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**SwissPedRegistry – Request for support**

Please send this request to claudia.kuehni@ispm.unibe.ch and anne.tscherter@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 ISPMSpecific 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. |
| **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:………………………………………………………..