

NATIONAL CHILDREN'S RESEARCH CENTRE

DATA PRIVACY POLICY

1 INTRODUCTION

The National Children's Research Centre (NCRC) has been in existence for over 50 years and has been funded since its inception by the Children's Medical and Research Foundation Crumlin (CMRF Crumlin). Situated on the grounds of the largest children's hospital in Ireland, Our Lady's Children's Hospital, Crumlin, the Centre was established with the key aim to improve the lives and health of children through research.

2 PURPOSE

This policy sets out the basis on which any personal data that we collect from you, or which you provide us with, 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, and they are outlined here. **Personal data** refers to 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.

For the purpose of the Data Protection Acts (the 'DPA'), the NCRC is a data controller relating to NCRC employees, applicants for open NCRC roles, applicants to, and users, of NCRC Resources.

The NCRC is a data processor were acting as a service provider to data controllers in the support of clinical trials, support for research studies involving patient samples and provision of access/use of the NCRC laboratory facilities including its freezers.

3 SCOPE

This policy applies to all staff within the NCRC (*meaning permanent, fixed term, and temporary staff, any third-party representatives or sub-contractors, agency workers, volunteers, interns and agents engaged with the NCRC in Ireland or overseas*). Adherence to this policy is mandatory and non-compliance could lead to disciplinary action.

4 POLICY STATEMENT

For ease of reference, we have organised this Statement into the following sections:

4.1 THE INFORMATION WE HOLD ABOUT YOU, HOW WE COLLECT AND USE IT, AND OUR LEGAL BASIS FOR DOING SO

The NCRC may collect personnel data from you when you in the following situations:

4.1.1 WHEN YOU VISIT THE NCRC WEBSITE

You may choose to give us certain information when you subscribe to our mailing list.

This information may include your:

- title, first name, and last name;
- email address.

Additionally, certain technical information is collected automatically when you use our website. This includes:

- standard internet log information, for example, your Internet Protocol (IP) address, browser type and version, and page interaction information;

The NCRC website uses cookies, that is, small text files that can help websites improve the service they offer to users, to automatically collect information about how you use our site.

We may collect this information from you to:

- send you updates you have opted in to receive.
- help us understand more about how you use our website and how we could improve what we do to better suit your needs.

We use the information we collect about you via our website in pursuit of our legitimate interest of engaging and informing the public about the NCRC. Where you opt-in to subscribe to updates, your consent is the legal basis for our use of your information. Information on how to withdraw consent will be included at the end of all emails sent to mailing list subscribers. Our mailing list is stored and operated by a third-party service provider – MailChimp. You are free to decline our cookies by modifying your web browser to either refuse cookies or let you know when you receive new cookies.

For further information please refer to the NCRC website for the Website Privacy and Cookie Policy.

4.1.2 WHEN YOU APPLY FOR AN NCRC RESEARCH GRANT

We may collect the following information from you, as a lead applicant or participant (e.g. co-applicant, supervisor, collaborator), when you apply for an NCRC research grant:

- title, first name, and last name;
- contact information including email address and phone number;
- organisation;
- ORCID ID;
- CV information including your education/training, work history, achievements, grant outputs such as publications, patents, clinical trials, and contributions to health policy;
- employment contract status;
- letters of support;
- details of your proposed research.

We may also collect additional information about you relating to your application from external sources such as publicly or privately curated databases (e.g. PubMed, Europe PMC) and peer reviewers.

We collect this information from you to award and manage grants. We use this information to:

- create and administer your user account on NCRC Grant Tracker so that you can submit your application;
- process your application and assess eligibility;
- ensure that your application is assessed in a fair and equitable manner in line with our Peer Review Policy;
- contact you about your application.

NCRC Grant Tracker is our online grant management system. It is provided by CC Technology, a UK based company. All data related to your application will be stored on this system. By creating an NCRC Grant Tracker account, you accept the terms and conditions as provided on the system login page.

We share your information with external reviewers (e.g. international peer reviewers and committee members) who may be based in academic institutes, public hospitals, or in the private sector for the purpose of reviewing your application and making funding recommendations. External reviewers may be based outside the EU.

We may share your information with our primary funding body, CMRF Crumlin, to facilitate their financial planning and to enable them to better understand the research they fund.

We use your information in this way on the legal basis that it is necessary for us to pursue our legitimate interests as a research charity in providing grant funding.

4.1.3 WHEN WE INVITE YOU TO ACT AS A PEER REVIEWER FOR THE NCRC

We collect the following information about you from third parties who recommend you, institution websites, and other external sources e.g. publicly or privately curated databases (PubMed, Europe PMC) and social networking sites for researchers (ResearchGate, Academia.edu).

- title, first name, and last name;
- address;
- organisation;
- area of expertise
- gender.

We use your information to:

- determine your suitability as a reviewer;
- contact you to invite you to participate in peer review;
- send you a link via email to review relevant application material through NCRC Grant Tracker;
- otherwise correspond with you in connection with peer reviewing an application;
- contact you for feedback and suggestions for improvements on the way we do things that would benefit you as a peer reviewer;
- Maintain a database of potential peer reviewers and to help us identify and prevent gender disparity in our selection of peer reviewers.

We do not share your personal data. We do, however, share details of your peer review with our Scientific Advisory Committee members, omitting any identifiable information, and use your comments to provide pseudonymised feedback to our applicants.

We use your information in this way on the legal basis that it is necessary for us to pursue our legitimate interests as a research charity in ensuring that only the highest quality of research, that is both novel and has real potential to impact child health, is funded by us.

For further information please refer to the NCRC International Peer Reviewer Guidelines.

4.1.4 WHEN YOU APPLY FOR A JOB WITH THE NCRC

You may provide the following information to us when you apply for a job at NCRC:

- title, first name, and last name;
- email address;
- contact phone number;
- home address;
- CV information including your education history, work experience, achievements, and interests;
- information about your right to work in Ireland;
- salary expectations;
- current notice period and planned periods of leave;
- previous employment references.

Due to the nature of our research, if you are successful in your application, you will be required to undergo Garda Vetting. This will be processed through Our Lady's Children's Hospital, Crumlin.

We collect this information from you to:

- consider your application for a job with the NCRC;
- check you are legally entitled to work in Ireland;
- comply with Children First Legislation (in relation to Garda Vetting).

Your information will be stored on BambooHR, a third-party operated HR management system.

We use this information on the legal basis that we are taking steps at your request to consider entering into an employment contract with you. We use information about your right to work in Ireland to meet our legal obligation to ensure that all NCRC staff have the right to work in Ireland, and your Garda vetting to ensure that we are in compliance with Children First Legislation.

For further information please refer to the NCRC Recruitment Policy.

4.1.5 WHEN YOU APPLY TO USE THE NCRC READING ROOMS, LAB, OR SAMPLE STORAGE FACILITIES

You give us, and we collect, the following information about you when you apply to use NCRC building facilities:

- title, first name, and last name;
- email address;
- contact phone number;
- organisation;
- employment and training information (i.e. are you a student, research assistant, postdoctoral researcher, what is your lab experience to date);
- emergency contact details;
- details of your proposed research project including roles and responsibilities;
- CCTV footage collected on our premises.

Due to our location on the grounds of a children's hospital, you may also be required to undergo Garda Vetting. This will be processed through Our Lady's Children's Hospital, Crumlin

We may collect this information from you to:

- issue you with a security card and provide you with access to our building;
- comply with our legal health and safety obligations (i.e. by ensuring that you have the required training and experience to work in our laboratory safely);
- assess your research/storage needs;
- comply with Children First Legislation (in relation to Garda Vetting);
- assist with the detection and prevention of crime, ensure public and staff safety, and enforce parking regulations on our premises (in relation to CCTV footage).

We use this information on the legal basis that it is necessary to pursue our legitimate interest of ensuring the health and safety of all building users and the security of our premises. We use your Garda vetting disclosure to ensure that we are in compliance with Children First Legislation.

For further information please refer to the NCRC Building Access Policy and NCRC Terms & Conditions of use of NCRC Facilities.

4.1.6 WHEN YOU VISIT THE NCRC BUILDING

You give us, and we collect, the following information about you when you visit the NCRC building:

- title, first name, and last name;
- organisation name;
- reason for visit;
- CCTV footage collected on our premises (external only);
- in the event you receive first aid during your visit, we will collect the following information: your full name, injury details, contact details (phone number and email address), location and description of accident or incident.

We may collect this information from you to:

- provide you with access to our building;
- assist with the detection and prevention of crime, ensure public and staff safety, and enforce parking regulations on our premises; and
- comply with our legal health and safety obligations (i.e. in connection with first aid and reporting health and safety incidents).

We use this information on the legal basis that it is necessary to pursue our legitimate interest of ensuring the security of our premises and the health and safety of all visitors to our building.

For further information please refer to the NCRC Building Access Policy.

4.1.7 WHEN YOU CONTACT US BY PHONE, EMAIL, OR SOCIAL MEDIA

You may give us certain information about you when you contact us by phone, by email or by social media, such as your:

- title, first name, and last name;
- organisation name;
- contact details including phone number or email address.

We may collect this information from you:

- to handle your query or otherwise engage with you.

We use this information on the legal basis that it is necessary to pursue our legitimate interest of answering your queries and engaging with you. Further, we would ask that disclose only as much information as is necessary for the purpose of your interaction with us.

4.1.8 WHEN YOU PARTICIPATE IN NCRC CHILDREN’S CLINICAL RESEARCH UNIT SUPPORTED RESEARCH

The NCRC employs staff, via our Children’s Clinical Research Unit (CCRU), who support hospital-based research. This may involve the collection of personal data, including special categories of personal data and sensitive personal data, from hospital patients. In order to fulfil our duties in providing support services to researchers, personal data may be held within the NCRC. In such cases, the data will always be pseudonymised/anonymised and the NCRC will be considered a data processor acting as a service provider to the data controller (the lead researcher and/or their organisation).

5 HOW WE USE PARTICULARLY SENSITIVE INFORMATION

Where necessary for the purposes described in this Statement, we may share your personal data within the NCRC, with our third-party service providers and our primary funding body, CMRF Crumlin.

In exceptional circumstances, we may be required to share your information under a court order or if requested to be so by the Garda, regulatory authorities, or other governmental authorities.

6 HOW WE LOOK AFTER YOUR INFORMATION

The NCRC is committed to safeguarding your personal data and we have put in place appropriate security measures to protect your privacy. We limit access to your personal data to persons and organisations with legitimate business needs to access your information. They will only process your personal data on our instructions, and they are subject to a duty of confidentiality. Where you have password related to NCRC services, for example to access NCRC Grant Tracker, you are responsible for keeping this password confidential.

We have policies in place to protect against personal data breaches. For further information please refer to the;

- Data Protection Policy,
- Data Breach Policy,
- Data Breach Incident Form,
- Subject Access Request Policy,
- Data Retention & Erasure Policy,
- Information Security Policy,
- Access Control & Password Policy,
- Clear Desk Policy,
- CCTV Policy.

7 HOW LONG WE KEEP AND USE YOUR INFORMATION

The time periods for which we retain your information depends on the type of information and the purposes for which we use it. We will keep your information for no longer than is required or permitted.

For further information please refer to our Data Retention and Erasure Policy.

8 YOUR RIGHTS OVER 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 mailing
- 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 information.

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.

For further information please refer to our Subject Access Request Policy.

You may exercise any of the above rights by writing to our Data Protection Officer by email or should you have any further queries please email at dataprotection@ncrc.ie or by post to National Children's Research Centre, Gate 5, Our Lady's Children's Hospital Crumlin, Crumlin, Dublin 12.

You may lodge a complaint with your local supervisory authority with respect to our processing of your information. In Ireland, the local Supervisory Authority is the Office of the Data Protection Commissioner with an address at Canal House, Station Road, Portarlinton, Co. Laois

9 CHANGES TO THIS STATEMENT

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.

10 CONTACT US

You can contact us a follow:

Phone: 01 409 6585

Email: Our Data Protection Officer can be contacted by email at dataprotection@ncrc.ie

Postal address: National Children's Research Centre, Gate 5, Our Lady's Children's Hospital Crumlin, Crumlin, Dublin 12

11 RESPONSIBILITIES

The NCRC has appointed a **Data Protection Officer** whose role it is to identify and mitigate any risks to the protection of personal data, for further information please refer to our Data Protection Policy.