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

Health Information
and Standards

Summary Report: Data Protection Impact Assessment (DPIA) for the National Public Engagement Survey on Health Information

September 2020

About the Health Information and Quality Authority (HIQA)

The Health Information and Quality Authority (HIQA) is an independent statutory authority established to promote safety and quality in the provision of health and social care services for the benefit of the health and welfare of the public.

HIQA's mandate to date extends across a wide range of public, private and voluntary sector services. Reporting to the Minister for Health and engaging with the Minister for Children and Youth Affairs, HIQA has responsibility for the following:

- **Setting standards for health and social care services** — Developing person-centred standards and guidance, based on evidence and international best practice, for health and social care services in Ireland.
- **Regulating social care services** — The Chief Inspector within HIQA is responsible for registering and inspecting residential services for older people and people with a disability, and children's special care units.
- **Regulating health services —** Regulating medical exposure to ionising radiation.
- **Monitoring services** — Monitoring the safety and quality of health services and children's social services, and investigating as necessary serious concerns about the health and welfare of people who use these services.
- **Health technology assessment** — Evaluating the clinical and cost-effectiveness of health programmes, policies, medicines, medical equipment, diagnostic and surgical techniques, health promotion and protection activities, and providing advice to enable the best use of resources and the best outcomes for people who use our health service.
- **Health information** — Advising on the efficient and secure collection and sharing of health information, setting standards, evaluating information resources and publishing information on the delivery and performance of Ireland's health and social care services.
- **National Care Experience Programme** — Carrying out national service-user experience surveys across a range of health services, in conjunction with the Department of Health and the HSE.

Background to the National Public Engagement Survey on Health Information

A major challenge for health and social care services in Ireland today is striving to achieve an appropriate balance between the protection of personal health information, and the use and sharing of such information to improve care. The complexity of Ireland's healthcare structures, with a predominantly paper-based system, makes the use and sharing of patient records difficult, particularly across different health and social care settings. Advances in eHealth and digital technologies have the potential to improve the quality of care provided to patients and promote organisational efficiency. The term 'eHealth and digital technologies' refers to the delivery and improvement of healthcare services, through the use of the internet and other online technologies. EHealth systems are an important feature in safe, effective, modern healthcare. EHealth can include electronic prescribing, electronic health records and the online exchange of health information between different services that provide care to patients. However, it is important to ensure that individuals are fully informed about the use of their data. Individuals should have a good understanding of how their data will be used and who will have access to their data. Every individual should feel confident that their personal data and information will be used and protected appropriately.

HIQA promotes safety and quality in the provision of health and social services for the benefit of the health and welfare of the public. HIQA's remit under the Health Act 2007 includes evaluating available information on health services and the health and welfare of the population. Based on this information, HIQA identifies potential deficiencies, provides advice and makes recommendations to the Department of Health and the HSE. HIQA is currently developing a set of recommendations on a consent model for the collection, use and sharing of personal health information. In order to inform these recommendations, HIQA is working in partnership with the Department of Health and the HSE to engage with the public on this topic. The National Public Engagement Survey on Health Information includes both a national telephone survey and a series of focus groups with the public, patient representatives and with special interest groups.

This National Public Engagement Survey on Health Information is a way of engaging with people living in Ireland and hearing their opinions and attitudes relating to the collection, use and sharing of personal health information. The key objective is to listen to the voice of the public, understand the findings, and make measurable improvements to how personal health information is collected, used and shared in Ireland.

People aged 18 years and over, living in Ireland will be invited to take part in the telephone survey. The sample of participants will be a broad representation of the population of Ireland. A representative sample of 1200 people living in Ireland will be included to provide a greater understanding of the general public's attitudes on:

- the use of personal health information for both direct patient care, and for 'secondary purposes', such as service planning, quality improvement and healthcare management
- how individuals would like to be asked for consent, in relation to how their personal health information is shared
- levels of acceptance individuals have in relation to new digital technologies in healthcare, such as electronic health records, electronic patient summaries and patient portals

- levels of trust individuals have in healthcare professionals, organisations and Government in relation to safeguarding their personal health information.

The survey will provide meaningful, quantitative and qualitative data, however, in order to get a more in-depth understanding of the issues that arise, it will be necessary to hold follow-up focus groups with the public, patient representatives and special interest groups. These will be held once the data for the telephone survey has been collected and analysed.

The findings of the National Public Engagement Survey on Health Information will be made available on www.hiqa.ie.

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1. Purpose of this document

This document summarises the findings of a Data Protection Impact Assessment (DPIA). The DPIA was carried out to identify and mitigate risks that survey and focus group participants who will be invited to take part in the National Public Engagement Survey on Health Information may encounter.

2. Why is it important to do a DPIA?

When personal, sensitive and special category data is processed, a DPIA must be carried out to identify and mitigate risks to the privacy of data subjects.

To carry out the National Public Engagement Survey on Health Information, HIQA will process the data of survey and focus group participants. 1,200 people will take the survey over the phone and a further 24 to 48 people will participate in focus groups.

A DPIA is necessary to ensure that all risks to the privacy of survey and focus group participants are identified and appropriate safeguards are put in place.

3. What is the legal basis for processing data?

The National Public Engagement Survey on Health Information complies with data protection laws, including the General Data Protection Regulation (GDPR) 2016. As per Article 6 (1) (a) of the GDPR, survey and focus group participants will be explicitly asked to provide their informed consent for the processing of their information.

The National Public Engagement Survey on Health Information aligns with HIQA's remit under Article 8 (1) of the Health Act 2007. This is to provide advice and make recommendations about deficiencies identified in information gathered on health services and the general health and welfare of the population.

4. Roles and responsibilities

HIQA is the data controller for data processed as part of the National Public Engagement Survey on Health Information. HIQA has contracted an external data processor, Behaviour and Attitudes. The data processor is responsible for the administration of the telephone survey and public focus groups, further information on which is provided in section 5, Lifecycle of the National Public Engagement survey data.

5. Lifecycle of the National Public Engagement Survey data

This section provides an overview of the lifecycle of the data collected to conduct the National Public Engagement Survey on Health Information.

Stage one: To source telephone survey participants, telephone numbers will be generated at random and tested to ensure that they are live. Following that, an interviewer will call the number and:

- apply the eligibility criteria by ensuring that the potential survey participant who has answered the call is 18 years of age or over
- provide information on the aims and conduct of the survey
- ask the potential survey participant if they would like to participate and if they consent to their data being processed.

Stage two: Survey participants provide information about themselves, such as their age and occupation, and provide feedback on a number of scenario-based questions.

Stage three: Participants responses are securely uploaded and stored in a participant response file. Participants responses are stored separately to survey participants contact details.

Stage four: Focus groups will take place with members of the public, patient representatives and representatives of special interest groups. Potential focus group participants will be:

- provided with information on the aims and conduct of the survey
- asked if they would like to participate and if they consent to their data being processed.

Stage five: The findings of focus groups are then combined with the findings of the survey responses. The findings are analysed and a report is published.

Stage six: A data retention and a destruction schedule is implemented. The contact details of telephone survey participants will be destroyed within 4 weeks of the survey closing. The contact details of focus group participants will be destroyed immediately after the focus group meetings. The anonymised responses of the survey are retained by HIQA indefinitely and the focus groups notes are retained by HIQA for five years following the publication of the report. The data processor will securely transfer the responses from the suvey and the public focus group notes to HIQA and will delete same from their servers by 30 June 2021.

6. Methodology to conduct the DPIA

The DPIA was conducted as per the steps outlined in the Privacy Impact Assessment toolkit for health and social care, developed by HIQA. The steps were as follows:

Step one: A threshold assessment was conducted. A threshold assessment is a short, initial assessment of a project to determine if a DPIA is required. GDPR states that a DPIA is required when any personal data is processed. Conducting the National Public Engagement Survey on Health Information involves processing personal information, for example, first names, telephone numbers and survey responses of telephone survey participants, therefore, a DPIA is required.

Step two: A data map is developed. The data map outlines the journey the data takes from its point of collection through to its use, distribution and destruction. It is used to identify potential risks to personal information throughout the data's lifecycle. Key stakeholders, such as staff who process the data, the Public Engagement Steering Group and representatives of people using services are consulted and involved in identifying risks.

The DPIA must also determine if the data processing is necessary and proportionate. This means that data should only be collected if the data has a specific use and if there is no other and less intrusive way to collect and process the data. For example, questions used in the telephone survey and focus groups are assessed to ensure that they are both relevant and that the answers will be used to make measurable improvements in how personal health information is collected, used and shared in Ireland.

Step three: With the input of stakeholders, controls are identified and put in place to reduce the risks as identified in step two. For example, to reduce the risk that individuals may disclose unsolicited, sensitive, health information to HIQA via healthdatasurvey@hiqa.ie (as outlined in risk number three in section 6.1 of this document), three controls were identified:

- HIQA does not request personal data from members of the public who contact them
- HIQA receives emails on secure, encrypted, password protected devices
- HIQA deletes all emails at the end of the survey.

A risk rating from 1 to 25 is then assigned to each risk, to determine the severity of the risk, 1 being the lowest rating and 25 being the highest, as per Table 1 in section 7. For example, the risk that consent is not explained adequately to participants and that they are not provided with the correct information to make an informed decision about participating in the survey (as outlined in risk number four in section 6.1 of this document) represents a low risk and therefore receives a risk rating of 4.

Step four: The DPIA report is produced. The report is reviewed by senior management and approved by the Director of Health Information and Standards, and this directorate will implement the survey.

Step five: The findings of the DPIA are incorporated into the project plan, to ensure that all controls are put in place. For example, the timelines for data destruction are incorporated into the project plan.

7. Overview of risks

The DPIA identified 5 risks, which are summarised below. The safeguards put in place to mitigate the risks are also summarised in this section. Each risk is assigned a risk rating on the basis of the matrix in Table 1 below. This matrix combines the likelihood of harm to a data subject, based on a scale of 1 to 5, with the severity of harm caused to the data subject, also based on a scale of 1 to 5. For instance, a risk that is almost certain to occur but only bears negligible consequences to a data subject's privacy would be assigned a rating of 5.

Table 1: Risk matrix

	Likelihood →				
Impact ↓	Rare 1	Unlikely 2	Possible 3	Likely 4	Almost certain 5
Negligible 1	1	2	3	4	5
Minor 2	2	4	6	8	10
Moderate 3	3	6	9	12	15
Significant 4	4	8	12	16	20
Substantial 5	5	10	15	20	25

Low (1-7) **Medium (8-14)** **High (15-25)**

7.1 Risks and controls

This section provides an overview of five risks identified in the DPIA and the controls put in place to mitigate each risk.

Risk 1: Data breach

There is a risk that during the collection, retention, transfer and the possible destruction of data, that personally identifiable or sensitive data could be breached.

Controls

The following controls will be put in place:

- information governance training will be provided for staff responsible for collecting, handling and analysing data
- a data retention and destruction schedule will be applied to ensure that data is only retained for the minimum amount of time necessary
- a data breach management procedure will be developed and followed by staff
- any transfer of data is conducted securely with end-to-end encryption
- a data processing agreement and non-disclosure agreement is in place with the data processor.

Risk-rating: 6 (unlikely/moderate) – this represents a low risk.

Risk 2: Non-adherence to processes and procedures

There is a risk that data processing activities are not conducted in line with agreed policies and procedures, for example, the data is not destroyed in line with the retention and destruction schedule.

Controls

HIQA:

- has put in place a contract with the data processor, which includes a non-disclosure agreement and a data processing agreement. HIQA has oversight of any sub-processors used by the data controller, including contractual obligations and the conduct of audits. The contract authorises and defines data processing activities that are necessary to administer the survey and focus groups
- has agreed information governance policies and procedures in place to ensure that all legislative requirements, such as those outlined in GDPR are met
- oversees the provision of information governance training for all staff who process data
- holds routine meetings with the data processor to ensure that all actions are completed
- oversees a project plan for the data processor
- has developed and oversees the implementation of a data retention and destruction schedule
- stores all information collected as part of the National Public Engagement Survey on Health Information securely
- arranges for the secure transfer of any data processed as part of the National Public Engagement Survey on Health Information
- limits access to data only to staff who will directly process data.

Risk-rating: 6 (possible/minor) – this represents a low risk.

Risk 3: Receipt of sensitive health information via healthdatasurvey@hiqa.ie

There is a risk that individuals may disclose unsolicited sensitive information about their healthcare to the HIQA via healthdatasurvey@hiqa.ie.

Controls

HIQA:

- does not request personal data from members of the public who contact them
- receives emails on secure, encrypted, password-protected devices
- deletes all emails at the end of the survey.

Risk-rating: 6 (unlikely/moderate) – this represents a low risk.

Risk 4: Transparency and consent

There is a risk that consent is not explained adequately to participants and they are not provided with the correct information to make an informed decision to participate.

Controls

HIQA:

- has developed a telephone script for staff to use when inviting participants to take the survey over the telephone
- provides all focus group and survey participants with information about how their data will be processed, if they choose to participate
- asks for the consent of all survey and focus group participants and facilitates an opt-out of the survey
- ensures that all communication for public distribution is accessible and adheres to the National Adult Literacy Association (NALA) guidelines on plain English
- provides an online Frequently Asked Questions (FAQ) leaflet and participant information leaflet, outlining details of the project, including its data-processing activities and information governance on www.hiqa.ie. Participants can request that the information be sent to them in the post
- adheres to HIQA's Data Subject Access Request and procedure policy.

Risk rating: 4 (unlikely/minor) – this represents a low risk.

Risk 5: Recording of sensitive information

There is a risk that those conducting the focus groups and survey will accidentally transcribe personal information that is not required or sought by the survey or focus groups.

Controls

HIQA:

- develops and approves all content for focus groups and for the survey to gather participant's perceptions on the use of health information, to avoid soliciting personal, sensitive and or extraneous information
- develops and applies anonymisation criteria for the qualitative survey responses, in the event that participants provide sensitive information. The criteria ensure that personal identifiers are removed and the privacy of all individuals is protected
- only collects combined data from the focus groups, that is the general and high level responses of focus groups. Names and other identifiable information of participants are not recorded, therefore removing any link to their contact details.

Risk-rating: 2 (rare/minor). This represents a low risk.

8. Next steps

This document reflects the feedback from all stakeholders in relation to identified risks for the National Public Engagement Survey on Health Information and will be published on www.hiqa.ie.

Published by the Health Information and Quality Authority (HIQA).

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