

National Office for Research Ethics Committees

Privacy Policy

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1. Who we are

We are the National Office for Research Ethics Committee, an independent statutory body based in the offices of the Health Research Board, Grattan House, 67-72 Lower Mount Street, Dublin 2, D02 H638.

The National Office is responsible for establishing National Research Ethics Committees (NRECs) in select areas of health research at the request of the Minister for Health and providing advice and support in the area of research ethics to the wider health research community in Ireland.

This notice sets out the basis on which any personal data we collect from you, or that you provide to Us, will be processed by Us. Please read the following carefully to understand our practices regarding your personal data and how we will treat it.

We use certain expressions throughout this document such as **Personal data**. This means any information relating to an identified or identifiable natural person ('data subject'); an identifiable natural person is one who can be identified, directly or indirectly, in particular by reference to an identifier such as a name, an identification number, location data, an online identifier or to one or more factors specific to the physical, physiological, genetic, mental, economic, cultural or social identity of that natural person;

Special categories of Personal Data and Sensitive personal data means information revealing racial or ethnic origin, political opinions, religious or philosophical beliefs, or trade union membership, and the processing of genetic data, biometric data for the purpose of uniquely identifying a natural person, data concerning health or data concerning a natural person's sex life or sexual orientation.

2. What information do we collect from you?

Information collected by the National Office relates to:

- I. Applicants seeking information about, or applying for, research ethics approval;
- II. Members of the National Research Ethics Committees;
- III. Individuals seeking information about, or applying for, employment with the National Office
- IV. Prospective Members of the National Research Ethics Committees;
- V. Newsletter subscribers;
- VI. Visitors to the nrecoffice.ie website.

You may give Us information by:

- I. Corresponding with Us by phone or e-mail or otherwise. We ask you to disclose only as much information as is necessary for your interaction with Us to enable Us to carry out the duties of the National Office;
- II. Applying for a position with Us as NREC member or employee of the National Office. The type of information you may provide includes your CV, a cover letter, your name, address, e-mail address and phone number, and special categories of Personal Data

and sensitive Personal Data such as gender, age, ethnic background, religious beliefs, sexuality and accessibility requirements. The sharing of special categories of Personal Data and sensitive Personal Data will always be optional. CVs / work summaries should include information relevant to your work inside and outside the home including employment history, and education (degrees obtained, places worked, positions held, relevant awards, and so forth);

- III. Supporting your duties as a member of a National Research Ethics Committee. For example, providing a photograph and professional biography as well as information needed to process relevant allowable payments such as travel expenses;
- IV. Subscribing to our newsletter through the nrecoffice.ie website or through social media channels;
- V. Visiting and using the nrecoffice.ie website.

The legal bases for the processing of your data are:

- I. That you have provided consent for the processing for one or more specific purposes. For example, when you subscribe to our newsletter or website alerts;
- II. Processing necessary for the performance of a contract which you have entered into with Us or to take steps at your request prior to entering into a contract;
- III. Processing necessary for compliance with a legal obligation to which we are subject;
- IV. For the performance of a task in the exercise of official authority vested in Us by our statutory functions.

3. Why do we collect this information?

Information is collected to process ethics review applications, improve the website, recruit staff to the National Office and members to National Research Ethics Committees (NRECs) respectively, and to operate the National Office and NRECs.

For Applicants

For Applicants, we will only collect and process personal information that is needed by Us to comply with the statutory functions of the National Office and the NRECs for the ethics review of health research. This Personal Data is limited to the names, contact details and professional background of Applicants and those involved in the research study as outlined in the application form.

Please note that Applicants should never provide personally identifiable information (names, patient identification numbers etc.) or any pseudonymised data of research subjects in their application forms.

As an Applicant your personal data will be used by Us to/for:

- Processing and assessing an Application that you have submitted to the National Office;

- Requesting more information to process your Application;
- Provide you with updates and decisions on your Application;
- Processing and assessing submissions for amendments to an approved ethics application;
- Discussing the annual review submitted by the Applicant on the anniversary date of ethics approval;
- Processing any Report of Breaches made to an NREC by the Applicant;
- Processing any Adverse Events made to the NREC by the Applicant;
- Informing you that ethics approval has been terminated;
- Maintaining a register of the decisions made by an NREC;
- Provide you with updates and decisions on your appeal of a decision made by an NREC;
- Corresponding with other bodies involved in the regulation of health research;
- Corresponding with the Applicant's host or collaborating research institution(s);
- Producing an annual report of activities to the Minister of Health.

The Personal Data processed for the purposes described above will be shared with the relevant NREC, the National Office, and if necessary for research governance, with the Applicant's host & / or collaborating research institution(s) including local REC &/or Research Office. Personal Data may also be shared with the Appeals Committee should an Applicant wish to appeal a decision made by an NREC in relation to their application. Personal Data shared with the Appeals Committee will be limited to the original Application and the information submitted by the Applicant and information on the decision made by the NREC.

To ensure openness and transparency, the following will be published on the National Office website as a transparent record:

- Applicant and associated organisation(s) as it relates to the Application reviewed by an NREC;
- Summary information about applications made to an NREC;
- Summary information about research sites for multi-site applications;
- Application reference number;
- Minutes of NREC meetings;
- A register of decisions made by the NREC;
- The annual report furnished to the Minister.

For the National Office and NRECs

When applying to join an NREC the type of information you may provide includes your CV / work summary, a cover letter, your name, address, e-mail address and phone number. CVs /

work summaries should include information relevant to your work inside and outside of the home including employment history, and education (degrees obtained, places worked, positions held, relevant awards, and so forth). You may be asked to include some special categories of Personal Data and sensitive Personal Data such as gender, age, ethnic background, religious beliefs, sexuality and accessibility requirements. The sharing of special categories of Personal Data and sensitive Personal Data will always be optional,

If you submit an expression of interest (Eol) to become an NREC member, the National Office as the Data Controllers will collect and store your Personal Data. Some Personal Data from the Eol, such as name and experience, will be shared with third-party panel members for the specific purpose of evaluating Eols for NREC membership. Special categories of Personal Data and sensitive Personal Data will not be shared with these third-party panel members. The National Office may contact applicants submitting an Eol about future NREC opportunities where it is deemed by the National Office relevant to do so.

NREC member attendance will be captured in minutes of meetings and other documentation that will be produced as part of the operations of the National Office and the NRECs. For transparency, NREC members will be asked to declare potential and / or actual competing interests, including conflict of interests, as they arise during the course of their duties.

The National Office will collect and store Personal Data of NREC members for the purpose of processing allowable expenses.

The names and short professional biographies of NREC members will be published on the National Office website.

The legal basis for the processing of your Personal Data is:

- Such that you have provided consent for the processing for one or more specific purposes. For example, when you subscribe to our newsletter or website alerts;
- For the performance of a contract which you have entered into with Us or to take steps at your request prior to entering into a contract;
- For compliance with a legal obligation to which We are subject;
- For the performance of a task in the exercise of official authority vested in Us by our statutory functions.

We will use this information:

- To carry out Our statutory duties;
- To create a Member profile for you;
- To communicate any upcoming National Office or NREC news and events;
- To fulfil Our statutory duties which includes the processing of an ethics application which you submit to Us and to communicate decisions as they relate to your application;
- To administer and improve Our website and for internal operations, including troubleshooting, data analysis, testing, research, statistical and survey purposes. For further information please see our Cookie Policy on our website;
- As part of our efforts to keep our website safe and secure;

- To make suggestions and recommendations to you and other users of Our website about services that may interest you or them.

4. What information about you do we obtain from others?

An NREC only obtains Personal Data that it receives as part of the ethics Application process and as required to fulfil the statutory duties of the NREC. The National Office may receive your Personal Data through email or telephone queries as they pertain to the duties of the ethics review process. These queries may be sent to Us by third parties for review, such as the Health Products Regulatory Authority.

5. Where did we get this information?

Ethics Applications

We obtain this information from you the Applicant and/or your research body/institution as part of an ethics application submitted to Us.

6. Who might we share this information with?

To allow Us to fulfil our statutory duties, We may share your Personal Data with selected third parties.

Such third parties may include the Department of Health or other Government agencies such as the Revenue Commissioners, Garda Síochana, or other agencies for the detection, investigation or prosecution of offences and to enable them to perform their functions.

To allow Us to fulfil our statutory duties, We may also share your Personal Data with selected third parties including suppliers and sub-contractors. A list of third parties with whom We share your data is as follows:

- Department of Health
- Host Institutions
- Cloud Service Providers
- IT Back-up Providers
- Archive/shredding companies
- Email, Website and IT service providers
- Auditors
- Accounting software
- CCTV service providers
- Security software
- Cookie analytics service provider

7. What are your rights with respect to your information?

You have the following rights:

- The right to access the information We hold about you.
- The right to require Us to rectify any inaccurate information about you without undue delay.
- The right to have Us erase any information We hold about you in circumstances such as where it is no longer necessary for Us to hold the information for your use of our services or if you have withdrawn your consent to the processing.
- The right to object to Us processing information about you such as processing for profiling or direct marketing, where consent has not been obtained for such activity.
- The right to ask Us to provide your information to you in a portable format or, where technically feasible, for Us to port that information to another provider provided it does not result in a disclosure of information relating to other people.
- The right to request a restriction of the processing of your Personal Data

Where our processing of your information is based on your consent to that processing, you have the right to withdraw that consent at any time but any processing that We have carried out before you withdrew your consent remains lawful.

You may exercise any of the above rights by: writing to the National Office at nationaloffice@nrec.ie or by post to the National Office for Research Ethics Committees, Grattan House, 67-72 Lower Mount Street, Dublin 2.

You may lodge a complaint with your local supervisory authority with respect to our processing of our information. In Ireland, the local Supervisory Authority is the Office of the Data Protection Commissioner with an address at either a) 21 Fitzwilliam Square South Dublin 2 D02 RD28 Ireland or b) Canal House, Station Road, Portarlinton, R32 AP23 Co. Laois.

8. What will happen if we change our privacy notice?

This notice may change from time to time, and any changes will be posted on Our website and will be effective when posted. Please review this notice each time you use Our website or Our services. This notice was last updated on the date appearing on the cover hereof.

9. How can you contact us?

You can contact Us:

by phone: (01) 2345000

by email: nationaloffice@nrec.ie

or by post: National Office for Research Ethics Committees, Grattan House, 67-72 Lower Mount Street, Dublin 2, D02 H638.

You can make a Data Subject Access Request by contacting Us as described in Section 9 of this document.