



## PATIENT CONSENT FORM

**Study title: The National Register for Children with Down syndrome.**

I have read and understood the <b>Information Leaflet</b> about this research project. The information has been fully explained to me and I have been able to ask questions, all of which have been answered to my satisfaction.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I understand that my son/daughter does not have to take part in this study and can opt out at any time without giving son for opting out and I understand that opting out won't affect my son/daughters future medical care.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I am aware of the potential risks, benefits and alternatives of this research study.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I give permission for researchers to look at my child's or son/daughters medical records to get information. I have been assured that information about my child's or son/daughters will be kept private and confidential.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I have been given a copy of the Information Leaflet and this completed consent form for my records.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I consent to my son/daughter taking part in this research study having been fully informed of the risks, benefits and alternatives.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I give informed explicit consent to have my son/daughter's data processed as part of this research study.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I consent to be contacted by researchers as part of this research study.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I consent to my son/daughter's data further processed to be fully anonymised when the research is complete.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I consent to my son/daughter's data being further processed destroyed/deleted when the research is complete.	Yes <input type="checkbox"/>	No <input type="checkbox"/>

<b>FUTURE CONTACT</b>		
I consent to be re-contacted by researchers about possible future research <b>related</b> to the current study for which my son/daughter may be eligible.	Yes <input type="checkbox"/>	No <input type="checkbox"/>

\_\_\_\_\_ | \_\_\_\_\_ | DD/MM/YYYY

Patient Name (Block Capitals)

| Patient Signature

| Date

Dr. /DNS Name (Block Capitals)	Dr. /DNS Signature	DD/MM/YYYY
		Date

Legal Representative/Guardian Name	Legal Representative/Guardian Signature	DD/MM/YYYY
		Date

**To be completed by the Principal Investigator/Doctor/Nurse**

I, the undersigned, have taken the time to fully explain to the above patient the nature and purpose of this study in a way that they could understand. I have explained the risks involved as well as the possible benefits. I have invited them to ask questions on any aspect of the study that concerned them.

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Name (Block Capitals)	Qualifications	Signature	Date

3 copies to be made: 1 for Patient, 1 for Patient’s Medical Chart, and 1 for The National Register team.

College Principal investigators name: Professor Edna Roche.

Principal investigators title: Professor in Paediatrics, Discipline of Paediatrics, Trinity, Dublin..

Contact Details: The National Register for children with Down syndrome, The Trinity Centre for health Sciences, Tallaght University Hospital Dublin 24.

Email: Grainne.OConnor@tuh.ie

Phone: Grainne at 01-4143013

Data protection officer’s identity: Ms Meiread Ashe, Board secretary and Data Protection officer, Children’s Health Ireland, Block A Herberton, St James Walk Rialto, Dublin 8.

Data Protection Officer’s contact details:Email;Meiread.ashe@nchg.ie

Study sponsor: This research is undertaken by the Department of Paediatrics, The University of Dublin, Trinity College Dublin by Professor Edna Roche, Professor Eleanor Molloy and Ms Grainne O Connor and Ms Fiona McGrane.