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**SwissPedRegistry – Request for support**

Please send this request to [claudia.kuehni@ispm.unibe.ch](mailto:claudia.kuehni@ispm.unibe.ch) and sandra.hunziker@ispm.unibe.ch

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| --- | --- |
| **Applicant** | |
| Name | Click here to enter text. |
| Institution | Click here to enter text. |
| Position | Click here to enter text. |
| Address | Click here to enter text. |
| Phone | Click here to enter text. |
| E-Mail | Click here to enter text. |
| Collaborators | Click here to enter Names and Institutions. |
| **Request** | |
| Support request | Main request:  establish a new registry  improve and further develop an existing registry  host a registry at the ISPM  Specific requests:  help to define basic dataset and variable list  discuss software options for database  discuss logistics of data collection  obtain advice for ethics application (confined to registry issues)  help to develop contracts and agreements  discuss possibilities to update addresses of patients  discuss possibilities for data linkage (e.g with routine datasets from the Federal Statistical Office) analysis and publication of data for monitoring purpose (e.g. annual report)  other: Click here to enter text. |

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| **Registry** | |
| Title of registry | Click here to enter text. |
| Acronym (if exist) | Click here to enter text. |
| Health condition or problem studied | Click here to enter text. |
| Goals of registry | Click here to enter text. |
| Coverage | regional  national  international  to be defined  *Define for regional or international:* Click here to enter text. |
| Start of the registry | Click to enter a date. |
| Initiator/sponsor of registry | *Initiating person/group, supporters, and other important stakeholders*  Click here to enter text. |
| Inclusion/exclusion criteria | *Disease, age range, etc.*  Click here to enter text. |
| Number of patients | Numbers of new patients per year: Click here to enter text.  Expected total number to be reached: Click here to enter text. |
| For existing registries only | Number of patients already in database: Click here to enter text.  Location of database: Click here to enter text.  Database type (e.g. Excel, REDCap,…): Click here to enter text. |
| Type of data to be collected | *Multiple choices possible*  data from medical records  questionnaires for patients and families  questionnaires for physicians  biological/genetic material  identifying data (e.g. names, addresses*)*  *If yes, describe* Click here to enter text.  other: Click here to enter text.  Short description of the variables:  Click here to enter text.  Storage of digitalized med. reports?  yes  no  to be defined  *If yes, describe:* Click here to enter text. |
| Procedure | *Describe the planned procedure. (How/who/where you will identify the patients. Who collects and enters which data? When/how often are data collected?)*  Click here to enter text.  baseline (cross-sectional only)  longitudinal  *If longitudinal, describe:* Click here to enter text. |
| Ethics application | to be obtained  approved: Ethics commission: Click here to enter text.  single-centre  multi-centre |
| Budget | *Describe available, planned or suggested funding sources.*  Click here to enter text. |
| Available time of applicant | *How much time can you or another person (who?) invest in the registry (h/week)?*  Click here to enter text. |
| Time frame for support | *When do you need support and how urgent is your request?* |
| **Questions/comments** | |
| Questions you would like to discuss and comments | Click here to enter text. |

Date: Click to enter a date. Signature:………………………………………………………..