Joint Action N° 20102204 under EU Health Programme 2008-2013

European Surveillance of Congenital Anomalies (EUROCAT)

Summary

1. General objectives
To facilitate the reduction of the public health burden of congenital anomalies (CA) by epidemiological surveillance through the EUROCAT network of population-based congenital anomaly registers.

2. Strategic relevance and contribution to the public health programme
Congenital anomalies are a major group of mainly rare diseases where concerted action across Europe has been identified as a priority in the Council Recommendation of 8 June 2009 on an action in the field of rare diseases, and in the Communication from the Commission on Rare Diseases: Europe’s challenges of November 2008. These recognise the need for registries and databases co-ordinated at a European level, for pooling of expertise at European level, for improving the coding and classification of rare diseases, for comparable epidemiological data at EU level, and for identifying the possibilities for primary preventive measures – all these areas being central to EUROCAT’s activities. Moreover, they emphasise the need for sustainability of successful European networks in these areas.

3. Methods and means
The EUROCAT network has been in existence since 1979, in the last ten years co-funded by DG Sanco’s Rare Diseases and Public Health Programmes. 1.5 million births per year, comprising 28% of births in the European Union as well as some non-European countries, are covered by 38 Registries in 21 countries. Cases of congenital anomaly among livebirths, stillbirths and terminations of pregnancy following prenatal diagnosis, are registered using multiple sources of information. A standard anonymised dataset is transmitted by each member Registry, using common software, to a central database at EUROCAT Central Registry, and subject to data quality validation. The Central Registry ensures the provision of updated prevalence and related data on the EUROCAT website in a user-driven interactive table generation format (www.eurocat-network.eu). It further conducts statistical monitoring for trends and clusters, and will provide data and assistance to the other workpackages to answer a variety of questions pertinent to prevalence, prevention and prenatal screening.

4. Expected outcomes
1. Available and accessible epidemiological info updated to 2011 on prevalence of CA, perinatal mortality due to CA, and prenatal detection rates, on EUROCAT website
2. The detection, investigation and reporting of clusters and trends in CA prevalence

Website: http://www.eurocat-network.eu/
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Project leader:
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Associated Partners:
✓ Academisch Ziekenhuis Groningen(Netherlands)
✓ Agencia de Salut Publica de Barcelona(Spain)
✓ Asociacion Espanola para el Registro y Estudio de las
3. Assessment of teratogenic impact of new or changing environmental exposures, including swine flu related exposures as well as maternal chronic diseases
4. Evaluation of potential for linkage between registers and e-info systems on exposure
5. A framework for national plans for primary prevention of CA, and evaluation of progress in the prevention of neural tube defects by raising periconceptional folic acid status
6. Evaluation of impact of delayed childbearing and changes in prenatal screening techniques as well as policies on Down Syndrome
7. The development of EUROCAT's role as core pregnancy-related pharmacovigilance system in Europe (EUROmediCAT)
8. The addition of at least 3 new registries to network, inc 2 new EU countries, the provision of guidelines and related software to interested regions/countries
9. Improved coding and classification of CA
10. Two European Symposia on Prevention of CA

**Keywords and portfolio**

**Keywords**
Newborn & perinatal health within Target groups
Rare diseases and disorders within Non communicables diseases
Screening within Methods
Patients registries within Methods
Environmental factor

**Portfolio**
Rare diseases within Taking Action against Diseases
<table>
<thead>
<tr>
<th>Organisation and Location</th>
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<tbody>
<tr>
<td>Zagreb (Croatia)</td>
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<tr>
<td>Ministry of Health Elderly and Community Care, Department of Health Information and Research (Malta)</td>
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<td>National Centre for Healthcare Audit and Inspection (Hungary)</td>
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<td>National Institute for Welfare and Health (Finland)</td>
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<td>Norwegian Institute of Public Health (Norway)</td>
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<td>Otto-von-Guericke University Madgeburg (Germany)</td>
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<td>Paris Registry of Congenital Malformations, Inserm (French National Institute of Health and Medical Research), Unit 953 (France)</td>
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<td>The Chancellor, Masters &amp; Scholars of the University of Oxford (United Kingdom)</td>
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<td>Université de Strasbourg (France)</td>
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✓ University Medical Centre of the Johannes Gutenberg University Mainz (Germany)
✓ University Medical Centre, Ljubljana (Slovenia)
✓ University of Groningen (Netherlands)
✓ University of Leicester (United Kingdom)
✓ University of Newcastle upon Tyne (United Kingdom)

Maximum EC Contribution: 1 106 302.00 €

Duration: 36
European Surveillance of Congenital Anomalies

Reports & deliverables

Final Report
✓ Final Report
   ✓ Final Report (EN) (P)

Assessment Report
✓ Internal Assessment
   ✓ Internal Assessment (EN) (C)

Deliverables
✓ Deliverables
   ✓ D01 - Final Report (P)
      ✓ D01-01 - Final Report (EN) (P)
      ✓ D01-02 - Interim Report (EN) (P)
      ✓ D01-03 - Interim Report (EN) (P)
   ✓ D02 - Two European Symposia (P)
      ✓ D02-01 - Two European Symposia (EN) (P)
      ✓ D02-02 - Two European Symposia (EN) (P)
   ✓ D03 - Evaluation Report (P)
      ✓ D03 - Evaluation Report (EN) (P)
   ✓ D04 - Website Epidemiological Tables updated to 2011 (P)
      ✓ D04-01 - Website Epidemiological Tables updated to 2011 (EN) (P)
      ✓ D04-02 - Website Epidemiological Tables updated to 2011 (EN) (P)
      ✓ D04-03 - Website Epidemiological Tables updated to 2011 (EN) (P)
   ✓ D05 - Statistical Monitoring Reports Part A (P)
      ✓ D05-01 - Statistical Monitoring Reports Part A (EN) (P)
      ✓ D05-02 - Statistical Monitoring Reports Part A (EN) (P)
      ✓ D05-03 - Statistical Monitoring Reports Part A (EN) (P)
   ✓ D06 - ICD11 Coding Revision Submission (P)
      ✓ D06 - ICD11 coding revision submission (EN) (C)
   ✓ D07 - Investigation Report (P)
      ✓ D07-01 - Investigation Report (EN) (P)
      ✓ D07-02 - Investigation Report (EN) (P)
      ✓ D07-03 - Investigation Report (EN) (P)
      ✓ D07-04 - Investigation Report (EN) (P)
      ✓ D07-05 - Investigation Report (EN) (P)
      ✓ D07-06 - Investigation Report (EN) (P)
      ✓ D07-07 - Investigation Report (EN) (P)
✓ D07-08 - Investigation Report (EN) (P)
✓ D07-09 - Investigation Report (EN) (P)
✓ D07-10 - Investigation Report (EN) (P)
✓ D08 - Report on Primary Prevention of Congenital Anomalies (P)
✓ D08 - Report on Primary Prevention of Congenital Anomalies (EN) (P)
✓ D09 - Set of 6 Scientific Dawn Syndrome and other Genetic Syndrome Papers (P)
  ✓ D09-01- Set of 6 Scientific Dawn Syndrome and other Genetic Syndrome Papers (EN) (C)
  ✓ D09-02- Set of 6 Scientific Dawn Syndrome and other Genetic Syndrome Papers (EN) (P)
  ✓ D09-03- Set of 6 Scientific Dawn Syndrome and other Genetic Syndrome Papers (EN) (P)
  ✓ D09-04- Set of 6 Scientific Dawn Syndrome and other Genetic Syndrome Papers (EN) (P)
  ✓ D09-05- Set of 6 Scientific Dawn Syndrome and other Genetic Syndrome Papers (EN) (C)
  ✓ D09-06- Set of 6 Scientific Dawn Syndrome and other Genetic Syndrome Papers (EN) (C)
✓ D10 - EUROmediCAT Papers (P)
  ✓ D10-01- EUROmediCAT Papers (EN) (P)
  ✓ D10-02- EUROmediCAT Papers (EN) (P)
  ✓ D10-03- EUROmediCAT Papers (EN) (C)

Others
✓ Others