# Childhood Cancer Registry

## **Individual Data Request –** Date request form for individual data (CRA Art. 23)

Please specify which data you need:

anonymized patient data

pseudonymized patient data (requires ethical approval) 1

identifying patient data (requires ethical approval) 1

|  |  |  |
| --- | --- | --- |
| **1.0 Requester** | | |
| 1.0.1 | Name | Click or tap here to enter text. |
| 1.0.2 | Institution/Department | Click or tap here to enter text. |
| 1.0.3 | Address | Click or tap here to enter text. |
| 1.0.4 | Phone | Click or tap here to enter text. |
| 1.0.5 | Email | Click or tap here to enter text. |
| **1.1 Project Investigator/Supervisor/Department Head** | | |
| 1.1.1 | Name | Click or tap here to enter text. |
| 1.1.2 | Institution/Department | Click or tap here to enter text. |
| 1.1.3 | Address | Click or tap here to enter text. |
| 1.1.4 | Phone | Click or tap here to enter text. |
| 1.1.5 | Email | Click or tap here to enter text. |
| **1.2 Billing Address/Administrative** | | |
| 1.2.1 | Administrative Name | Click or tap here to enter text. |
| 1.2.2 | Institution/Department | Click or tap here to enter text. |
| 1.2.3 | Address | Click or tap here to enter text. |
| 1.2.4 | Phone | Click or tap here to enter text. |
| 1.2.5 | Email | Click or tap here to enter text. |
| **2.0 Request Information** | | |
| 2.0.2 | Research project Title | Click or tap here to enter text. |
| 2.0.3 | Research project start date | Click or tap here to enter text. |
| 2.0.4 | Research project end date | Click or tap here to enter text. |
| 2.0.5 | Ethics approval 2 | *Does the project have an ethics approval?*  yes no  *Ref.-Num.:*  *Name of ethics committee:*  *Valid from:* |
| 2.0.6 | Research background  *(max. 300 words)* | Click or tap here to enter text. |
| 2.0.7 | Research question  *(max. 300 words)* | Click or tap here to enter text. |
| 2.0.8 | Research aims  *(max. 300 words)* | Click or tap here to enter text. |
| 2.0.9 | Research methods  *(max. 300 words)* | Click or tap here to enter text. |
| 2.0.10 | Research significance  *(max. 300 words)* | Click or tap here to enter text. |
| 2.0.11 | Singular/recurring request? | This is a singular request  *(e.g. I will request this dataset only once)*  This is a recurring request  *(e.g. I will routinely request an updated dataset)* |
| **2.1 Data specification (the attached list of variables must also be filled in)** | | |
| 2.1.1 | Incidence years to be included | *< e.g. year of diagnosis between 1990 – 1999 (10 years) >* |
| 2.1.2 | Age groups (age at Diagnosis) to be included | *< e.g. age at Dx < 15 years >* |
| 2.1.3 | Diagnoses to be included | *<if you search for specific diagnoses, best is to give ICCC-3 Main Groups, ICD-O-3 Morphology and Topography codes or text>* |
| 2.1.4 | Other inclusion or exclusion criteria | Click or tap here to enter text. |
| 2.1.5 | Please describe exactly what information is needed | *< e.g. number of children diagnosed with PNET in 2000-2010>* |

*1 To receive non-anonymized individual data, the requesting researcher needs an ethical approval for the specific research question by the competent ethics committee, according to Art. 45 par. 1 HRA. In this case the requirements of the HRA must be met, e.g., for informed consent and / or waiver of informed consent in exceptional cases (HRA, Art. 34). The ChCR requests that researchers provide a draft of the ethics application for review prior to submission to ensure an accurate and consistent description of the requested ChCR data.*

*2 Data delivery will be subject to prior ethical approval and signing of a data transfer agreement.*

Date: \_\_\_\_\_\_\_\_\_\_\_\_