European Surveillance of Congenital Anomalies

Supported by the EU-Commission Public Health Directorate
Programme of Community Action on Rare Diseases
/Public Health Programme
WHO Collaborating Centre for the Epidemiological Surveillance
of Congenital Anomalies
What is EUROCAT?

- European network of population-based registries for the epidemiologic surveillance of congenital anomalies.
- Started in 1979
- More than 1 million births surveyed per year in Europe
- 39 registries in 19 countries
- 25% of European birth population covered
- High quality multiple source registries, ascertaining terminations of pregnancy as well as births.
EUROCAT management structure

- Central Registry at University of Ulster with Project Leader, administration, database management and research assistance
- Experts in other institutions work with Central Registry on co-ordination tasks
- Committees and Working Groups of EUROCAT registry members and experts
- Project Management Committee: elected registry leaders + working group/committee leaders
Objective 1:
To provide essential epidemiologic information on congenital anomalies in Europe

- Data harmonisation
- Data management
- Data dissemination (www.eurocat.ulster.ac.uk)
Data harmonisation

- Full members (34): data on individual cases with population denominators. Associate members (5): aggregate case data with population denominators.
- Agreed information (variable) set and coding guidelines (EUROCAT Guide 1.2)
- Data Validation
  - Range errors and improbable values, logical relationships between variables
  - Diagnostic and reporting/registration methods (eg: hypospadias)
Data Management

- Central database: >250,000 cases of congenital anomaly among livebirths, stillbirths and terminations of pregnancy since 1980
- EUROCAT Data Management Programme (“EDMP”) for local data management and transmission to Central Registry
- Computing developments at Central Registry provided to local registries in EDMP
EUROCAT Data Management Program
Central Registry

Main Menu

Add New Case  Print Case  Reports
Edit Existing Case  Import Data  Error Log
View Case  Export Data to Eurocat  System Menu

Choose Dataset Input / Output
- Core Data Only
- Core & Non-Core Data

Exit EDMP
Selection Criteria

- A1: Total number of cases, number of cases by type of birth (liveborn, fetal death, induced abortion), and total prevalence rate per 10,000 births congenital anomaly subgroups in selected registries (registries combined), selected time period (available for 20 full member registries)

- A5: Selected congenital anomaly: Total number of cases, number of cases by type of birth (liveborn, fetal death, induced abortion), population and total prevalence per 10,000 births per year and per registry in selected registries, selected time period (available for 32 registries)

- B3: Selected congenital anomaly: Total number of cases, number of cases by type of birth (liveborn, fetal death, induced abortion), total, birth, livebirth prevalence rates per 10,000 births, per registry, in selected registries, selected time period (available for 32 registries)

- F1: Selected congenital anomaly: Line graph of total, birth and livebirth prevalence rate per 10,000 births per year, in selected registries, selected time period

(NB: Italicised type indicates that choice is available from an option menu).

Date From: [ ] (eg. 1997)

Date To: [ ]

Continue

Click Here to view table and definitions

Programming by BioMedical Com
(E3) - Cleft lip with or without palate (prevalence per 10,000 births) for the following registries: Galway, Dublin, Mersey, North Thames (West), Glasgow, From 1980 - 1999

<table>
<thead>
<tr>
<th>Registry</th>
<th>LB N</th>
<th>FD N</th>
<th>IA N</th>
<th>LB+FD+IA N</th>
<th>LB Rate</th>
<th>LB+FD Rate</th>
<th>LB+FD+IA Rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dublin (Ireland)</td>
<td>347</td>
<td>20</td>
<td>0</td>
<td>367</td>
<td>6.31</td>
<td>8.73</td>
<td>8.73</td>
</tr>
<tr>
<td>Galway (Ireland)</td>
<td>31</td>
<td>5</td>
<td>0</td>
<td>36</td>
<td>5.44</td>
<td>6.28</td>
<td>6.28</td>
</tr>
<tr>
<td>Mersey (UK: England)</td>
<td>110</td>
<td>2</td>
<td>5</td>
<td>117</td>
<td>6.66</td>
<td>6.64</td>
<td>6.94</td>
</tr>
<tr>
<td>North Thames (West) (UK: England)</td>
<td>338</td>
<td>19</td>
<td>74</td>
<td>431</td>
<td>7.14</td>
<td>7.55</td>
<td>9.11</td>
</tr>
<tr>
<td>Glasgow (UK: Scotland)</td>
<td>191</td>
<td>13</td>
<td>22</td>
<td>226</td>
<td>7.49</td>
<td>7.96</td>
<td>8.81</td>
</tr>
<tr>
<td>Wales (UK: Wales)</td>
<td>61</td>
<td>1</td>
<td>10</td>
<td>72</td>
<td>6.26</td>
<td>6.32</td>
<td>7.34</td>
</tr>
<tr>
<td><strong>Total (full member registries)</strong></td>
<td><strong>1070</strong></td>
<td><strong>60</strong></td>
<td><strong>111</strong></td>
<td><strong>1249</strong></td>
<td><strong>7.34</strong></td>
<td><strong>7.72</strong></td>
<td><strong>8.47</strong></td>
</tr>
</tbody>
</table>

LB = Live Births  
FD = Fetal Deaths / Still Births from 20 weeks gestation  
IA = Induced Abortions following prenatal diagnosis

For total live birth rates where the live birth denominator is not available, the denominator has been substituted by the total number of births (live births + stilts). This applies to the following registries: North Thames (West)

<table>
<thead>
<tr>
<th>Description Of Anomaly</th>
<th>ICD9</th>
<th>ICD10</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clefting of the upper lip with or without clefting of the maxillary alveolar process and hard and soft palate</td>
<td>7491, 7492</td>
<td>036-037</td>
<td></td>
</tr>
</tbody>
</table>
Objective 2.
To co-ordinate the establishment of new registries throughout Europe collecting comparable, standardised data

- Recent new members: Hungary, Sweden, 4 UK regions
- Ready protocols and software
- Annual Registry Leaders Meetings and biannual European Symposium on the Prevention of Congenital Anomalies
Objective 3.
To co-ordinate the detection and response to clusters and early warning of teratogenic exposures

– Statistical monitoring of clusters and trends
– Rapid communication and reaction network
– Monitoring of multiple malformations
– Collaborative investigation of exposures of concern
– Web-based Cluster Advisory Service
EUROCAT Cluster Advisory Service

• Web-based
• Make accumulated European (and American) experience easily accessible to registries/local health authorities
• Balance epidemiologic investigation with appropriate risk communication and public health response
Objective 4.
To evaluate the effectiveness of primary prevention

- Survey of policy and practice in relation to periconceptional folic acid supplementation and fortification in 18 European countries
- Analysis of neural tube defect prevalence up to 2001
- EUROCAT Special Report 2003 on website
NTD Prevalence per 10,000 births 1980-2001

NTD rate by year in the UK and Ireland: adjusted for registry

NTD rate by year in Europe: adjusted for registry

UK registries

Continental Europe
Objective 5:
To assess the impact of developments in prenatal screening

• Regional variation in proportion of anomalies prenatally diagnosed and in proportion of terminations
• Down Syndrome: joint impact of maternal age and screening changes
The rise in proportion of older mothers in selected EUROCAT regions 1980-99
Objective 6.
To provide an information and resource centre and ready collaborative research network to address the causes and prevention of congenital anomalies and the treatment, care and outcome of affected individuals.

• Provision of data
• Analysis of data
• Provision of network
• European Symposia
Current Research

- WHO World Craniofacial Anomalies Database
- ICBD Gastroschisis Study
- Maternal age-specific rates of Down Syndrome for mothers 40+
- Multiple births/assisted conception and congenital anomalies
- Epidemiology of specific anomalies: Hydrocephaly, Hypospadias, Trisomy 18, renal anomalies
- Multiple malformations
- Impact of prenatal diagnosis on postnatal outcome (cardiac anomalies)
- Socioeconomic variation and clustering in Britain
- Evaluation of Capture-recapture techniques
Why European collaboration?

• Pooling of data
• Comparison of data
• Common response to public health questions
• Sharing of expertise and resources
Phase 2004-2007 (1)

- **Objective 1:**
  - Updating of prevalence data
  - Revision of common dataset
  - Provision of data to other organisations
  - Compilation of data quality indicators

- **Objective 2:**
  - Assistance to and exchange with new/applicant members
  - One day induction workshops before annual Registry Leaders meetings
Phase 2004-2007 cont (2)

• Objective 3
  – Testing, training and implementation of new statistical monitoring software
  – Annual Central statistical monitoring
  – Response to clusters or public health concerns through analysis of Central database or co-ordination of extra data collection
  – Drug surveillance (collaboration ICBDMS Madre)
  – Multiple malformation monitoring (with ICBDMS)
  – EUROCAT internal Communications as rapid reaction and response facility
  – Maintenance, updating and translation of web-based Cluster Advisory Service
Phase 2004-2007 cont (3)

• Objective 4:
  – Yearly updating of website re NTD prevalence
  – Annual survey of periconceptional folic acid policy and practice
  – Analysis of available data on protective effect of folic acid on other anomalies

• Objective 5:
  – Annual updating of website re frequency of termination following prenatal diagnosis
  – Analysis of Central database regarding joint impact of prenatal screening and maternal age changes on geographic inequalities in livebirth prevalence and perinatal mortality.
Phase 2004-2007 cont (4)

- Objective 6:
  - European Workshop on methodological approaches to the assessment of the impact of environmental pollution on the risk of congenital anomalies
  - 8th European Symposium on the Prevention of Cong Anomalies
  - Central Registry administrative and database support for research, and provision of anonymised data extracts on request
Phase 2004-2005 cont (5)

• Other:
  – Annual registry leaders meeting
  – Collaboration with other organisations e.g.
    • Orphanet: weblinks and provision of prevalence summaries
    • EURORDIS: weblinks and exchange of expertise
    • ENCR: consideration of common issues
    • NEPHIRD: weblinks, provision of data, project collaboration
    • PERISTAT: weblinks, exchange of expertise, consideration of common issues
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