



Department of Children and Youth Affairs

Inventory of Data Sources on Children's Lives

A19 Cystic Fibrosis Registration and Diagnosis Form

Data owner	Cystic Fibrosis Registry of Ireland (www.cfri.ie)
Brief description	The Cystic Fibrosis Registry of Ireland project was established in 2001 to keep the relevant medical records of each patient with cystic fibrosis in a central database. Enrolment on the Register is voluntary and currently over 90% of the Cystic Fibrosis (CF) population are registered.
Primary function of data	Disease registration and the collection and analysis of information relating to cystic fibrosis. Data are used to facilitate research and provide accurate reports in order to monitor and improve treatments that will contribute to the quality of care of persons with cystic fibrosis.
Key classificatory variables	ID Other; Sex; DOB; County; Geog Sub County; Geog Other; Ethnicity; Nationality; Traveller
Themes/domains	Health; Demographics
Unit of observation	Person diagnosed with cystic fibrosis
Start date of data collection	Established in 2001
Frequency of data collection	Enrolment on the Register occurs twice per patient. If a person is on the Register before they turn 18 years of age, re-consent to continue on the Register is sought after turning 18.
Data format	Separate record for each unit of observation
Method of data collection	Enrolment on the Register is done through the specialist Cystic Fibrosis centres and by CFRI Researchers. The patient records are entered on the computer database by Clinical Research Associates from the Cystic Fibrosis Registry of Ireland.
Access/further information	Cystic Fibrosis Registry of Ireland: www.cfri.ie . The Registry is accessible through the Internet to permitted users only. Publications available at: www.cfri.ie/publications.php