

PRIVACY NOTICE - DONOR CONCEIVED REGISTER INFORMATION FOR REGISTRANTS

Introduction

This document summarises who we are, what information we hold about you, what we will do with the information we hold including who we may share it with and how long we will keep the information for. This document also explains what rights you have to control how we use your information.

Who are we?

The Liverpool Women's Hospital is a public organisation providing specialist medical services such as Gynaecology, Maternity, Fertility and Genetics services.

The Trust is registered with the Information Commissioner's Office (Registration Number **Z7119932**)

Our name, address and contact details are:

Liverpool Women's Hospital NHS Foundation Trust
Crown Street
Liverpool L8 7SS
Tel: 0151 7089988
www.liverpoolwomens.nhs.uk

The Hewitt Fertility Centre ("HFC") is the provider of fertility services within Liverpool Women's Hospital. As of 1 May 2019, HFC took over responsibility for provision of the Donor Conceived Register ("the DCR"), which is a register for donor-conceived people born from treatment in UK clinics before August 1991. It enables such people to find their biological parents and/or other family members who are also registered with the DCR.

The Hewitt Fertility Centre, Liverpool Women's Hospital is licensed by the Human Fertilisation and Embryology Authority (HFEA) allowing us to perform licensed fertility treatments. Our HFEA licensed centre number is 0007.

Contact details for the Donor Conceived Register:

Hewitt Fertility Centre
Liverpool Women's Hospital
Crown Street
Liverpool L8 7SS

Telephone number: 0151 702 4339

Email: donorconceivedregister@lwh.nhs.uk

Why do we collect information about you?

We need information about you so that we can provide support services to you when you come into contact with the Donor Conceived Register team.

The source of your **personal data** will come directly from you when you register to join the DCR.

We will collect and process personal characteristics plus any information known about the donor such as the date of treatment and the clinic involved, which can be used to help with the matching process and establishing links with other registrants if you choose to register with your DNA.

What types of information do we use?

Personal data means any information relating to an identified or identifiable individual; an identifiable person is one who can be identified directly or indirectly.

Special category data means any information relating to racial or ethnic origin, political opinions, religious or philosophical beliefs, trade union activities, physical or mental health, sexual life or genetic or biometric data

The personal and sensitive data we process includes:

Name

Date of Birth

Contact details (address, phone number, email address)

Preferred method of contact

Personal characteristics (including eye colour, hair colour, height, ethnicity)

Any details known regarding donor, date of treatment and the clinic involved

Any known genetic siblings who are also registrants

Details of a DNA match if identified

Contact details of intermediary (if requested)

You can remain registered with the DCR without providing all the information requested but if this is the case then it may limit our ability to contact you with updates.

We will be unable to provide DNA testing services without your up to date contact details and your full name, date of birth and DNA sample.

What do we use your information for?

When you register with us, the Hewitt Fertility Centre will process the **personal data** you have provided to us in order to allow us to identify you and to keep in contact with you.

If you have given **consent** to DNA matching, personal characteristics and any information you have provided about the donor such as the date of treatment and the clinic involved, will be used to help with the matching process and establishing links with other registrants who have chosen to register with their DNA.

The hospital may also record telephone conversations for training and monitoring purposes

We will process your information outlined above because you have given us **consent** to do so

Information we may receive about you which may not be supplied by you

We may receive information about you which you haven't provided to us. This could be, for instance:

- If we are dealing with a legal claim to which you are a relevant party
- If we are dealing with the safety, security, health and wellbeing of someone associated with you
- If we receive information in the form of an alert or warning and are legally obliged to act on it

What is the lawful basis for processing your information?

The General Data Protection Regulations and the Data Protection Act 2018 allow us to process your data under the following conditions:

Because we are a healthcare provider we may need to process your **personal data** for healthcare purposes in which case it will be necessary **for the performance of a task carried out in the public interest**. Where we process your **special category** data we will do so because it is necessary **for the purposes of preventive medicine, medical diagnosis, the provision of healthcare or treatment or the management of healthcare systems**

There may be occasions when we will be obliged to process your **personal** or **special category** data in order to comply with a court order, coroner's instruction, to prevent or detect crime, or to comply with the law. Where we do this, we will process your data to **comply with a legal obligation** to which the Trust is subject.

If we plan to process your information for other purposes that are not described above then we will seek your **consent** to do so before we process it.

The Trust does not undertake automated decision-making or profiling of your personal information

With whom do we share your information?

Your information will be held securely within Liverpool Women's Hospital with access strictly restricted to only individuals who have a need to access the information.

Your personal information including name, date of birth and contact details, will be provided to **Kings College London DNA Testing Laboratory** if you wish to be registered with your DNA for potentially identifying a donor/donor-conceived and/or genetic half-siblings match.

Personal data will only be shared with Kings College DNA Testing Laboratory and the HFEA. No information will be shared with any other national or international organisation.

If we wish to share your information for any other purposes than those listed above, we will contact you directly and ask for your consent.

How long do we keep your personal information for?

The NHS has a comprehensive Code of Practice, which governs the length of time that we may keep your records for, which are called the NHS Retention Schedules. The Liverpool Women's Hospital NHS Foundation Trust will comply with the NHS Retention Schedules.

There may be occasions where the Trust will be obliged to vary from the NHS Retention Schedules, for example, in response to a Court Order or other equivalent legal requirement.

Information about the NHS Retention Schedules may be found via the NHS Digital Website at: <https://digital.nhs.uk/article/1202/Records-Management-Code-of-Practice-for-Health-and-Social-Care-2016>

What measures do we take to protect your information?

We take our duty to protect your personal information and confidentiality seriously. We are committed to taking all reasonable measures to ensure the confidentiality and security of personal data for which we are responsible, whether computerised or on paper.

We have appointed a Senior Information Risk Owner (SIRO), a Caldicott Guardian, and a Data Protection Officer, who between them are responsible for the management of confidentiality. We also have a specific department led by a Head of Confidentiality and Data Protection. We have control systems in place to allow only those that have a need to access your health records to do so, and we have monitoring systems in place to verify who has accessed your health records.

Under the NHS Confidentiality Code of Conduct, all our staff are required to protect your information, and we must inform you of how your information will be used. Also, everyone working for the NHS is subject to the common law duty of confidentiality. Information provided in confidence will only be used for the purpose(s) advised or consented to, unless it is required or permitted by the law.

What are your rights in relation to your personal information?

Unless subject to an exemption, you have the following rights with respect to your personal data:

- The right to request a copy of your personal data which the Liverpool Women's Hospital holds about you
- The right to request that the Liverpool Women's Hospital corrects any personal data if it is found to be inaccurate or out of date
- The right to request your personal data is erased where it is no longer necessary for Liverpool Women's Hospital to retain such information
- The right to withdraw your consent to the processing at any time if you have previously given consent for processing
- The right to request that the Liverpool Women's Hospital provide you with your personal information and where possible, to transmit that data directly to another data controller, where your information has been processed with your consent
- The right, where there is a dispute in relation to the accuracy or processing of your personal data, to request a restriction is placed on further processing
- The right to object to the processing of personal data
- The right to lodge a complaint with the Information Commissioners Office.

Further information about your rights can be found via the Information Commissioners website, which is <https://ico.org.uk/>

What happens if we need to transfer your information abroad?

The Donor Conceived Register team will not routinely transfer information to anyone other than the HFEA and Kings College DNA testing laboratory, but if there is a need to do so we will ensure

that the security and protections that are put in place are of equivalent standard to those standards that we would use internally when processing your information.

What if we wish to use your information for another purpose?

If we wish to use your personal information for a new purpose not covered by this Privacy Notice, then we will provide you with a new Notice explaining the new relevant purposes and processing conditions. Where and whenever necessary, we will always ensure there is a legal justification for such processing.

Where can you get further information?

For general enquiries you can contact the DCR team:

Patricia Lambert
Senior Fertility Counsellor
Hewitt Fertility Centre
Liverpool Women's Hospital
Crown Street
Liverpool L8 7SS

Telephone number: 0151 702 4339

Email: donorconceivedregister@lwh.nhs.uk
patricia.lambert@lwh.nhs.uk

If you do not wish to have your information used in any of the ways described or wish to enact any of your rights under this notice, please contact the Head of Confidentiality and Data Protection at Liverpool Women's Hospital via email dataprotectionofficer@lwh.nhs.uk or telephone on 0151 702 4386.

The Trust website address is www.liverpoolwomens.nhs.uk

