it from the analysis.

### 4.2 Quantitative methodology

This section describes how scores were calculated and describes the quality assurance of the survey data.

#### 4.2.1 Question scores

The frequency of responses to all questions individually were provided in tables and graphs.

#### 4.2.2 Comparisons of groups

Cross tabulations of all questions by demographics and health questions were provided in tables to identify whether frequency of responses varied according to demographic characteristic.

The data were subjected to a factor analysis to examine its underlying factor structure. The output is included in Appendix 8. The analysis revealed eight separate factors, the strongest of which was the 'Trust' factor. The Cronbach's Alpha for the 'Trust' factor was 0.87. The 'Transparency' factor was the second strongest factor. The Cronbach's Alpha for this factor was 0.83. Using the strongest factor generated, three segments were created on this spectrum of trust: those with high levels of trust (**88%**), those with medium levels of trust (**10%**) and those with low levels of trust (**2%**). These three segments were then used as a profile in crosstabs against the demographics and against a list of selected questions. 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.

## 4.2.3 Quality assurance

### 4.2.3.1 Data collection

Quality assurance was built into the design of the data capture for the survey responses. 249 backchecks were completed in total which is 20% of the total sample. The CATI Quality Control team called 20% of the participants to check that the interview was undertaken in accordance with the ESOMAR code and guidelines<sup>2</sup> and the Market Research Society Code of Conduct<sup>3</sup>. The backchecking script included five key questions:

- 1) Did you take part in a survey recently?
- 2) And which county are you based?
- 3) What was the central topic about?
- 4) Can I just confirm your age?
- 5) Finally, was the interviewer polite and professional?

If any one of these answers did not match what had been expected, further backchecks on an interviewer's work was conducted and feedback was given to the interviewer ahead of further working shifts.

A number of assurances were in place to minimise missing data. Respondents could 'pass' on a question should they not wish to answer. Several questions throughout the survey had a 'pass' option, which appeared as 'Pass (DO NOT READ OUT)' on the interviewers' screens. Interviewers mentioned the option of passing on questions during the introduction, as per the survey tool document, but did not offer it at each question in an effort to reduce the number of skipped questions and missing data.

All interviewers were trained in how to ask probing questions in order to clarify vague responses and expand on responses to open ended questions. Supervisors performed quality control by observing interviewers' screens and checking that they were following the script, interviewing at a good pace and not selecting an excessive number of don't know responses.

### 4.2.3.1 Data analysis

A series of quality assurance checks were undertaken on the survey findings to check the accuracy of the figures. The original dataset was re-analysed and checked against the original figures. Where inaccuracies were found, figures were updated.

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<sup>2</sup> ESOMAR. 2016. ICC/ESOMAR International Code on Market, Opinion and Social Research and Data Analytics. Available from: [https://www.esomar.org/uploads/public/knowledge-and-standards/codes-and-guidelines/ICCESOMAR\\_Code\\_English\\_.pdf](https://www.esomar.org/uploads/public/knowledge-and-standards/codes-and-guidelines/ICCESOMAR_Code_English_.pdf)

<sup>3</sup> MRS. 2019. Code of Conduct. Available from: <https://www.mrs.org.uk/pdf/MRS-Code-of-Conduct-2019.pdf>

### **4.3 Qualitative methodologies: Survey**

This section describes the processing of the qualitative data collected via the survey questionnaire, that is, responses to the open-ended questions:

- S1: 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?
- S2: Q10. Can you think of any situation where you would not want your health information to be used for purposes beyond your direct care?
- S3: Q4a. Please give us examples of such types of sensitive information that people might not want healthcare professionals to access without permission?
- S3: Q7a. Please tell us what concerns you would have about healthcare professionals treating you having access to your electronic medical record?
- S3: Q10a. Do you have any additional comments in relation to electronic medical records?

#### **4.3.1 Anonymisation of qualitative data**

Interviewers did not collect any information of a personal nature when recording the responses to these open-ended questions during the phone survey. The anonymisation criteria can be found in Appendix 7.

#### **4.3.2 Developing thematic codes for the qualitative data**

A coding framework was developed to code the open-ended questions from the telephone survey. A sample of the responses from the open-ended questions was analysed by two researchers and a draft coding framework was developed. This was then reviewed by other team members and the final coding framework was developed and finalised. Please see Appendix 9 for the full coding framework used.

#### **4.3.3 Quality assurance of qualitative data**

3% of all the verbatim responses to the open-ended questions were quality controlled to ensure that the correct code(s) were assigned to the verbatim. The percentage of agreement between the quality controller and the coder was above 95% for each of the open-ended questions in the survey.

## 5. Focus groups methodology

Between January and March 2021, 14 focus groups were held with members of the public, patient representatives and representatives of different service user groups. Due to restrictions in place due to COVID-19, all focus groups were held online. A total of 85 people took part in these groups. The aims of the focus groups were 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. International evidence and engagement with healthcare professionals highlighted that certain categories of health information may be considered more sensitive than others. It is important to capture the views of people with experience of using services that collect, use, and share sensitive health information. Three focus groups with members of the public were undertaken by the managed service. HIQA carried out the remaining focus groups with representatives of patients and representatives of different service user groups.

### 5.1 Topic guide development

A semi-structured topic guide (see Appendix 10) was developed that incorporated a standard schedule of questions and relevant prompts related to the areas of interest. The areas of interest were chosen based on those survey findings where a greater understanding was needed, and important issues identified in the international literature. Questions were adapted to the participants of each focus group based on their understanding of the topic and their particular perspective. The schedule of questioning was flexible and allowed for participants to discuss additional topics they considered relevant, and for the facilitator to probe particular points for a better understanding.

### 5.2 Consent

In advance of the focus group, participants were sent details of the study in the form of a Participant Information Leaflet (see Appendix 11) and a briefing document which outlined ground rules for the focus group and the general questions that would be discussed in the group. Participants were provided with an email address to contact in the event that they had any further questions about the focus group. Participants were required to sign a consent form in advance of participating in the focus group, this was returned by email (see Appendix 12). At the beginning of each focus group, the facilitator confirmed that participation was voluntary and participants had the right to withdraw from the focus group at any point. Recruitment of patients and representatives of different service user groups was via representative or advocacy groups and HIQA worked closely with these

organisations to ensure that participants had all the required supports to make an informed consent.

### **5.3 Data retention and destruction**

All personal details of the focus group participants were held on a password protected file and stored on a secure server. Access to this data was limited to the project team. All contact details of focus group participants were deleted as soon as the focus groups were completed. Focus group recordings were deleted once transcription was completed. All focus group anonymised response data will be retained for five years. For files held by the managed service, HIQA representatives oversaw their deletion via Zoom and the managed service provided a certificate of deletion to HIQA.

## 6. National Public Engagement on Health Information: Focus group fieldwork

### 6.1 Sampling

When recruiting participants for the public focus groups, three groups were identified with differing attitudes towards information sharing. 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. Participants for these public focus groups were recruited by the managed service through their online panel, which is an online group of people that had previously agreed to take part in different research studies. Panellists were invited via email to fill out a questionnaire which assessed their trust and comfort level in relation to the sharing of health information in different scenarios. Panellists were categorised into one of the above three groups and were then invited to take part in the focus group. Only those aged over 18 were eligible to participate in the public focus groups.

The method of sampling for the remaining 11 focus groups was purposive sampling where participants were invited to participate based on a common characteristic relevant to the objective of the focus group. HIQA invited specific representative organisations to ask individuals they represent to take part in these focus groups. Representative organisations were identified from a range of locations across Ireland, as per standard HIQA procedures. An overview of focus group participants is provided in Table 6.1.

**Table 6.1 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 <sup>4</sup>	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

## 6.2 Data collection

Focus groups were carried out according to the approved HIQA focus group methodology. Due to restrictions in place due to COVID-19, focus groups were held online using a virtual meeting platform. There were three members of staff present: the facilitator, the moderator and a note-taker. The facilitator informed participants at the start of the focus group that audio would be recorded. The facilitator read an introductory script (see Appendix 13) at the beginning of each focus group. Participants were given the opportunity to ask questions in relation to the information and consent form that had been provided. A standard schedule of questions was used for the focus group discussions, as detailed in section 5.1. After each segment of questions, the moderator summarised the emerging themes and requested validation from participants that it reflected their opinions and was an accurate representation of what they shared. The note-taker took detailed notes of the discussion, but did not record names. Focus groups lasted between 60 and 90 minutes.

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<sup>4</sup> 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.

## **7. Data processing, analysis, and reporting: Focus groups**

### **7.1 Transcription**

Focus group recordings were transcribed within four weeks of the focus group taking place.

### **7.2 Anonymisation**

Any personal information was removed from the focus group notes and transcripts, as detailed in the anonymisation criteria in Appendix 7. Names and other identifiable information of participants were not recorded in the focus group, therefore there are no links to their contact details. It is not possible to attribute specific comments or statements to any individual participant and no individuals can be identified in the focus group results.

### **7.3 Analysis**

Anonymised transcripts were imported to NVivo 12 to facilitate data organisation, management, and analysis. Analysis was undertaken in line with the Framework Method approach.<sup>(2)</sup> Two researchers, who acted as facilitators and moderators at the focus groups, undertook data analysis.

As soon as possible after the focus groups, researchers read each transcript and associated notes to familiarise themselves with the discussions. A coding framework was developed based on initial focus groups, where codes related to substantive points of interest related to the objectives of the research. Developing the coding framework was an ongoing process where codes were adapted, added, or removed based on additional readings of the transcripts. The coding framework was then applied to all transcripts (see Appendix 14). Each transcript was initially coded by one of the researchers and subsequently coded by the other researcher to ensure the framework was applied appropriately. Draft themes were subsequently developed drawing on the relationships between codes. A summary of initial themes was developed, discussed with the wider project team and adapted in line with their feedback. A selection of quotes were chosen to best illustrate each theme and are presented in the findings report.

## **8. Publication of findings: National Public Engagement on Health Information**

The findings of the National Public Engagement on Health Information were published in September 2021. The related documents published include:

- Findings from the National Public Engagement on Health Information
- Technical Report for the National Public Engagement on Health Information
- Responding to the National Public Engagement on Health Information
- The anonymised survey data file.<sup>5</sup>

All published reports and outputs can be downloaded from [www.hiqa.ie](http://www.hiqa.ie).

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<sup>5</sup> Certain variables were redacted from the anonymised survey data file to protect the identities of participants. Further details are provided in the data file.

## **9. Response to findings and next steps**

HIQA will use the findings to develop a set of recommendations on a consent model for the use of health information in Ireland.

The Department of Health will use the findings to inform national policy and strategy in relation to health information.

The findings will be used by the HSE to help them introduce new eHealth and digital technologies to support the health system.

You can read more about what HIQA, the Department of Health and the HSE are going to do in response to the findings in the document 'Responding to the National Public Engagement on Health Information'

## 10. International comparisons

This section briefly outlines public engagements and previous research that have been undertaken in other jurisdictions. It is difficult to make comparisons due to variations in health systems, differences in survey instruments and methods, as well as cultural differences in how health systems are perceived.

A systematic review on public views on the use of patient data in Ireland and the UK found there is general support for the use of personal health information to benefit society through secondary use. However, this needs to be balanced with public awareness of how this information will be stored and processed.<sup>(3)</sup> In the UK, a survey was conducted to explore levels of public awareness about electronic health records and to examine attitudes towards different consent models with respect to sharing identifiable and de-identified health information. The survey found differences in awareness levels and consent expectations between groups with different socio-demographic characteristics.<sup>(4)</sup>

Five examples of public engagements undertaken in different jurisdictions were reviewed in relation to the collection, use and sharing of personal health and social care information. These are:

- National Data Guardian – Review of data security, consent and opt-outs (UK)
- Scottish Health Council – Our Voice Citizens’ Panel (Scotland)
- Canada Health Infoway – Connecting patients for better health (Canada)
- Social Investment Agency – Your Voice, your data, your say (New Zealand)
- Data Futures Partnership, Our Data, Our Way (New Zealand).

The National Data Guardian – Review of Data Security, Consent and Opt-Outs (UK) highlighted the need for more focused and tailored engagement with specific groups including ethnic minorities, Roma, Gypsy and Traveler communities.<sup>(5)</sup>

In 2016, the Scottish Health Council set up Our Voice to ensure that the views of all Scottish people are heard and have an input into health and social care services. Surveys have been carried out with the Our Voice panel on issues including how personal health information is shared and managed and the use of de-personalised health information for research and development.<sup>(6,7)</sup>

Canada Health Infoway conducts research into the benefits of digital health and collects citizens’ perspectives of these initiatives. Infoway regularly commissions research, surveys and focus groups to better understand the areas of patient access that need attention. Its research highlights important issues for policy and decision-makers to consider as jurisdictions move forward with their consumer health strategies.<sup>(8)</sup>

In New Zealand, Our Data, Our Way was implemented over a six-week period in 2017 to test people's preferences and tolerance for data sharing and use, and to examine the measures that need to be in place for them to be comfortable sharing their data.<sup>(9)</sup> The findings indicate that there are practices that will improve the levels of comfort and trust among those individuals providing data as well as within the wider community.

Additionally, in Australia, from March to October 2016, research trials of different participation arrangements for My Health Record were run. The aim of the trials was to understand consumer reaction to different participation arrangements, as well as healthcare provider usage and upload of clinical information to the patients' records, when most of their patients have a My Health Record. The trials also involved a survey and focus groups with the public. The key findings included that there was almost universal support for the automatic creation of electronic health records and that concerns regarding privacy and security are mitigated once the system is explained to the public.<sup>(10)</sup>

## 11. References

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

#### 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) <i>Health Information Quality Manager</i>
Cathy Duggan	Health Information and Quality Authority (HIQA) <i>Health Information Programme Lead</i>
Orla Bruton	Health Information and Quality Authority (HIQA) <i>Health Information Research Officer</i>
Sarah Jane Flaherty	Health Information and Quality Authority (HIQA) <i>Health Information Research Officer</i>
Cathal Collier	Health Service Executive (HSE) <i>Senior Project Manager</i>
Mark Brady	Health Service Executive (HSE) <i>Project Manager</i>
Pauline White	Department of Health <i>Statistician</i>



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

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

## Appendix 2 – Organisations represented in engagement meetings to inform survey development

Organisation
Camphill Communities
College of Psychiatrists of Ireland
Digital Rights Ireland
Faculty of Public Health Medicine
Health Informatics Society of Ireland
Health Research Board
HSE Clinical Dietician Manager
HSE Community Dietetics
HSE Community Services
HSE Disability Strategy and Planning
HSE Mental Health Services
HSE National Immunisation Office
Irish College of General Practitioners
Irish Council for Civil Liberties
Irish Pharmacy Union
National Cancer Control Programme
National Office of Clinical Audit
Tusla

### **Appendix 3 - Key themes identified in engagement meetings to inform survey development**

The key themes identified in the thematic analysis of the notes from the interviews with health and social care professionals and focus groups with HIQA staff to inform the design of the survey were:

- 1.** The importance of health information in health and social care
- 2.** The use of health information for direct patient care
- 3.** The use of health information for purposes beyond direct patient care
- 4.** eHealth and digital technologies for healthcare
- 5.** Consent for the collection, use and sharing of personal health information in Ireland
- 6.** Patient-centred care
- 7.** Integrated care
- 8.** Legislation

## Appendix 4 - 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
<b>identifiable information</b> was included, such as your name and address?	1	2	3	4	5
<b>Non-identifiable information</b> 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
<b>identifiable information</b> was included, such as your name and address?	1	2	3	4	5
<b>Non-identifiable information</b> 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 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 5 - Frequently asked questions (FAQ)**

### **National Public Engagement Survey on Health Information Frequently Asked Questions**

#### **About the survey**

##### **1. What is this survey about?**

This survey is about you and your health information. Health information is information that is recorded when you attend a health or social care professional such as a GP or social worker. The record can include details about your medical conditions, lists of medication you may be taking and also includes personal details such as date of birth. We want to understand what you expect in terms of how your health information is collected, used and shared by health and social care services in Ireland and your opinion on the use of digital technologies in this area. Everyone has a right to know that their personal health and social care information is safe, and is used and shared appropriately in ways that are acceptable to them. We want to understand any concerns you might have about where your information is held, who can see it, and what it is used for.

##### **2. Who is running the survey?**

The survey is being run by the Health Information and Quality Authority (HIQA) in partnership with the Department of Health and the Health Service Executive (HSE). HIQA will also be using a data processor to assist with carrying out this survey.

##### **3. Why is it important?**

The partnership organisations involved in this survey want to understand the expectations of people living in Ireland in relation to their health information. This survey will enable people living in Ireland to voice their opinion on this topic and in doing so provide a rich source of information that will inform national policy and future developments and recommendations in the area of health information, consent and health technology.

##### **4. Why now?**

At the moment, the complexity of Ireland's health and social care structures, with a predominantly paper-based system, makes the collection, use and sharing of health information difficult, particularly across organisations. Part of the aim of the [Sláintecare Implementation Strategy](#) (Ireland's 10-year healthcare plan) is to address these difficulties. This will include the introduction and use of eHealth and digital technologies. Improvements in this area will lead to greater availability of health information, improvements in decision-making and ultimately safer care and better outcomes for patients.

##### **5. Who will be asked to complete the survey?**

The survey will be completed by 1200 people living in Ireland aged 18 and over. To ensure that we include people of all ages who broadly represent the wider population, the statistical technique of selecting a random sample of the population has been chosen. Therefore the study is not open to volunteers of the general public.

## **6. Does the survey comply with data protection laws?**

Yes. The survey complies with all data retention and protection laws including the General Data Protection Regulation (GDPR). A Data Protection Impact Assessment has also been carried out. Further details on data protection are available at [www.hiqa.ie](http://www.hiqa.ie).

## **7. Where can I find the results of the survey?**

The results of the survey will be available on [www.hiqa.ie](http://www.hiqa.ie). You can also sign up to receive the results by emailing [healthdatasurvey@hiqa.ie](mailto:healthdatasurvey@hiqa.ie).

### **For survey participants**

#### **1. What does taking part involve?**

The survey involves answering 32 questions over the telephone with a researcher who will note your answers in an online survey form. It takes approximately 20 minutes to complete.

#### **2. Why should I complete the survey?**

Completing this survey gives you the opportunity to have your opinion heard on this topic and have a meaningful impact on future plans for health information in Ireland including the use of digital technologies and recommendations for the development of a consent model.

#### **3. What types of questions will I be asked?**

You will be asked for your opinion about the use of personal health information for both primary purposes (for your own personal health and social care including diagnosis, care and treatment by health and social care professionals) and secondary purposes (purposes beyond your own diagnosis, care and treatment such as research or service planning). You will also be asked for your opinion about new digital technologies and consent relating to how your health information is used.

#### **4. What will you do with my answers?**

All survey responses will be anonymised. The findings will be published in a report setting out people's opinions about how their health data is collected, used and shared and what changes they would like to see. Results will be made publicly available on [www.hiqa.ie](http://www.hiqa.ie).

#### **5. Will my answers be treated confidentially?**

Yes, your answers will be processed in strict confidence and kept separate from your personal contact details (first name and telephone number). Your answers will be analysed for the purposes of this survey. The answers will not be given to commercial entities or used for commercial purposes. All information gathered during this survey will be managed in line with HIQA's Information Governance and Data Protection policies. For information on how HIQA uses personal data please see the HIQA Privacy Notice: <https://www.hiqa.ie/reports-and-publications/corporate-publication/hiqa-privacy-notice>

## **6. Who will have access to my personal information, where will it be stored and for how long?**

Your personal contact information (first name and telephone number) will be collected by the telephone interviewer and stored securely for quality control purposes for 4 weeks after the completion of the survey. Access to personal information is controlled and is in line with HIQA information governance policies. Once the data quality checks are completed, your personal contact details (first name and telephone number) will be deleted and responses will no longer be linked with your personal contact information. These non-identifiable responses will be kept by HIQA indefinitely. If you request to have additional information on the survey posted to you, your name and address will be collected for this purpose and deleted four weeks after the completion of the survey. For more information on how and where your personal information will be stored, please visit ([dedicated HIQA webpage link](#))

## **7. Where can I find out more?**

To find out more, you can contact us by:

**Email:** [healthdatasurvey@hiqa.ie](mailto:healthdatasurvey@hiqa.ie)

**Postal address:**

National Health Information Survey  
c/o HIQA  
Unit 1301 City Gate  
Mahon  
Cork T12 Y2XT



## Appendix 6 - Participant information leaflet – Survey

### National Public Engagement Survey on Health Information

#### Participant Information Leaflet

This leaflet is intended for members of the public who are taking part in the National Public Engagement Survey on Health Information. The aim of this survey is to understand your opinion about how your health information is collected, used and shared. Taking part in this telephone survey is voluntary. Before you decide whether or not you wish to take part, you may wish to read the information provided below.

#### Why is this telephone survey being done?

The survey is being run by the Health Information and Quality Authority (HIQA) in partnership with the Department of Health and Health Service Executive (HSE).

We want to understand what people living in Ireland expect in relation to how their health information is collected, used and shared.

Your opinions will help to inform national policy and future developments and recommendations in the area of health information, consent and eHealth.

At the moment, Irish healthcare services operate using a mostly paper-based system. This makes the collection, use and sharing of a person's health information between different healthcare services during treatment difficult.

Ireland's 10-year healthcare plan, [Sláintecare](#), aims to address these difficulties with the introduction and use of eHealth and digital technologies. eHealth and digital technologies refers to the use of information and communication technologies for health, for example: electronic health records, patient summaries, patient portals and electronic prescriptions. These new technologies have the potential to lead to greater availability of health information, improvements in decision-making and ultimately safer care and better outcomes for patients.

The information from this survey will be used by HIQA to make recommendations on a consent model for the collection, use and sharing of health and social care information in Ireland. The Department of Health and the HSE will also use this information for informing national policy and future developments in health technology.

#### Who is organising and funding this survey?

HIQA is conducting this survey in partnership with the Department of Health and the HSE. The survey is funded by the partnership organisations.

The survey is being conducted by a market research company, Behaviour and Attitudes, on behalf of HIQA, the Department of Health and the HSE.

#### Why am I being asked to take part?

The survey will be completed by 1,200 people who live in Ireland and are aged 18 years and over. A survey recruitment method called 'random digit dialling' will be used. Both mobile phones and landlines will be called randomly. If you receive a phone call asking you to take part, this means that your phone number was generated at random. The 'random digit dialling' will allow us to ensure that the results of this survey are a true reflection of the Irish public's opinion about the collection, use and sharing of personal health information. The study is not open to volunteers.

You can change your mind about taking part any time you like, even if the survey has started, and you do not need to tell us why.

#### **How will the survey be carried out?**

The telephone survey will begin in October 2020 and will continue until 1,200 survey responses are received. If you receive the call asking you to take part in this survey, you will be asked if you are happy to complete the survey. If you cannot complete the survey when you receive the call, you can request to be called back at a date and time that suits you.

#### **What will happen to me if I agree to take part?**

If you agree to take part in this survey, you will be asked to participate in a 20-minute telephone call. An interviewer will ask you a number of questions in relation to age, gender, region, working status, ethnicity and how often you use Irish health services. These questions help us to make sure that we collect responses from a variety of people with different backgrounds. It is important to collect responses from a variety of different backgrounds to ensure that the survey results are a true reflection of the opinions of all the people living in Ireland. Other questions are designed to help us to understand your views on the collection, use and sharing of health information in Ireland. The interviewer will describe a health related scenario or situation, based on the Irish healthcare system, and will then ask you questions about how you would like your health information to be collected, used and shared in this scenario.

This is a once-off survey. You may receive a follow-up call within four weeks of taking part for quality control purposes. The interviewer will be employed by the managed service (a market research company based in Ireland) and is fully trained in conducting telephone surveys. All information collected will be kept in the strictest confidence and combined results will be reported only. It will not be possible to identify any particular individual in the results and no information that could identify you will be provided to anyone.

#### **Will the phone call be recorded?**

Telephone interviews will not be audio recorded. The interviewer will input your answers to the questions on a computer programme.

#### **What are the benefits?**

Completing this survey gives you the opportunity to have your opinion on the future of health information in Ireland heard. The survey results will have a meaningful impact on future plans for health information in Ireland, including the use of digital technologies and recommendations for the development of a health information consent model.

#### **What are the risks?**

We do not foresee any risks to taking part in this survey. The survey requires your commitment to a 20-minute survey. If we call you at a time that is not suitable to you, we can reschedule the call to a time that suits you. We have taken the necessary steps to ensure your personal information is protected. Further information can be found below in 'Is this survey confidential?'

#### **Is the survey confidential?**

All information collected will be kept in the strictest confidence. The Personal information — your phone number (which has been randomly generated) and your first name, which is asked at the end of the call for quality control purposes — will be kept for four weeks after the survey closes for quality control purposes, before being deleted permanently. Access to survey answers will be restricted to selected individuals. Survey answers will be stored by the managed service and sent securely to HIQA. Survey responses will not include any personally identifiable information. It will not be possible

to identify any particular individual in the survey results and combined results will be reported only. In the event that a survey participant includes personal details in their answers, the interviewer will not record, collect or store this personal information. Merged anonymous survey responses will remain on HIQA's secure server for at least 10 years. If you request to have additional information on the survey posted to you, your name and address will be collected for this purpose and deleted within four weeks after the survey ends. If you would like to find out more or get results, please email [healthdatasurvey@hiqa.ie](mailto:healthdatasurvey@hiqa.ie) for more information.

### Data Protection

You will be asked to give verbal consent before taking part in the survey. Participation is voluntary and you have the right to withdraw from the survey at any time. The information you provide will be used to ensure that the survey includes responses from a variety of people living in Ireland. This will allow us to ensure that the results accurately represent the Irish public's opinion about the collection, use and sharing of personal health information.

We will be processing your personal information under Section (8)(1)(j) of the Health Act 2007. Under Section (8)(1)(j), HIQA has responsibility to provide advice and make recommendations to the Minister and the Executive about deficiencies identified by the Authority.

Initially you will be identified by your telephone number through a random digit dialling process. Your first name will also be asked for at the end of the call for quality control purposes. This personal information will be stored for four weeks after the survey is completed. A file containing non-identifiable survey answers will be stored separately for at least 10 years after the completion of the project.

There will be a four-week period between the closing of the survey and the deletion of first names and telephone numbers. Within this four-week period, participants have the right, should they wish, to review, edit or delete their survey responses. After the four-week period, survey answers will no longer be linked to personal information (first name and phone number) and it will no longer be possible to make amendments or delete to survey responses. If you request to have additional information on the survey posted to you, your name and address will be collected for this purpose and deleted four weeks after the survey ends.

As the data subject, you have the right to:

- request access to your personal data (first name and telephone number) and survey responses and request a copy of same (this will be available for up to four weeks after completion of the survey, after which time the survey answers are no longer linked to personal details [first name and telephone number] and therefore are no longer individually retrievable)
- restrict or object to processing
- have any inaccurate information about you corrected or deleted.
- lodge a complaint with the Data Protection Commission (DPC) if you are unhappy with how your personal data is being used.

Should you have any further queries or should you want to make a complaint you can do so by emailing [healthdatasurvey@hiqa.ie](mailto:healthdatasurvey@hiqa.ie). You may also contact HIQA's Data Protection Officer: [dpo@hiqa.ie](mailto:dpo@hiqa.ie)

**Where can I get further information?**

If you need any further information now or at any time in the future, please contact:

Website: [www.hiqa.ie](http://www.hiqa.ie)

Email: [healthdatasurvey@hiqa.ie](mailto:healthdatasurvey@hiqa.ie)

**Postal address:**

National Public Engagement Survey on Health Information  
c/o HIQA  
Unit 1301 City Gate  
Mahon  
Cork  
T12 Y2XT

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021 2409300

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Head of eHealth & Information Policy, Department of Health

**Consultant co-investigator's name (2):**

Fran Thompson  
Chief Information Officer, HSE

**Data Controller's/joint Controller's Identity:**

Health Information and Quality Authority  
021 2409300

**Data Protection Officer:**

Lydia Buckley  
[dpo@hiqa.ie](mailto:dpo@hiqa.ie)

## Appendix 7 - Anonymisation criteria

The collection of personal identification will be minimised during the survey and focus groups by not recording the following personal information.

If a participant says:	Please record the following:
<b>Names and titles</b> Dr. James Murphy Mr. James Murphy	Remove specific names and record as follows: [Dr. Name] [Mr Name]
<b>Dates and Days &amp; times</b> 28 <sup>th</sup> May 2020 Monday, Tues etc. 09:30	[Date] No redaction No redaction
<b>Religions, Nationality</b> Muslim doctor, Indian etc	[Rel] [Nat] [Eth]
<b>Hospital Names</b> Cork University hospital	Remove specific hospital name and record as follows: [hospital name]
<b>Location identifiers</b> The consultant from Donegal	The consultant from [County]

## Appendix 8 - Factor analysis and segmentation

As part of the analysis of the survey findings, a 'factor analysis' was conducted, which is a statistical technique for identifying which underlying factors are measured by a (much larger) number of observed variables. Eight factors were identified; the relevant factor score is included in brackets:

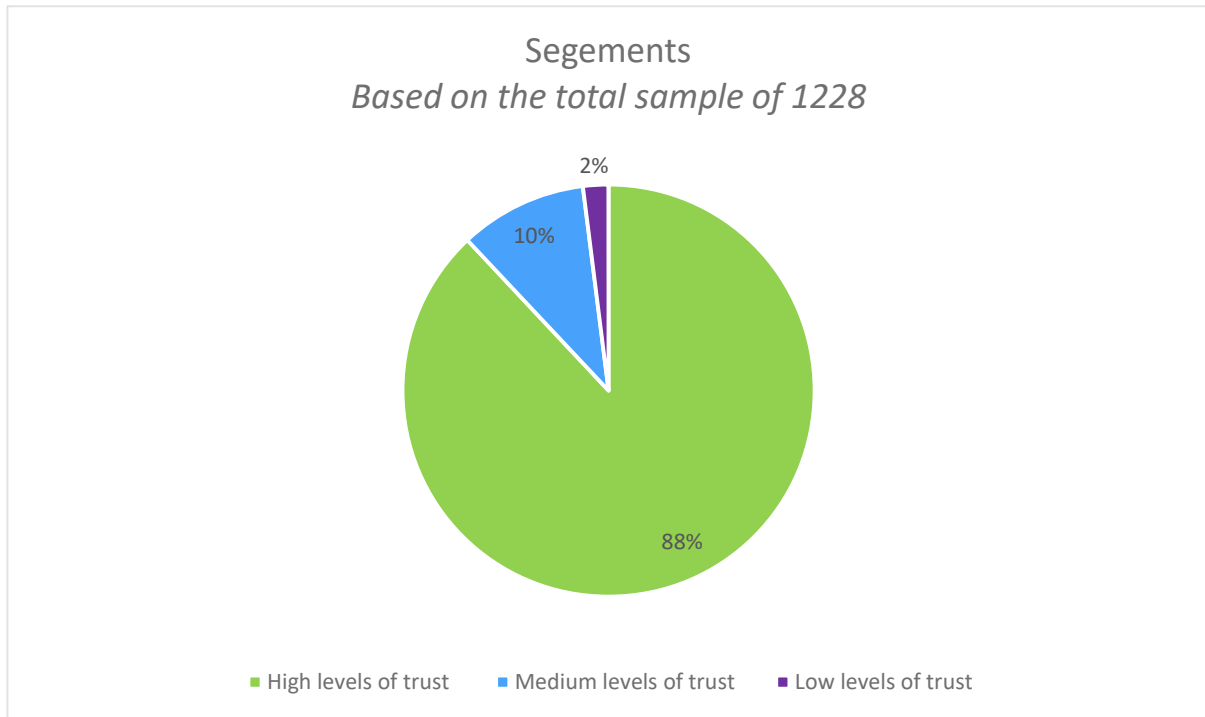
- Trust (0.868)
- Transparency (0.830)
- Identity (0.761)
- Non-Identity (0.750)
- Access (0.747)
- History (0.707)
- Prescription/records (0.528)
- Other healthcare professionals (0.432).

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).



**Table 1:** Segment profiles

		TOTAL	Trust Level		
			Low	Medium	High
<b>Base (unweighted):</b>		<b>1228</b>	<b>27</b>	<b>118</b>	<b>1,083</b>
<b>Gender</b>	<b>Male</b>	49% 601	<b>59%</b> 17	<b>54%</b> 63	<b>48%</b> 521
	<b>Female</b>	51% 623	<b>37%</b> 9	<b>45%</b> 53	<b>52%</b> 561
	<b>Gender fluid</b>	0% 1	- -	<b>1%</b> 1	- -
	<b>Other</b>	0% 1	- -	<b>1%</b> 1	- -
	<b>Prefer not to say</b>	0% 2	<b>4%</b> 1	- -	<b>0%</b> 1
<b>Age</b>	<b>&lt;24</b>	11% 115	<b>5%</b> 1	<b>11%</b> 12	<b>12%</b> 102
	<b>25-34</b>	17% 176	<b>27%</b> 7	<b>22%</b> 21	<b>16%</b> 148
	<b>35-49</b>	33% 419	<b>38%</b> 9	<b>30%</b> 39	<b>33%</b> 371

	<b>50-64</b>	20% 299	<b>17%</b> 6	<b>21%</b> 31	<b>20%</b> 262
	<b>65+</b>	19% 219	<b>13%</b> 4	<b>16%</b> 15	<b>19%</b> 200
<b>Regular healthcare service user</b>	<b>Yes</b>	34% 422	<b>18%</b> 5	<b>29%</b> 37	<b>35%</b> 380
	<b>No</b>	66% 801	<b>82%</b> 22	<b>71%</b> 81	<b>65%</b> 698
<b>Long-term or chronic condition</b>	<b>Yes</b>	20% 257	<b>18%</b> 5	<b>18%</b> 22	<b>21%</b> 230
	<b>No</b>	80% 962	<b>82%</b> 22	<b>82%</b> 95	<b>79%</b> 845
<b>Disability</b>	<b>Yes</b>	6% 69	<b>13%</b> 3	<b>6%</b> 7	<b>5%</b> 59
	<b>No</b>	94% 1153	<b>87%</b> 24	<b>94%</b> 110	<b>95%</b> 119

### 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 their 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 2)
- were less likely to want to know exactly how their information is used beyond their direct care – 44% compared with 47% of total respondents (Table 3)

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 2)
- were more likely to want to know exactly how their information is used beyond their direct care, with 63% wanting this information compared with 47% of total respondents. (Table 3)



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 78% wanting this information compared with 54% of total respondents. (Table 2)
- were more likely to want to know exactly how their information is used beyond their direct care, with 85% wanting this information compared with 47% of total respondents. (Table 3)
- were more likely to have increased comfort if they could view the health information that is held about them. With 84% saying their comfort would be increased a lot compared with 70% of total respondents. (Table 4)

**Table 2:** 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
<i>Base (unweighted):</i>	<i>1227</i>	<i>27</i>	<i>118</i>	<i>1080</i>
I am happy for the healthcare professionals to take care of this	29% <i>385</i>	<b>11%</b> <i>3</i>	<b>12%</b> <i>15</i>	<b>32%</b> <i>340</i>
I would like to know what information will be shared between the GP and hospital	17% <i>205</i>	<b>11%</b> <i>4</i>	<b>13%</b> <i>15</i>	<b>18%</b> <i>186</i>
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% <i>659</i>	<b>85%</b> <i>23</i>	<b>75%</b> <i>88</i>	<b>51%</b> <i>551</i>

**Table 3:** 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
<i>Base (unweighted):</i>	1225	27	118	1080
I am happy for the healthcare professionals to take care of this	23% 283	<b>4%</b> 1	<b>8%</b> 10	<b>26%</b> 272
I would like some general information about how my health information is used and shared	29% 347	<b>11%</b> 3	29% 30	30% 314
As well as general information, I would like to be informed about exactly how my information will be used beyond my direct care	47% 595	<b>85%</b> 23	<b>63%</b> 78	<b>44%</b> 494

**Table 4:** 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
<i>Base (unweighted):</i>	1228	27	118	1083
5 – Would increase my comfort a lot	70% 874	<b>84%</b> 22	<b>63%</b> 75	<b>71%</b> 777
4 – Would increase my comfort	16% 192	<b>7%</b> 2	<b>23%</b> 26	<b>15%</b> 164
3 – Not sure	9% 106	- -	<b>9%</b> 10	<b>9%</b> 96

2 – Would not increase my comfort	1%	-	<b>1%</b>	<b>1%</b>
	<i>14</i>	-	<i>1</i>	<i>13</i>
1 – Would not increase my comfort	3%	<b>9%</b>	<b>4%</b>	<b>3%</b>

## Appendix 9 - Coding framework for open-ended responses

### **QS1Q8**

**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?**

1. None
2. If the healthcare professional knows me personally
3. If information is included that is not relevant to the healthcare professional it is being shared with
4. If it is shared with healthcare professionals who are not involved in my care
5. If sensitive information is included, for example photographs, mental health, sexual health, addiction, terminal illness
6. If information is not kept securely and kept confidential
7. If I have not given consent for it to be used
8. If it will be used by a pharmaceutical company
9. If it will be used by my employer or potential future employers
10. If it will be used by insurance companies
11. If it will be used for profit, by marketing companies or commercial companies
12. If it will be used outside the Irish Healthcare system
13. Other

### **S2Q10**

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

1. None
2. If someone who knew me personally would see my personal information If sensitive information is included, for example photographs, mental health, sexual health, addiction, terminal illness
3. If information is not kept securely and kept confidential
4. If I have not given consent for it to be used
5. If it will be used by a pharmaceutical company
6. If it will be used by my employer or potential future employers
7. If it will be used by insurance companies
8. If it will be used for profit, by marketing companies or commercial companies
9. If it was personally identifiable

10. If it will be used for purposes that are against my beliefs, for example religion, animal testing or organ/blood donation
11. If it will be used outside the Irish Healthcare system
12. If it's not for my direct care, then it shouldn't be used at all.
13. No, I would be happy for it to be used if it is for the greater good
14. Other

**S3Q4a**

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

1. None
2. Mental health issues
3. Sexual health issues including STI's and men and women's reproductive issues
4. Sexual orientation/gender reassignment
5. Pregnancy / termination
6. Fertility treatment/Reproductive help
7. Addiction issues - drug/drink
8. Illegal drug use
9. Social care information
10. Any personal details - name, address etc./Access to the contact details of the person's relatives
11. Any information not relevant to care
12. Genetic conditions and genetic information
13. Any type of abuse including mental/physical/domestic abuse/sexual assault
14. Religion
15. Cosmetic surgery/cosmetic enhancements
16. HIV status
17. Other

**S3Q7a**

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

1. No
2. It is important that my records are processed in line with GDPR/security of the records
3. I would like to be able to view my own record
4. I would like to be able to see a list of who has viewed my record
5. I would like to be able to control who can see my record
6. I would like to be able to control what information is contained in my record
7. It will definitely help speed up the healthcare system in Ireland/good initiative
8. Only the relevant healthcare professionals who are treating me should have access to the record
9. I would not like people who know me personally to have access to my records
10. Unnecessary information should not be passed on to other healthcare professionals/Only information relevant to my care be permitted
11. I would not like my information to be shared with pharmaceutical companies
12. I would not like my information to be shared with insurance companies
13. I would not like my information to be shared with current or potential employers
14. I would not like information to be shared with other third parties who may use it for marketing or commercial purposes
15. I would not like to see a diagnoses before it has been explained to me by a healthcare professional
16. More comfortable with paper records/keep paper records for backup in case of system issues
17. Other

**S3Q10**

**Do you have any additional comments in relation to electronic medical records?**

1. No
2. Information governance including access, security and data protection (GDPR), how long it is stored for
3. It is important that my records are processed in line with GDPR
4. I would like to be able to view my own record
5. I would like to be able to see a list of who has viewed my record
6. I would like to be able to control who can see my record

7. I would like to be able to control what information is contained in my record
8. It will definitely help speed up the healthcare system in Ireland/good initiative
9. Only the relevant healthcare professionals who are treating me should have access to the record
10. I would not like people who know me personally to have access to my records
11. Unnecessary information should not be passed on to other healthcare professionals/Only information relevant to my care be permitted
12. I would not like my information to be shared with pharmaceutical companies
13. I would not like my information to be shared with insurance companies
14. I would not like my information to be shared with current or potential employers
15. I would not like information to be shared with other third parties who may use it for marketing or commercial purposes
16. I would not like to see a diagnoses before it has been explained to me by a healthcare professional
17. More comfortable with paper records/keep paper records for backup in case of system issues
18. Only the relevant healthcare professionals that are treating me, can alter my records
19. Other

## Appendix 10 - Topic guide – focus group

### **Question 1**

The survey found that people overall have more trust in GPs, than in hospitals and community healthcare professionals, when it comes to keeping their health information safe and secure. Would that be your feeling too?

Prompts:

- How important do you think it is that healthcare professionals have access to your health information when they are providing you with care?
- What would increase your trust in healthcare professionals who handle your personal health information?
- What would make you less confident in a healthcare professional who is handling your health information?
- How would you like to be informed about how your health information is kept safe and secure?

### **Question 2**

What would increase your trust when it comes to the use of health information for purposes beyond your direct care, such as service planning, quality improvement and research?

Prompts:

- Do you have any concerns about health information being used for purposes beyond direct care?
- Can you see the benefits to using HI in this way?
- What are your thoughts on sharing your health information (for uses beyond your direct care) when it contains identifiable information (such as your name and address)?
- Public/private

### **Question 3**

The survey found that people think it is important for healthcare professionals to have access to their full electronic medical record, but some people were concerned about information being shared that wasn't relevant (example broken leg, sexual health history). What are your thoughts on this?

Prompts:

- Would you have concerns about the introduction of electronic health records?
- What types of information would you be less happy to share?
- Would you like to be able to access your own information online eg portal? Any concerns about this?
- Would you like to be able to view who has accessed your health information?
- Would you like to have more control over what information is shared?
- Would you like to be able to see what information is held about you?  
(i.e. *focus on solutions that could be put in place here?*)

### **Question 4**

Does anyone have any additional comments that they would like to add about this topic?



## Appendix 11 - Participant Information Leaflet – Focus Groups

### Public Engagement Focus Group on the collection, use and sharing of personal health information in Ireland

<b>Data Controller's/joint Controller's Identity:</b>	HIQA. C/O Rachel Flynn
<b>Data Controller's/joint Controller's Contact Details:</b>	HIQA, Unit 1301 City Gate, Mahon, Cork T12 Y2XT
<b>Data Protection Officer's Identity:</b>	Lydia Buckley
<b>Data Protection Officer's Contact Details:</b>	dpo@hiqa.ie

The Health Information and Quality Authority (HIQA) in partnership with the HSE and the Department of Health has recently conducted a national survey on the collection, use and sharing of personal health information. This nationwide survey asked people living in Ireland about their views on the collection, use and sharing of their personal health and social care information.

You are being invited to take part in a focus group (a small group that meets to discuss a topic) to further explore this topic. The focus group will take place online using Zoom and will be run by HIQA staff.

Before you decide whether or not you wish to take part, you should read the information provided below carefully. Take time to ask questions – don't feel rushed and don't feel under pressure to make a quick decision.

You should clearly understand the risks and benefits of taking part in this focus group so that you can make a decision that is right for you. This process is known as 'Informed Consent'.

You don't have to take part in this focus group. You can change your mind about taking part in the focus group any time you like. Even if the focus group has started, you can still opt out. You don't have to give us a reason.

#### Why is this focus group being conducted?

We will be holding focus groups with:

- Members of the public
- Patient representatives
- Representatives of special interest groups

These focus groups will aim to get a deeper understanding of the results from the recent National Public Engagement Survey on Health Information. The survey was conducted to gather the views of the Irish public on the collection, use and sharing of personal health information. By conducting focus groups with these important stakeholders, HIQA, the Department of Health and the HSE will be assured that the results of the survey are an accurate representation of the Irish people's opinion on the collection, use and sharing of health information. These focus groups will investigate the accuracy of the survey results as well as adding to the overall findings of this survey.

#### Who is organising and funding this focus group?

The Health Information and Quality Authority (HIQA) is conducting this focus group. The survey is funded by the partnership organisations (HIQA, the Department of Health and the Health Service Executive (HSE)).

#### **Why am I being asked to take part?**

We want to gain a deeper understanding of the survey results and to do this, we need to fully understand the views of the public, patients and special interest groups. You are being asked to take part in this focus group as a member of or a representative of [insert group].

#### **How will the study be carried out?**

Focus groups will be carried out in line with HIQA approved methods for conducting focus groups. Focus groups will take place in [insert date] and will last for approximately 60 minutes. There will be 4-8 participants and there will be 2-3 focus group facilitators present. Focus groups (small discussion groups) are a forum where a facilitator asks questions to start a discussion on a certain topic. The focus groups will take place on-line using Zoom video conferencing application.

#### **What will happen to me if I agree to take part?**

You will be asked to attend a focus group with 4-8 of your peers for approximately 60 minutes. The focus groups will take place online. You will be expected to take part in a discussion about your views in relation to the collection, use and sharing of health information. You will need to fill in a consent form before taking part.

#### **Video/and or Audio recordings?**

The audio from the focus groups will be recorded. Video will not be recorded. The audio recording will be used for the specific purpose of writing up detailed notes from the focus group. Recordings will be deleted as soon as the written notes have been completed, this will be completed within 4 weeks of the focus group.

#### **What are the benefits?**

Taking part in this focus group gives you the opportunity to have your opinion heard on this topic. It also allows you to have a meaningful impact on future plans for health information in Ireland, including the use of digital technologies and recommendations for the development of a health information consent model.

#### **What are the risks?**

We do not foresee any risks in taking part in these focus groups. The focus groups will run for approximately 60 minutes. We will try to make sure that focus group times and locations are suitable to you. No personal information about you will appear in the focus group findings.

#### **Is the study confidential?**

All information that we collect will be kept in the strictest confidence and results will be reported at a merged level only. Focus group notes will be stored securely on HIQA servers. There will be restricted access to these files. It will not be possible to identify any particular individual in the focus group notes and no information will be provided to anyone that could identify you. Personal contact details (name, email address and telephone number) are kept separate from focus group notes, and will be deleted once the focus group has been completed. Focus group notes will be deleted 5 years after the completion of the project. Focus groups notes will not include any personally identifiable information. If you would like to find out more or get results, please email [healthdatasurvey@hiqa.ie](mailto:healthdatasurvey@hiqa.ie) for more information.

### Data Protection

We will be using your personal information to make contact with you regarding date, time and location of focus groups. Personal contact details (name, email address and telephone number) will be deleted once the focus group has taken place. Your personal opinion on health information will be audio recorded and transcribed into detailed notes. These notes will not contain your personal contact details (name, phone number etc.). Access to these notes will be restricted. Notes will be deleted 5 years after publication of results. You will be asked to give consent before taking part in this focus group. Participation is voluntary and you have the right to withdraw from the focus group at any time.

We will be processing your personal information under Section (8)(1)(j) of the Health Act 2007. Under Section (8)(1)(j) the Health Information and Quality Authority has responsibility to provide advice and make recommendations to the Minister and the Executive about deficiencies identified by the Authority.

As the data subject you have the right to

- request access to your personal data and a copy of it (this will be available for up to four weeks after completion of the survey, after which time the survey answers are no longer linked to personal details and therefore are no longer individually retrievable)
- restrict or object to processing
- have any inaccurate information about you corrected or deleted
- lodge a complaint with the Data Protection Commission (DPC).

Personal information will be processed in line with HIQA information governance policies. For more information on our data breach policy, please see [www.hiqa.ie](http://www.hiqa.ie).

Should you have any further queries or should you want to make a complaint you can do so by emailing [healthdatasurvey@hiqa.ie](mailto:healthdatasurvey@hiqa.ie). You may also contact HIQA's Data Protection Officer if you wish to do so: [dpo@hiqa.ie](mailto:dpo@hiqa.ie)

### Where can I get further information?

If you need any further information now or at any time in the future, please contact:

**Email:** [healthdatasurvey@hiqa.ie](mailto:healthdatasurvey@hiqa.ie)

**Postal address:**

National Health Information Survey  
c/o HIQA  
Unit 1301 City Gate  
Mahon  
Cork  
T12 Y2XT

## Appendix 12 - Consent form for focus groups

<b>Focus group to inform recommendations on the collection, use and sharing of health and social care information.</b>		
I have read and understood the <b>Participant Information Sheet</b> about this focus group. The information has been fully explained to me and I have been able to ask questions, all of which have been answered to my satisfaction.	<b>Yes</b> <input type="checkbox"/>	<b>No</b> <input type="checkbox"/>
I consent to the collection, use, and storage of my personal data for the purposes of conducting the focus groups	<b>Yes</b> <input type="checkbox"/>	<b>No</b> <input type="checkbox"/>
I consent to the use of audio recording of focus groups	<b>Yes</b> <input type="checkbox"/>	<b>No</b> <input type="checkbox"/>
I understand that I don't have to take part in this focus group and that I can opt out at any time. I understand that I don't have to give a reason for opting out.	<b>Yes</b> <input type="checkbox"/>	<b>No</b> <input type="checkbox"/>
I am aware of the potential risks and benefits of this focus group.	<b>Yes</b> <input type="checkbox"/>	<b>No</b> <input type="checkbox"/>
I have been assured that information about me will be kept private and confidential.	<b>Yes</b> <input type="checkbox"/>	<b>No</b> <input type="checkbox"/>
I have been given a copy of the Participant Information Sheet and this completed consent form for my records.	<b>Yes</b> <input type="checkbox"/>	<b>No</b> <input type="checkbox"/>
I consent to take part in this focus group having been fully informed of the risks and benefits.	<b>Yes</b> <input type="checkbox"/>	<b>No</b> <input type="checkbox"/>
I give informed explicit consent to have my data processed as part of this research study.	<b>Yes</b> <input type="checkbox"/>	<b>No</b> <input type="checkbox"/>
I consent to be contacted by researchers as part of this research study.	<b>Yes</b> <input type="checkbox"/>	<b>No</b> <input type="checkbox"/>

Participant Name (Block Capitals) \_\_\_\_\_

Participant Signature \_\_\_\_\_

Date \_\_\_\_\_

## Appendix 13 - Introductory script for focus groups

### Managed Service:

Good Morning/afternoon/evening my name is [insert name] and I work for [managed service name], an independent research company who are providing support to Department of Health, the HSE and the Health Information and Quality Authority on a project relating to the collection, use and sharing of health information.

### **OR**

### HIQA:

Good Morning/afternoon/evening my name is [insert name] and I work for the Health Information and Quality Authority (HIQA). We are working in partnership with the Department of Health and the HSE to gather information on people's opinion and attitudes surrounding the collection and sharing of personal health information.

The purpose of this focus group is to listen to your views on this topic. The focus group should take around one hour. Thank you for completing and returning the consent form in advance of today. You also received a copy of the Participant Information Leaflet. Do you have any questions about the leaflet, or this focus group before we get started?

The focus group will be conducted in line with HIQA's Focus Group protocol. All information collected will be kept in the strictest confidence. This focus group will be audio recorded. Your name and contact details are kept separate from these notes. Any comments you make today will not be linked to your name. It will not be possible to identify any particular individual in the findings and no information will be provided to anyone that could identify you. Personally identifiable data (name and contact details) will be deleted, once this focus group is over. Participation is voluntary and you have the right to withdraw from the focus group at any time. Should you have any further queries, or should you want to make a complaint, you can do so by emailing [healthdatasurvey@hiqa.ie](mailto:healthdatasurvey@hiqa.ie) or in writing to HIQA.

### **Ground rules**

- Introductions (HIQA staff)
- Focus group is confidential we ask that you do not repeat what you hear today
- Each person's voice is important we will try to make sure each person gets a change to speak
- Put up your hand and we will try to come to you

## **Appendix 14 - Coding framework for focus groups**

### **1. Direct patient care**

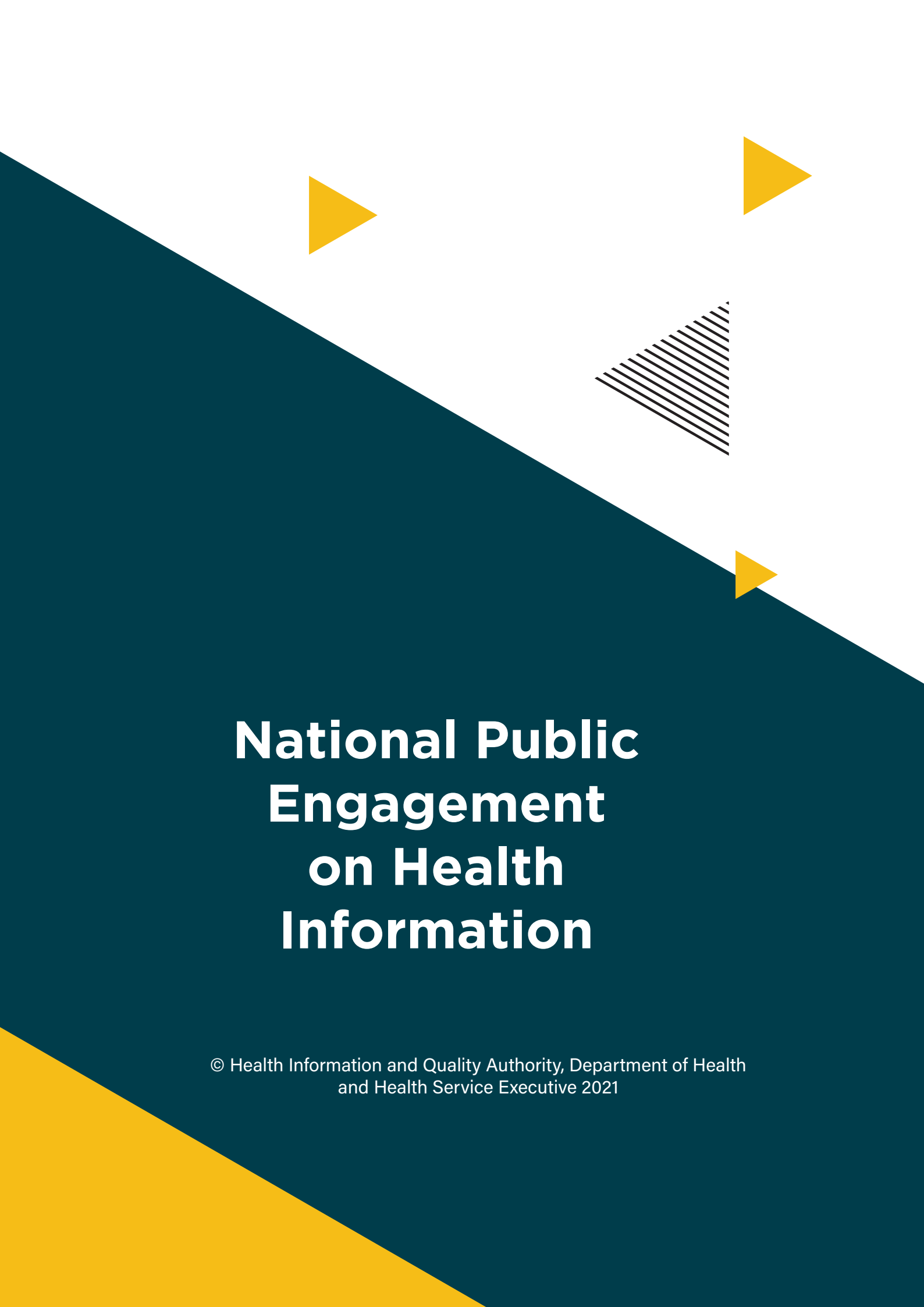
1. Trust/comfort
  - a. How to improve trust/comfort
  - b. Discrimination
  - c. Other
2. Access to own data/Ownership of the data
3. Sharing relevant data
4. HCPs having access to health information when needed
5. Sensitivity of some types of information
6. Privacy, confidentiality and security of data
7. The need for more integrated care
8. Concerns with using/sharing data for direct patient care
  - a. Only HCPs involved in a person's care should access their record
  - b. Someone who knows them personally accessing their information
  - c. Other
9. Informing people about how health information is collected/used/shared/stored
  - a. Consent
  - b. Control
  - c. Other
10. Benefits of health information being shared for direct patient care
11. Peoples experiences on the use of health information for direct patient care

### **2. Use of health information beyond direct patient care**

1. Trust/comfort
  - a. How to improve trust/comfort
  - b. Discrimination
  - c. Other
2. Access to own data/Ownership of the data
3. Use of identifiable/non-identifiable information
4. Sensitivity of some types of data/information
5. Use of data for research purposes
6. Use of data for service planning/quality improvement
7. Data being used by private organisations
8. Privacy, confidentiality and security of data
9. Not willing to share data for purposes beyond their direct care
10. Concerns with using/sharing data for purposes beyond direct patient care
11. Informing people about how health information is collected/used/shared/stored
  - a. Consent
  - b. Clarity about intended use of health data
  - c. Other
12. Benefits of health information being shared for purposes beyond direct patient care
  - a. Sharing for the greater good
  - b. Other
13. Peoples experiences of the use of health information for purposes beyond direct patient care

### **3. Digital records**

1. Trust/comfort
  - a. How to improve trust/comfort
  - b. Discrimination
  - c. Other
2. Access to own data (via portal or similar)/ownership of data
3. HCPs treating you having access to data electronically
4. Relevant/Non-relevant data being included in electronic record
5. Sensitivity of some types of data/information
6. Privacy, confidentiality and security of data
7. The need for more integrated care
8. Health and e-literacy
9. Concerns about the introduction of electronic records
  - a. HCPs not involved in your care accessing electronic record
  - b. Prefer not to share information with a HCP who knows them personally
  - c. Other
10. Informing people about how health information is collected/used/shared/stored
  - a. Consent
  - b. Control
  - c. Being able to view who has accessed record
  - d. Being able to control who can access record
  - e. Being able to control what is contained in record
  - f. Other
11. Benefits/perceived benefits of introducing digital records



# National Public Engagement on Health Information

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