

# A Guide to the National Cleft Database



Incorporating Children's Health Ireland at  
Temple Street Children's, Children's Health  
Ireland at Crumlin and St James's Hospital

Sláinte Leanaí Éireann



Children's Health Ireland



## **What is a Cleft Database**

The cleft database is a set of information on children or adults who present with cleft lip and/or palate. This information is stored on a computer.

## **Why is a Database needed?**

- To promote agreed standards in service provision
- To audit and report on quality of care
- To monitor the frequency and incidence of cleft lip / cleft palate or both
- To support research
- To plan and develop appropriate services and to coordinate these services

## **How will a Database work?**

A database registration form will be completed for each individual by the consultant in conjunction with the parents/ guardian and Cleft Coordinator. This information is centralised onto a database, which is located in St.James's Hospital. This is known as a Cleft Database.

## **What information will be held on the Cleft Database?**

The database holds demographic information such as patient name and address, PPSN, next of kin, details on the type of clefting, feeding at birth and other clinical information, such as family history of associated syndromes etc: dates and details of clinical procedures, assessment, audit and outcome.

## **Who will see the records on the Database?**

The database records will be available to the individual or in the case of a child, their parent / guardian and to the Cleft Team. The General Data Protection Regulation (GDPR) 2018 emphasises transparency, security and accountability by database controllers while standardising and strengthening

European citizens right to data privacy. The Cleft Database is managed by the Cleft Database Manager and the Cleft Coordinators, who are have a special interest in cleft care.

Data Protection is the means by which your privacy rights are safe guarded in relation to the processing of personal data. The Irish Data Protection Acts of 1988 - 2018 confer rights on individuals as well as placing responsibilities on those persons processing personal data.

### **Who will have access to statistical information from Cleft Database records?**

Statistical information refers to anonymous information from the database, and it contains no identifying information such as name, address or next of kin. Statistical information may be made available to:

- The HSE
- The Health Research Board
- Others with legitimate research interest.

### **How will information be used?**

- To monitor service provision
- To assess future service requirements
- Research
- Statistical analysis
- Annual reports

### **For how long will the records be kept on the Database?**

The information is retained on the database while the individual is on receipt of, or in need of services.

### **Will the Database be secure and confidential?**

The database will maintain a consent, confidentiality and security policy in line with appropriate GDPR and Irish Data Protection Acts 1988 - 2018 Further information can be found at [www.dataprotection.ie](http://www.dataprotection.ie)

## How do I give consent?

Each individual, or in the case of a child, the parent/guardian will be asked to give a written consent prior to entry on the database. Persons 16 and over can consent for themselves.

## Is participation voluntary?

Yes consent is voluntary, but we hope that everyone will participate.

## How do I get more information on the Cleft Database?

If you would like more information on any aspect of the Cleft Database, you can contact one of the Cleft Coordinators below Monday to Friday 9.00am to 5.00pm

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