**JRC - Central Registry**

european surveillance of congenital anomalies



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| **EUROCAT Data Request Form (v13.03.2017)** |

This Data Request Form has been prepared in accordance with the JRC-EUROCAT Collaboration Agreement.

|  |  |
| --- | --- |
| 1 | **Title of the project** |
|  |  |
|  |  |
| 2 | **Researcher/s Name** (\*Lead Investigator first then include anyone who will have access to the data or a role in the project) |
|  |  |
|  |  |
|  |  |
|  |  |
| 3 | **Current positions held** (of named researchers above) |
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|  |  |
|  |  |
| 4 | **Address and Contact Details of Lead Investigator** (Lead Investigator - please attach a brief CV with your application giving the name, address, qualifications, current position, most recent publications, and most recent research projects) |
|  |  |
|  | **Address:**  |
|  |  |
|  | **Telephone / Fax:**  |
|  |  |
|  | **Email:** |
|  |  |

|  |  |
| --- | --- |
| 5 | **Ethical Approval**  |
|  | Has ethical approval been granted by Lead Investigator’s Institution (tick answer)? |
|  | [ ]  ethical approval granted\* |
|  | [ ]  ethical approval pending\*[ ]  ethical approval not required (please state why) |
|  |  |
|  |  |
| 6 | **Proposed study start date** |
|  |  |
|  | **Proposed study completion date** |
|  |  |
|  |  |
| 7 | **Summary of the study** (please attach a full research protocol where available) |
|  | **Background:****Aim:** |

|  |  |
| --- | --- |
| 8 | **Method** (please outline the design of the study, population and definition of main outcome measures) |
|  | **Registers to be included:**  |
|  | **Cases to be included:** |
|  | **Anomalies to be included:** |
|  |  |
|  | **Statistical Methods:** |
|  |  |
| 9 | (a) **Type of data required** (please select ‘yes’ or ‘no’) |
|  | Unidentifiable case data yes/no |
|  | Aggregate data (i.e. numbers of cases) yes/no |
|  |  |
|  | (b) **Case definition** (please tick) |
|  | [ ]  All congenital anomalies |
|  | [ ]  Selected congenital anomalies |
|  | Please specify text description and BOTH ICD 9/BPA codes and ICD 10 codes (attach if necessary) |
|  |  |
|  |  |
|  | [ ]  live births |
|  | [ ]  fetal deaths or still births from 20 weeks gestation |
|  | [ ]  terminations of pregnancy |
|  | [ ]  other, please state |
|  |  |
|  | (c) Variables requested from EUROCAT Central Registry (for those needing unidentifiable case data only). Tick boxes on attached variable list (Annex A). The full list of variables and derived variables can be seen in Chapters 2.2.1 and 2.2.2 of Guide 1.3 and/or Guide 1.4 <http://www.eurocat-network.eu/ABOUTUS/DataCollection/GuidelinesforRegistration/Guide1_3InstructionManual> <http://www.eurocat-network.eu/aboutus/datacollection/guidelinesforregistration/guide1_4> |

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|  | (e) **Registries and Years requested** (please tick) |
|  | (Please see EUROCAT website for details: Members & Registry Descriptions <http://www.eurocat-network.eu/ABOUTUS/MemberRegistries/MembersAndRegistryDescriptions/AllMembers> and website tables <http://www.eurocat-network.eu/ACCESSPREVALENCEDATA/PrevalenceTables> ) |
|  |  |
|  | [ ]  All registries |
|  | [ ]  All Full Member Registries |
|  | [ ]  All Associate Member Registries |
|  | Selected Registries: see **Annex B** |
|  | Years:  |
|  |  |
|  | (f) **Denominator (birth) data required** (please tick) |
|  | [ ]  none[ ]  maternal age |
|  | [ ]  total births per year  |
|  | [ ]  live births per year  |
|  | [ ]  still births per year  |
|  | [ ]  other (please specify)  |
|  |  |
| 10 | **Format of data for transmission**  |
|  | Electronic yes/no Zip disk 250MB yes/no |
| 11 | **How do you intend to publish your research?** |
|  |  |

**Please sign and return the JRC-EUROCAT Data Request Form (by email and by post) to:**

**European Commission**DG Joint Research Centre
Directorate F – Health, Consumers and Reference MaterialsHealth in Society Unit (F.1)
JRC-EUROCAT Central Registry

TP 127
Via Enrico Fermi 2749,
I-21027 ISPRA (VA), ITALY

Tel.: +39 0332 78 9926
Fax: +39 0332 78 3858

**JRC-EUROCAT Central Registry Email:** **JRC-EUROCAT@ec.europa.eu**

**Applicant Checklist**

|  |  |
| --- | --- |
|  | *[ ]  supplied research protocol (where applicable)**[ ]  supplied brief CV of lead investigator* |
|  | *[ ]  supplied proof of ethics approval (where applicable)*  |
|  | *[ ]  completed Annex A*  |
|  | *[ ]  signed form*  |
|  |  |
|  | *Signed:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_* |
|  |  |
|  |  |
|  | *Date:* |

####  Annex A: VARIABLES LIST (core variables are shaded in grey)

####  *(please tick the selected variables)*

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|  |  |  |
| --- | --- | --- |
| **Variable Name** | **Variable Heading** | **Tick to Select** |
| CENTRE | Centre Number |  |
| NUMLOC | Local ID |  |
| BYEAR | Year of Birth (derived variable) |  |
| SEX | Sex |  |
| NBRBABY | Number of babies/fetuses delivered |  |
| SP\_TWIN | Specify twin type of birth, like or unlike, zygosity |  |
| NBRMALF | Number of malformed in multiple set |  |
| Birth\_TYPE | EUROCAT recoded birth type (derived variable) |  |
| CIVREG | Civil registration status |  |
| WEIGHT | Birth weight |  |
| GESTLENGTH | Length of gestation in completed weeks |  |
| SURVIVAL | Survival beyond one week of age |  |
| DEATH\_DATE | Date of death  |  |
| DATEMO | Date of birth of mother |  |
| AGEMO | Age of mother at delivery |  |
| RESIDMO | Mother’s residence code |  |
| TOTPREG | Total number of previous pregnancies |  |
| WHENDISC | When discovered |  |
| CONDISC | Condition at discovery |  |
| AGEDISC | If prenatally diagnosed, gestational age at discovery |  |
| FIRSTPRE | First positive prenatal test |  |
| SP\_FIRSTPRE | Specify first prenatal test in text if coded 7 (“other test positive“) |  |
| KARYO | Karyotype of infant/fetus |  |
| SP\_KARYO | Specify karyotype |  |
| PM | Post mortem examination |  |
| SURGERY | First surgery for malformation performed or planned |  |
| SYNDROME | Syndrome |  |
| SP\_SYNDROME | Specify Syndrome |  |
| MALFO1 | Malformation |  |
| SP\_MALFO1 | Specify malformation |  |
| MALFO2 | As MALFO1 |  |
| SP\_MALFO2 | Specify malformation |  |
| MALFO3 | As MALFO1 |  |
| SP\_MALFO3 | Specify malformation |  |
| MALFO4 | As MALFO1 |  |
| SP\_MALFO4 | Specify malformation |  |
| MALFO5 | As MALFO1 |  |
| SP\_MALFO5 | Specify malformation |  |
| MALFO6 | As MALFO1 |  |
| SP\_MALFO6 | Specify malformation |  |
| MALFO7 | As MALFO1 |  |
| SP\_MALFO7 | Specify malformation |  |
| MALFO8 | As MALFO1 |  |
| SP\_MALFO8 | Specify malformation |  |
| MCKUSICK | McKusick Code / Type of Mendelian Inheritance |  |
| AETIOLOGY | Aetiological classification of malformation |  |
| ASSCONCEPT | Assisted conception |  |
| OCCUPMO | Mother’s occupation at time of conception |  |
| ILLBEF1 | Illness before pregnancy 1 |  |
| ILLBEF2 | Illness before pregnancy 2 |  |
| ILLDUR1 | Illness during pregnancy  |  |
| ILLDUR2 | Illness during pregnancy 2 |  |
| FOLIC | Folic acid supplementation |  |
| DRUGS1 | Drugs |  |
| SP\_DRUGS1 | Specify drug exposures |  |
| DRUGS2 | As for DRUGS1 |  |
| SP\_DRUGS2 | Specify drug exposures |  |
| DRUGS3 | As for DRUGS1 |  |
| SP\_DRUGS3 | Specify drug exposures |  |
| DRUGS4 | As for DRUGS1 |  |
| SP\_DRUGS4 | Specify drug exposures |  |
| DRUGS5 | As for DRUGS1 |  |
| SP\_DRUGS5 | Specify drug exposures |  |
| CONSANG | Consanguinity |  |
| SP\_CONSANG | Specify text information on consanguinity |  |
| SIBANOM | Siblings with anomalies |  |
| SP\_SIBANOM | Specify type of anomaly and describe the malformation |  |
| PREVSIB | Previous malformed sibs notified to EUROCAT |  |
| SIB1 | Local ID number notified to the Central Registry |  |
| SIB2 | As SIB1 |  |
| SIB3 | As SIB1 |  |
| MOANOM | Mother’s family with anomalies |  |
| SP\_MOANOM | Specify type of anomaly and describe the malformation |  |
| FAANOM | Father’s family with anomalies |  |
| SP\_FAANOM | Specify type of anomaly and describe the malformation |  |
| Al1 to al97 | EUROCAT subgroups (0=No, 1=Yes). Derived variable based on EUROCAT coding |  |

####  Annex B: List of Registries requested to participate

*(please tick the selected registries)*

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Registry Number** | **Country** | **Registry name** | **Membership status** | **Type of data** | **Requested (tick to select)** |
| 2 | Belgium | Hainaut-Namur | Full | Individual |  |
| 5 | France | Paris | Full | Individual |  |
| 8 | Italy | Tuscany | Full | Individual |  |
| 10 | Ireland | Dublin | Full | Individual |  |
| 13 | Netherlands | North Netherlands | Full | Individual |  |
| 18 | Italy | Emilia Romagna | Full | Individual |  |
| 20 | Switzerland | Vaud | Full | Individual |  |
| 21 | Croatia | Zagreb | Full | Individual |  |
| 23 | Malta | Malta | Full | Individual |  |
| 28 | Portugal | South Portugal | Full | Individual |  |
| 29 | Belgium | Antwerp | Full | Individual |  |
| 30 | Spain | Basque Country | Full | Individual |  |
| 33 | Germany | Saxony Anhalt | Full | Individual |  |
| 34 | Germany | Mainz | Full | Individual |  |
| 38 | Finland | Finland | Associate | Aggregate |  |
| 39 | Austria | Styria | Full | Individual |  |
| 49 | Ireland | Cork & Kerry | Full | Individual |  |
| 55 | Spain | Hospital Network  | Associate | Aggregate |  |
| 57 | United Kingdom | Wales  | Full | Individual |  |
| 59 | Norway | Norway | Full | Individual |  |
| 60 | France | Auvergne | Full | Individual |  |
| 62 | Ukraine | OMNI-Net | Full | Individual |  |
| 66 | France | Isle de Reunion | Full | Individual |  |
| 67 | Poland | Wielkopolska | Full | Individual |  |
| 68 | United Kingdom | PHE/Thames Valley | Full | Individual |  |
| 70 | United Kingdom | PHE/Wessex | Full | Individual |  |
| 71 | Sweden | Sweden | Associate | Aggregate |  |
| 72 | United Kingdom | PHE/East Midlands & South Yorkshire | Full | Individual |  |
| 73 | United Kingdom | PHE/Northern England | Full | Individual |  |
| 76 | Poland | Polish Registry | Associate | Aggregate |  |
| 79 | Ireland | South East Ireland | Full | Individual |  |
| 81 | France | French West Indies | Full | Individual |  |
| 83 | Czech Republic | Czech Republic | Associate | Aggregate |  |
| 84 | United Kingdom | PHE/South West England | Full | Individual |  |
| 86 | Spain | Valencia Region | Full | Individual |  |
| 88 | France | Brittany | Full | Individual |  |