



Privacy Notice Research Participant

About Children's Health Ireland

The Children's Health Act 2018 ("the Act") established the statutory body known as Children's Health Ireland (CHI) on 04 December 2018, with Our Lady's Children's Hospital Crumlin (OLCHC) formally transferring into CHI on the 01 January 2019 along with Temple Street Children's University Hospital and the National Children's Hospital Tallaght. Our Lady's Children's Hospital Crumlin is now known as CHI at Crumlin.

The object of Children's Health Ireland is to improve, promote and protect the health, mental health and well-being of children in a manner that embodies the values of child-centred, compassionate and progressive care provided with respect, excellence and integrity and in doing so it shall have the right and responsibility to promote the culture and traditional principles of voluntarism in the conduct of its internal and external affairs.

CHI's Mission is to: Promote and provide child-centred, research-led and learning informed healthcare, to the highest standards of safety and excellence. We do this in partnership with each other, with children, young people and their families through a network of children's services in Ireland.

The key functions of the CHI are set out in [Section 6 of the 2018 Act](#) and includes the requirement to plan, conduct, maintain, manage, provide and develop paediatric services in the hospital and to facilitate, foster, promote and carry out research and innovation aimed at improving paediatric services and advancing medical and scientific knowledge relating to paediatric services through research and scientific investigation and inquiry.

CHI is an information-based organisation and its operational activities are dependent on its efficiency in creating, using, storing and securing information

Section 6(1) of the Act specifically outlines the following functions:

6(2) Children's Health Ireland shall have the following functions:

(c) to promote excellence in the practice and provision of paediatric services and provide leadership in the advancement, development, organisation and delivery of paediatric services in an integrated clinical network for paediatric services;

(e) to facilitate, foster, promote and carry out research and innovation aimed at improving paediatric services and advancing medical and scientific knowledge relating to paediatric services through research and scientific investigation and inquiry.



Background

This Privacy Notice sets out how Children’s Health Ireland processes personal identifiable information that it generates and holds in the course of its work.

It explains:

- what personal information CHI collect as a data controller on data subjects;
- how CHI use that data;
- who CHI shares that data with;
- the security in place to protect that data.
- It also sets out the privacy rights that data subjects have under the General Data Protection Regulation (GDPR), Data Protection Act 2018 (36(2)) (Health Research) Regulations 2018 and Irish data protection legislation.

To assist in safeguarding a data subject’s information, CHI has developed a set of fundamental information governance principles and policies to ensure that it minimises the amount of personal data it collects, that it uses personal data only for the purpose it was obtained and in accordance with its legal obligations including the EU General Data Protection Regulation (“GDPR”) including the Data Protection Act 2018 (36(2)) (Health Research) Regulations 2018.

CHI promotes good information governance practices among its staff. CHI continually monitors and improves internal policies, procedures and information communications technology (ICT) security tools to ensure that all personal data is protected against theft, accidental loss, unauthorised access or alteration, erasure, use or disclosure.

CHI understands that your privacy is important to you and that you care about how your personal data is used. We respect and value the privacy of all of our research participants and will only collect and use personal data in ways that are described here, and in a way that is consistent with our obligations and your rights under the GDPR.

For the purposes of the GDPR Children’s Health Ireland is a “**Data Controller**” registered with the Data Protection Commission.



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1.0 What Does This Privacy Notice Cover?

This **Privacy Notice** explains how we use your personal data when you engage in a research project with CHI, how your personal data is collected, how it is held, who it is shared with and how it is processed.

It also explains your rights under the law relating to your personal data.

2.0 What is Personal Data?

Personal data is defined by the GDPR as *'any information relating to an identifiable person who can be directly or indirectly identified in particular by reference to an identifier'*.

Personal data is, in simpler terms, any information about you that enables you to be identified. The personal data that we use is set out in [Section 4.0](#), below.

3.0 What Are My Rights?

Under the GDPR, you have the following rights, which CHI Researchers will always work to uphold:

- (a) The right to be informed about our collection and use of your personal data. This Privacy Notice should tell you everything you need to know, but you can always contact us to find out more or to ask any questions using the details in [Section 4.0](#)
- (b) The right to access the personal data we hold about you. [Section 11.0](#) will tell you how to do this.
- (c) The right to have your personal data rectified if any of your personal data held by us is inaccurate or incomplete. Please contact us using the details in [Section 4.0](#) to find out more.
- (d) The right to be forgotten, i.e. the right to ask us to delete or otherwise dispose of any of your personal data that we have.
Please contact us using the details in [Section 4.0](#) to find out more.
- (e) The right to restrict (i.e. prevent) the processing of your personal data.



Data Protection Act 2018 (section 36(2)) (health research) Regulations 2018

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- (f) The right to object to us using your personal data for a particular purpose or purposes.
- (g) The right to data portability. This means that if possible we will provide you with a copy of your data in electronic format.
- (h) Rights relating to automated decision-making and profiling. We do not use your personal data in this way.

Please note: Many of these rights do not apply when your personal data is being used for Research purposes. For more information about our use of your personal data or exercising your rights as outlined above, please contact us using the details provided in [Section 4.0](#).

4.0 Making a complaint or providing us with feedback

We hope you have found this privacy notice useful and we are always happy to hear your feedback. However, if you want to provide us feedback in relation to any aspect of how CHI has handled your personal information and/or would like to make a complaint, you can contact our Data Protection Officers by post, email or phone through the contact details below.

Communication by	Location	Location	Location	Location
	CHI at Crumlin	CHI at Temple Street	CHI at Tallaght	CHI at Connolly
Letter	Data Protection Officer Children's Health Ireland (CHI) at Crumlin, Crumlin, D12 N512, Ireland	Data Protection Officer Children's Health Ireland (CHI) at Temple Street, Temple Street, D01 YC67, Ireland	Data Protection Officer Tallaght University Hospital, Tallaght, Dublin 24 D24 NROA	Data Protection Officer Children's Health Ireland (CHI) at Temple Street, Temple Street, D01 YC67, Ireland
Email	dataprotection@OLCHC.ie	Maryanne.Culhane@cuh.ie	Meiread.ashe@nchg.ie (temp)	Maryanne.Culhane@cuh.ie
Telephone	+353 01 4096100	+ 353 (1) 878 4814	+353 076 695 9171	+353 (0) 1 428 2857



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If you are unhappy with the outcome of a review of your complaint by our Data Protection Officer, you also have the right to make a complaint to the Data Protection Commission directly.

Emailing: info@dataprotection.ie

Calling: 1890 25 22 31

Posting:

Data Protection Commission,
Canal House,
Station Road,
Portarlinton,
R32 AP23,
Co. Laois.

5.0 What Personal Data Does CHI Collect?

Research has a vital role to play in the development of healthcare and health service delivery. Children Health Ireland's hospitals are academic teaching hospitals associated with, Trinity College Dublin, University College Dublin, the Royal College of Surgeons, and DCU. CHI support and promote research activity within our hospitals. Our Health Research Ethics Committee must approve research before it takes place. If we wish to use your personal information for research, then we will ask you for permission first. You will not be identified in any published results without your prior agreement.

All research projects are different and the information we collect will vary. However, researchers will only collect information which is essential for the purposes of the research.

Research data is generally pseudonymised as quickly as possible after data collection so that an individual cannot be readily recognised, and their privacy is protected. Where this is not the case the research team will let you know. When your personal data has been anonymised, you will not be able to withdraw your consent after that point.

Some data e.g. survey data is frequently collected anonymously so cannot be withdrawn once you have given permission for it to be used. Where you may be identifiable in a research publication (e.g. an attributable quote or a photograph), we will seek your explicit consent.



Data Protection Act 2018 (section 36(2)) (health research) Regulations 2018

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We may collect some or all of the following personal data (this may vary according to your relationship with us):

- Name, Address, Telephone Number, email
- Information on special requirements and Health or medical conditions
- Name, postal address, telephone number, email address of parents/legal guardian
- the child's gender, date of birth, nationality, language(s) spoken,
- photographs and/or moving film images of parents/guardian,

Your Personal Data is maintained using a unique ID number to prevent your identity being revealed. The link between your unique ID number and your identity is only known to your study doctor. This is known as pseudonymising your data.

How Do You Use My Personal Data?

Your Personal Information (including your pseudonymised data) will be processed to:

- Determine if you are eligible for this study;
- Verify that the study is conducted correctly, and that study data are accurate;
- Store, process and test biological samples collected from your child during the study;
- Answer questions from government or regulatory agencies;
- Contact you during and after the study (if necessary);
- Follow-up on your health status, including using publicly available sources should the study team be unable to contact you using information held on file;
- Protect your vital interests (for example, a critical medical situation, such as providing information to an emergency department of a hospital where you are being treated); and
- Answer your data protection requests (if any).

Under the GDPR, we must always have a lawful basis for using personal data. This may be because you have consented to our use of your personal data, or processing is necessary for tasks carried out in the public interest or in the exercise of an official authority vested in CHI in this instance the Health Act 2004.



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CHI's lawful basis for processing personal data of research participants are as follows:

- You (the data subject) have given explicit consent to the processing of your personal data for one or more specified purposes;
- The processing is necessary in order to protect your vital interests.

Special categories of data are defined by the GDPR and include things like racial or ethnic origin, religious or philosophical beliefs, genetic data, biometric data, health data, sex life details and sexual orientation.

Your personal data may be used for one of the following purposes:

- research purposes;
- health and safety reporting;
- where necessary, arranging for medical care.

If the purpose of the processing is for a reason other than the reasons above, we will seek **explicit consent** to process your sensitive personal data (referred to as 'special categories' of data under the GDPR).

For children, young people and other vulnerable groups our research ethics committee will agree an appropriate consent procedure to ensure participants rights are protected.

Full details will be given to you in a consent form related specifically to the research project your personal information is collected in relation to.

6.0 How Do we obtain your personal data?

We may obtain your information from a variety of sources, including information you give to us. We may also receive your personal information from third parties, for example your GP, your social worker, or your pharmacist.

7.0 How do you keep my data secure and confidential?

We are committed to ensuring that your information is secure with us and with the third parties who act on our behalf. We have a number of security precautions in place to prevent the loss, misuse or alteration of your information.

All staff working for CHI have a legal duty to keep information about you confidential and all staff are trained in information security and confidentiality. CHI has in place strict information security policies and procedures in place to ensure that information about you is safe, whether it is held in paper or electronic format.



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8.0 How Long Will You Keep My Personal Data?

We will retain your personal data in accordance with our record retention policy and it will be kept for no longer than is necessary and generally in an anonymised format. This policy operates on the principle that we keep personal data for no longer than is necessary for the purposes for which we have collected it. It is also kept in accordance with any legal requirements that are imposed on us.

9.0 How and Where Do You Store or Transfer My Personal Data?

We may store or transfer some or all of your personal data in countries that are not part of the European Economic Area (the “EEA” consists of all EU member states, plus Norway, Iceland, and Liechtenstein). These are known as “third countries” and may not have data protection laws that are as strong as those in the UK and/or the EEA. This means that we will take additional steps in order to ensure that your personal data is treated just as safely and securely as it would be within the EEA and under the GDPR as follows.

We use specific contracts with external third parties that are approved by the European Commission for the transfer of personal data to third countries. These contracts ensure the same levels of personal data protection that would apply under the GDPR.

10.0 Do You Share My Personal Data?

To communicate our research to the public and the academic community your anonymised data is likely to form part of a research publication or conference presentation or public talk. Where Researchers wish to use any information that would identify you, specific consent will be sought.

Your data may be shared with:

- Immediate health research project team who are authorised to work on the project and access the information. This may include staff or collaborators at other organisations authorised to work on the project. This will be clearly identified in your information sheet.
- Investigating doctors, principal investigators and researcher collaborators (including industry partners).
- Where a student is undertaking the research, the data will be shared with their supervisors.
- Our research may be audited and access to the data may be required. CHI puts in place safeguards to ensure that audits are conducted in a secure and confidential manner.



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We are required to provide statistical information to the HSE and Department of Health. We will make sure that you cannot be identified by anonymising your information. If it is not possible to anonymise the information, we will contact you for consent to share your child's information.

Your personal data may also be shared with third party service providers who we engage to assist us in conducting the research. We may instruct a third party to monitor and support the study on our behalf or we may send samples externally from CHI for testing. If this is the case, CHI will enter into an agreement with this third party which will also safeguard the security and confidentiality of the processing of your Personal Data by such third party on behalf of CHI.

We may disclose your personal data to governmental authorities for regulatory and supervision purposes.

If any of your personal data is required by a third party, as described above, we will take steps to ensure that your personal data is handled safely, securely, and in accordance with your rights, obligations, and the third party's obligations under the law.

If any personal data is transferred outside of the EEA, we will take suitable steps in order to ensure that your personal data is treated just as safely and securely as it would be within the EEA and under the GDPR, as explained above in [Section 9.0](#).

In some limited circumstances, we may be legally required to share certain personal data, which might include yours, if we are involved in legal proceedings or complying with legal obligations, a court order, or the instructions of a government authority.

11.0 How Can I Access My Personal Data?

If you want to know what personal data we have about you, you can ask us for details of that personal data and for a copy of it (where any such personal data is held). This is known as a "subject access request".

All subject access requests should be made in writing and sent to the email or postal addresses shown in [Section 4.0](#). To make this as easy as possible for you, a Subject Access

Request Form is available for you to use. You do not have to use this form, but it is the easiest way to tell us everything we need to know to respond to your request as quickly as possible.



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We will respond to your subject access request within a month. Normally, we aim to provide a complete response, including a copy of your personal data within that time. In some cases, however, particularly if your request is more complex, more time may be required up to a maximum of three months from the date we receive your request. You will be kept fully informed of our progress.

12.0 Withdrawal of your consent at any time

You can withdraw your consent where we are relying on consent to process your personal data. However, this will not affect the lawfulness of any processing carried out before you withdraw your consent. This only applies if consent is the basis on which we process your data and where your information has not been anonymised.

13.0 Changes to this Privacy Notice

We may change this Privacy Notice from time to time. This may be necessary, for example, if the law changes, or if we change our practices in a way that affects personal data protection.

Any changes will be made available on our website.