**JRC - Central Registry**

european surveillance of congenital anomalies



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| **EUROCAT Data Request Form (v07.02.2023)** |

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

|  |  |
| --- | --- |
| 1 | **Title of the project** |
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|  |  |
| 2 | **Researcher/s Name** (\*Lead Investigator first then include anyone who will have access to the data or a role in the project) |
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| 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’) |
|  | Pseudonymised case data select yes/no  |
|  | Aggregate data (i.e. numbers of cases) select yes/no  |
|  |  |
|  | **(b)** **Case definition – anomalies** (please tick) |
|  | [ ]  All congenital anomalies |
|  | [ ]  Selected congenital anomalies |
|  | Please specify text description and BOTH ICD9-BPA codes and ICD10 codes (attach if necessary) |
|  |  |
|  | **(c)** **Case definition – birth outcomes** (please tick) |
|  | [ ]  Live births |
|  | [ ]  Fetal deaths or still births from 20 weeks gestation |
|  | [ ]  Terminations of pregnancy for fetal anomalies (TOPFA) |
|  | [ ]  Other, please state |
|  |  |
|  | (d) Variables requested from the JRC-EUROCAT Central Registry (for those needing pseudonymised case data only). To select the variables please tick boxes in the variable list in Annex A. The full list and description of variables can be found in Sections 2.2.1 and 2.2.2 of the [EUROCAT Guide 1.5](https://eu-rd-platform.jrc.ec.europa.eu/eurocat/data-collection/guidelines-for-data-registration_en).  |
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|  | (e) **Registries included** (please tick)  *see EUROCAT website* [*Members & Registry Descriptions*](https://eu-rd-platform.jrc.ec.europa.eu/eurocat/eurocat-members/registries_en) *and* [*Prevalence tables*](https://eu-rd-platform.jrc.ec.europa.eu/eurocat/eurocat-data/prevalence_en)*)* |
|  |  |
|  | [ ]  All registries |
|  | [ ]  All Full Member Registries |
|  | [ ]  All Associate Member Registries |
|  | If data only from a selection of registries is requested, please indicate the names selected registries below: Please list selected registries here |
|  | (f) **Years requested** Indicate the **birth years** for which the data are requested: Please list birth years here |
|  |  |
|  | (g) **Denominator (birth) data required** (please tick) |
|  | [ ]  none[ ]  maternal age |
|  | [ ]  total births per year  |
|  | [ ]  live births per year  |
|  | [ ]  still births per year  |
|  | [ ]  other (please specify)  |
|  |  |
|  |  |
| 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**Joint Research Centre
Directorate F – Health and FoodDisease Prevention Unit (F.1)
JRC-EUROCAT Central Registry

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

Tel.: +39 0332 78 9246

**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, EUROCAT core variables are shaded in blue

#### Please tick the selected variables:

|  |  |  |  |
| --- | --- | --- | --- |
| **Variable Name** | **Variable heading** | **Variable available since:** | **Tick to select** |
| CENTRE | Centre Number | All years |[ ]
| NUMLOC | Local ID | All years |[ ]
| BYEAR | Year of Birth (derived variable) | All years |[ ]
| SEX | Sex | All years |[ ]
| NBRBABY | Number of babies/fetuses delivered | All years |[ ]
| SP\_TWIN | Specify twin type of birth, like or unlike sex, zygosity | Guide 1.3, 2005 |[ ]
| NBRMALF | Number of malformed in multiple set | Guide 1.1, 1990 |[ ]
| TYPE | Type of Birth | All years |[ ]
| CIVREG | Civil registration status | Guide 1.3, 2005 |[ ]
| WEIGHT | Birth weight | All years |[ ]
| GESTLENGTH | Length of gestation in completed weeks | All years |[ ]
| SURVIVAL | Survival beyond one week of age | Guide 1.1, 1990 |[ ]
| AGEMO | Age of mother at delivery | All years |[ ]
| BMI | Maternal Body Mass Index | Guide 1.4, 2013 |[ ]
| TOTPREG | Total number of previous pregnancies | All years |[ ]
| WHENDISC | When discovered | All years |[ ]
| CONDISC | Condition at discovery | All years |[ ]
| AGEDISC | If prenatally diagnosed, gestational age at discovery | Guide 1.1, 1990 |[ ]
| FIRSTPRE | First positive prenatal test | Guide 1.3, 2005 |[ ]
| SP\_FIRSTPRE | Specify first prenatal test in text if coded 7 (“other test positive“) | Guide 1.3, 2005 |[ ]
| KARYO | Karyotype of infant/fetus | All years |[ ]
| SP\_KARYO | Specify karyotype | All years |[ ]
| GENTEST | Genetic test | Guide 1.4, 2013 |[ ]
| SP\_GENTEST | Specify genetic test | Guide 1.4, 2013 |[ ]
| PM | Post mortem examination | All years |[ ]
| SURGERY | First surgery for malformation performed or planned | Guide 1.3, 2005 |[ ]
| SYNDROME | Syndrome | All years |[ ]
| SP\_SYNDROME | Specify Syndrome | All years |[ ]
| MALFO1 | Malformation | All years |[ ]
| SP\_MALFO1 | Specify malformation | All years |[ ]
| MALFO2 | As MALFO1 | All years |[ ]
| SP\_MALFO2 | Specify malformation | All years |[ ]
| MALFO3 | As MALFO1 | All years |[ ]
| SP\_MALFO3 | Specify malformation | All years |[ ]
| MALFO4 | As MALFO1 | All years |[ ]
| SP\_MALFO4 | Specify malformation | All years |[ ]
| MALFO5 | As MALFO1 | All years |[ ]
| SP\_MALFO5 | Specify malformation | All years |[ ]
| MALFO6 | As MALFO1 | All years |[ ]
| SP\_MALFO6 | Specify malformation | All years |[ ]
| MALFO7 | As MALFO1 | All years |[ ]
| SP\_MALFO7 | Specify malformation | All years |[ ]
| MALFO8 | As MALFO1 | All years |[ ]
| SP\_MALFO8 | Specify malformation | All years |[ ]
| PRESYN | Prenatal diagnosis for syndrome | Guide 1.4, 2013 |[ ]
| PREMAL1 | Prenatal diagnosis for malformation | Guide 1.4, 2013 |[ ]
| PREMAL2 | As PREMAL1 | Guide 1.4, 2013 |[ ]
| PREMAL3 | As PREMAL1 | Guide 1.4, 2013 |[ ]
| PREMAL4 | As PREMAL1 | Guide 1.4, 2013 |[ ]
| PREMAL5 | As PREMAL1 | Guide 1.4, 2013 |[ ]
| PREMAL6 | As PREMAL1 | Guide 1.4, 2013 |[ ]
| PREMAL7 | As PREMAL1 | Guide 1.4, 2013 |[ ]
| PREMAL8 | As PREMAL1 | Guide 1.4, 2013 |[ ]
| OMIM | OMIM code / type of Mendelian inheritance | Guide 1.1, 1990 |[ ]
| ASSCONCEPT | Assisted conception | Guide 1.1, 1990 |[ ]
| OCCUPMO | Mother’s occupation at time of conception | All years |[ ]
| ILLBEF1 | Illness before pregnancy 1 | Guide 1.1, 1990 |[ ]
| ILLBEF2 | Illness before pregnancy 2 | Guide 1.1, 1990 |[ ]
| MATDIAB | Maternal Pregestational Diabetes | Guide 1.4, 2013 |[ ]
| ILLDUR1 | Illness during pregnancy  | Guide 1.1, 1990 |[ ]
| ILLDUR2 | Illness during pregnancy 2 | Guide 1.1, 1990 |[ ]
| FOLIC\_G14 | Folic acid supplementation | Guide 1.4, 2013\* |[ ]
| FIRSTTRI | First trimester medication | Guide 1.4, 2013 |[ ]
| DRUGS1 | Drugs | All years |[ ]
| SP\_DRUGS1 | Specify drug exposures | Guide 1.1, 1990 |[ ]
| DRUGS2 | As for DRUGS1 | Guide 1.1, 1990 |[ ]
| SP\_DRUGS2 | Specify drug exposures | Guide 1.1, 1990 |[ ]
| DRUGS3 | As for DRUGS1 | Guide 1.1, 1990 |[ ]
| SP\_DRUGS3 | Specify drug exposures | Guide 1.1, 1990 |[ ]
| DRUGS4 | As for DRUGS1 | Guide 1.3, 2005 |[ ]
| SP\_DRUGS4 | Specify drug exposures | Guide 1.3, 2005 |[ ]
| DRUGS5 | As for DRUGS1 | Guide 1.3, 2005 |[ ]
| SP\_DRUGS5 | Specify drug exposures | Guide 1.3, 2005 |[ ]
| EXTRA\_DRUGS | Extra drugs | Guide 1.3, 2005 |[ ]
| CONSANG | Consanguinity | All years |[ ]
| SP\_CONSANG | Specify text information on consanguinity | All years |[ ]
| SIBANOM | Siblings with anomalies | All years |[ ]
| SP\_SIBANOM | Specify type of anomaly and describe the malformation | All years |[ ]
| PREVSIB | Previous malformed sibs notified to EUROCAT | All years |[ ]
| SIB1 | Local ID number notified to the Central Registry | All years |[ ]
| SIB2 | As SIB1 | All years |[ ]
| SIB3 | As SIB1 | All years |[ ]
| MOANOM | Mother’s family with anomalies | All years |[ ]
| SP\_MOANOM | Specify type of anomaly and describe the malformation | All years |[ ]
| FAANOM | Father’s family with anomalies | All years |[ ]
| SP\_FAANOM | Specify type of anomaly and describe the malformation | All years |[ ]
| MATEDU | Maternal education | Guide 1.3, 2005 |[ ]
| SOCM | Socioeconomic status of mother | Guide 1.3, 2005 |[ ]
| SOCF | Socioeconomic status of father | Guide 1.3, 2005 |[ ]
| MIGRANT | Migrant status | Guide 1.3, 2005 |[ ]
| Al1 to al131 | EUROCAT subgroups (derived variable based on EUROCAT coding) |  |[ ]

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For more details concerning the EUROCAT variables please refer to the [EUROCAT Guide 1.5](https://eu-rd-platform.jrc.ec.europa.eu/eurocat/data-collection/guidelines-for-data-registration_en), Section 2.2.2