



DATA PRIVACY IMPACT ASSESSMENT

2022 IPPOSI CITIZENS' JURY ON 'GENOMICS'

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Background

Why is it important to do a DPIA?

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

To carry out the Citizens' Jury on Genomics, IPPOSI will process the data of survey and jury participants. It is expected that approximately 1,000 people will complete the initial application form on MS teams and a further 25 people will participate in the online Citizens' Jury itself, with up to 5 reserves.

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

What is the legal basis for processing data?

The IPPOSI Citizens' Jury on Genomics complies with data protection laws, including the General Data Protection Regulation (GDPR) 2016. As per Article 6 (1) (a) of the GDPR, survey and Citizens' jury participants will be explicitly asked to provide their informed consent for the processing of their information.

Roles and responsibilities

IPPOSI is the data controller for data processed as part of the Citizens' jury on Genomics. IPPOSI is responsible for the administration of the online surveys and the Citizens' Jury.

IPPOSI shall be responsible for: (i) ensuring that it complies with Articles 12, 13 and 14 of the GDPR in respect of data subjects whose personal data it obtains and processes; (ii) complying with any data subject requests under Articles 12 to 22 of the GDPR in a timely manner; and (iii) for compliance with Articles 33 and 34 of the GDPR in respect of data breach notifications to appropriate supervisory authorities and affected data subject, where applicable.

A separate, follow-on activity (a series of deliberative dialogue workshops) with diverse population-based groups will be organised by the RCSI University's Public Patient Involvement (PPI) Office, in September 2022. RCSI is the data controller for this initiative which will be run completely separately to the IPPOSI Citizens' Jury with no exchange of any personal, sensitive or special category data processed by IPPOSI.

Lifecycle of the data

This section provides an overview of the lifecycle of the data collected to conduct the IPPOSI Citizens' Jury on Genomics.

Stage one:

To source survey participants, a number of public communications channels (broadcast radio, press release, social media, email) will be used by IPPOSI to advertise the opportunity to express an interest via an online survey.

Initial survey participants provide information about themselves, such as their age range, gender, location, as well as their consent to be contacted by IPPOSI about the Citizens' jury initiative.

IPPOSI staff:

- apply the eligibility criteria by ensuring that the potential survey participant is 18 years of age or over
- provide links to public information on the aims and conduct of the jury survey and the jury itself.

Stage two:

Participants' responses are securely uploaded and stored in a participant response file. The file is stored within the IPPOSI Microsoft-licenced cloud-based server, located in Dublin, Ireland.

Stage three:

IPPOSI staff uploads the email addresses of participants to the IPPOSI Mailchimp account. Mailchimp is a group email software whose server is located in the European Union and is GDPR compliant¹. The IPPOSI mailchimp account is restricted to designated IPPOSI staff and is password protected.

IPPOSI staff emails each survey participant with a link to a second, follow-up, online survey. The purpose of the follow-up survey is to obtain further information on each potential juror participant so that the final 25 jurors can be selected on the basis of being as representative of the general population as possible. Potential Citizens' jury participants will be:

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

Stage four:

Participants responses to the follow-up survey are securely uploaded and stored in a participant response file. The file is stored within the IPPOSI Microsoft-licenced cloud-based server, located in Dublin, Ireland (i.e. the same location as the information from the initial survey).

Stage five:

A stratification model has been created whereby a number of criteria are applied to create a 25-person representative sample of the general population. The numbers selected from each criteria will (as closely as possible) reflect the Central Statistics Office Census data. The selection process will be completed independently of IPPOSI, overseen by an academic expert in data protection, informatics and ethics.

The selection of jurors will be done randomly, based on a priority criteria (gender, age, location, ethnicity, education, and attitudes). This criteria is designed so that we get a true representation of Irish society on the final jury. The criteria are based on guidance from The Jefferson Center and will be agreed by the Citizens' Jury Oversight Panel.

Stage six:

The 25 prospective jurors (and the five reserves) are emailed to confirm their willingness to participate in the jury process in June 2022. The deliberations and findings of the jury process are hosted on IPPOSI Microsoft-licenced cloud-based server, located in Dublin, Ireland.

Deliberations of the jury participants are recorded using the GDPR-compliant Zoom Video online platform for the purposes of ensuring that all contributions are captured by the Juror facilitators and

¹ <https://mailchimp.com/gdpr/>

rapporteurs. All jury facilitators and rapporteurs will sign voluntary contract agreements to ensure confidentiality with IPPOSI in advance of the jury process.

The overall, anonymised jury findings will be analysed, and a policy-focused report will be published by IPPOSI.

Stage seven:

A data retention and a destruction schedule is implemented.

The contact details of initial survey participants who are not shortlisted for the jury will be destroyed by June 30th, 2022, unless consent is given to be contacted by IPPOSI for future opportunities beyond this date. The contact details of Citizens' Jury participants and reserves will be destroyed by 31st December 2022, unless consent is given to be contacted by IPPOSI for future opportunities beyond this date.

The responses from the survey, the Citizens' jury notes and recordings will be deleted from the IPPOSI server by 30th June 2023. This is necessary to ensure that IPPOSI can cross-check any content in the final verdict with the session deliberations – if a query arose as to the validity of a statement / theme / recommendation taken in the final jury verdict.

The overall statistics and analysis of the surveys are retained by IPPOSI indefinitely and the anonymised Citizens' jury notes are retained by IPPOSI for five years following the publication of the policy report.

Methodology to conduct this DPIA

This DPIA was conducted as per the steps outlined in the Privacy Impact Assessment toolkit for health and social care, developed by HIQA². 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 Citizens' jury on Genomics involves processing personal information, for example, first names, email addresses and survey responses of 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 Citizens' jury Oversight Panel and patient representatives 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 online survey 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

² [Privacy-Impact-Assessment-toolkit-A5.pdf \(hiqa.ie\)](https://www.hiqa.ie/privacy-impact-assessment-toolkit-A5.pdf)

unsolicited, sensitive, health information to IPPOSI via jmoran@ipposi.ie (as outlined in risk number three below), three controls were identified:

- IPPOSI does not request personal data from members of the public who contact them
- IPPOSI receives emails on secure, encrypted, password protected devices
- IPPOSI deletes all emails at the end of the jury process in June 2022

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 below. 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 below) represents a low risk and therefore receives a risk rating of 4.

Step four: The DPIA report is produced. The report is reviewed by Citizen Jury Oversight Panel members, IPPOSI board members and approved by the IPPOSI CEO before implementation of 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.

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 (adopted from HIQA guidance):

Impact	Likelihood				
	Rare 1	Unlikely 2	Possible 3	Likely 4	Highly likely 5
Negligible - 1	1	2	3	4	5
Minor - 2	2	4	6	8	10
Moderate - 3	3	6	9	12	15
Major - 4	4	8	12	16	20
Critical - 5	5	10	15	20	25

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

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:

- 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 any data processor.
- 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

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: The following controls will be put in place:

IPPOSI:

- has put in place a contract with data processors, which includes a non-disclosure agreement and a data processing agreement. IPPOSI 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 Citizen Jury.
- 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 Citizens' Jury on Genomics securely.
- arranges for the secure transfer of any data processed as part of the Citizens' Jury on Genomics
- 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 jmoran@ipposi.ie

There is a risk that individuals may disclose unsolicited sensitive information about their healthcare to IPPOSI via jmoran@ipposi.ie

Controls: The following controls will be put in place

IPPOSI:

- 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 jury process in June 2022

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: The following controls will be put in place:

IPPOSI:

- provides all Citizens' Jury 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 Citizen jury participants and facilitates an opt-out of the survey
- provides an online Frequently Asked Questions (FAQ) information and a participant information leaflet, outlining details of the project, including its data-processing activities and information governance on www.ipposi.ie. Participants in the Jury can request that the information be sent to them in the post.
- ensures that all communication for public distribution is accessible and adheres to the National Adult Literacy Association (NALA) guidelines on plain English
- adheres to IPPOSI'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 Citizens' Jury and survey will accidentally transcribe personal information that is not required or sought by the survey or jury process.

Controls: The following controls will be put in place

IPPOSI:

- develops and approves all content for the Citizen Jury and for the survey to gather Jurors' perceptions on genomics, to avoid soliciting personal, sensitive and or extraneous information.
- develops and applies anonymisation criteria for the second 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 Citizens' jury, that is the general and high level responses of jurors. 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.

Next steps

This document reflects the feedback from all stakeholders in relation to identified risks for the Citizens' Jury on Genomics and will be published on www.ipposi.ie