



Down Syndrome National Register

Uniting for your Future

Who we are:

Children's Hospital Ireland CHI (at Tallaght University Hospital) TUH as the data controller is responsible for safely and securely managing the personal data which you provide to us. TUH is the Data Processor.

We take this responsibility seriously and want to let you know a few things about what we do to protect your privacy.

Only clinical and research staff working with The National Register for Down syndrome Project have access to your data.

Purposes of the data processing

The information you share with us on our registry form provides a record of your consent and early diagnosis information. We record this information on our IT system which helps us securely manage your data and assists in the planning of services for children with Down syndrome. We process your data to provide statistical information regarding Down syndrome birth prevalence and any other conditions your child may be born with.

Why we need your data

If you are not happy to give us information, we respect your right not to participate in the Register. However, participation in this enables us gather accurate information regarding Down syndrome.

Data storage

Consent and data forms are stored securely in The Trinity Centre for Health Sciences, Tallaght University Hospital. Our IT system is stored on the hospital network which is secure and backed up to prevent data loss. We protect your data with the highest levels of encryption and firewalls to prevent unauthorised access. We do not store any of your identifying details on our database.

We are required to keep your data for the duration of The Register project. Data retention period. Data will be anonymised at the end of the Register Project.

Consent/Assent

We always ask for your consent when requesting your or your child's participation in health care research, this is why we offer you a consent form. You can withdraw your consent for the registry at any time, Please contact us if this is your wish.



We will seek assent from your child, participants themselves at 9 years of age to participate in the study and will seek the own consent to remain on the Register at 18 years.

Accessing your data

We can provide you with access to the data we hold about you or your child at any time, before it is fully anonymised, free of charge, you just have to ask. You can request this by contacting us. If the data we hold about you is not accurate or up to date, please contact us and we will update our records. You are also able to make a standard access request (SAR) which means we must tell you all the information we store on you. Simply make a request in writing to the address below. We are obliged to respond within 30 days.

How to get in touch

Our office is based in: The Trinity Centre for Health Sciences, Tallaght University Hospital, Dublin 24.

Contact us at: Grainne.OConnor@tuh.ie

Contact for hospital Data Protection Officer:

Ms Meiread Ashe, Board Secretary and Data Protection Officer, Children's Health Ireland Block A, Herberton, St. James's Walk, Rialto, Dublin 8.

Email: meiread.ashe@nchg.ie

Complaints: We strive to manage your data appropriately, however if you wish to make a complaint please let us know. You can also make a complaint on yoursay@hse.ie or to the Data Protection Commissioner on info@dataprotection.ie

