RHEOP - Register of Childhood Disabilities and Perinatal Data - Isère et deux Savoie counties

Head :Cans Christine, Service d'information et informatique médical

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| General | | |
| Identification | | |
| Detailed name | Register of Childhood Disabilities and Perinatal Data - Isère et deux Savoie counties | |
| Sign or acronym | RHEOP | |
| CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation | 997086 | |
| General Aspects | | |
| Others (details) | Induced therapeutic abortions | |
| Keywords | Stillbirth and Induced therapeutic abortions Severe deficiencies of the child | |
| Scientific investigator(s) (Contact) | | |
| Name of the director | Cans | |
| Surname | Christine | |
| Address | Pôle d'exploitation SIIM, pavillon Taillefer, CHU Grenoble, BP 217 38043 Grenoble Cedex 09 | |
| Phone | 04 76 76 94 03 | |
| Email | CCans@chu-grenoble.fr | |
| Unit | Service d'information et informatique médical | |
| Organization | CHU de | |
| Collaborations | | |
| Funding | | |
| Funding status | Public | |

| Details | Institut de veille sanitaire - InVS Institut national de la santé et de la recherche médicale - INSERM Conseils Généraux de l'Isère, de la Savoie et de la Haute-Savoie |
|---|--|
| Governance of the database | |
| Sponsor(s) or organisation(s) responsible | Université de Grenoble Joseph Fourier |
| Organisation status | Public |
| Sponsor(s) or organisation(s) responsible | Conseils Généraux de l'Isère, de la savoie et de la Haute-Savoie |
| Organisation status | Public |
| | |
| Additional contact | |
| Additional contact Main features | |
| | |
| Main features | Morbidity registers |
| Main features Type of database | Morbidity registers A selection of health institutions and services |
| Main features Type of database Type of database Database recruitment is carried | |
| Main features Type of database Type of database Database recruitment is carried out by an intermediary Database recruitment is carried out as part of an interventional | A selection of health institutions and services |

| Main objective | In the area of public health: (1) monitor the change in the prevalence of severe deficiencies in children on a geographical basis (three counties starting in 2005) (2) monitor the change in the rate of stillbirths and more particularly of the prevalence of induced abortions for medical reasons over the same geographical base (3) describe the educative and medical care (4) assist in the planning of needs, in order to ensure optimal care for these children In the area of research: (1) encourage analytical surveys that are specific to each type of deficiency, or that cover the |
|----------------|--|
| | |
| | (2) identify the etiologies of the deficiencies and serious perinatal events(3) Collect information on the perinatal events that |

| | may be in relation with the occurence of deficiencies |
|--|--|
| Inclusion criteria | Deficiency pool: All children under the age of 7 years having at least one main severe deficiency and residing in one of the départements of Isère, Savoie or Haute-Savoie. Perinatal pool: serious perinatal events such as cases of stillbirth and abortion occurring each year for the women domiciled in one of these three départements. |
| Population type | |
| Age | Newborns (birth to 28 days) Infant (28 days to 2 years) Childhood (6 to 13 years) |
| Population covered | Sick population |
| Gender | Male Woman |
| Geography area | Regional |
| French regions covered by the database | Auvergne Rhône-Alpes |
| Detail of the geography area | Isère, Savoie, Haute Savoie |
| Data collection | |
| Dates | |
| Date of first collection (YYYY or MM/YYYY) | 1991 |
| Size of the database | |
| Size of the database (number of individuals) | [1000-10 000[individuals |
| Details of the number of individuals | 2717 : several deficiency 2414 : stillbirths 2317 : medical termination of pregnancy |
| Data | |
| Database activity | Current data collection |
| Type of data collected | Clinical data Administrative data |

| Clinical data (detail) | Direct physical measures |
|---|---|
| Administrative data (detail) | profession of the parents, canton and county of residence, disability rate |
| Presence of a biobank | No |
| Health parameters studied | Health event/morbidity Health event/mortality Health care consumption and services Quality of life/health perception |
| Care consumption (detail) | Hospitalization |
| Procedures | |
| Data collection method | A systematic collection of information intended to identify the cases is conducted with: (1) the Départementale Bureau for Autonomy (MDA) and the départementale bureaus for people with disabilities (MDPH) of the départements involved (2) clinical departments of neonatology, pediatrics, maternity wards and specialized departments using medical dossiers (3) medical information departments (4) early-action medical centers (5) child psychiatry sectors (6) PMIs and networks of liberal pediatricians (7) cytogenetics departments (8) Multi-disciplinary centers for prenatal diagnostics (CPDNP) (9) anatomopathology laboratories |
| Participant monitoring | No |
| Links to administrative sources | Yes |
| Linked administrative sources (detail) | PMSI MDPH |
| Promotion and access | |
| Promotion Access | |
| Terms of data access (charter for data provision, format of data, availability delay) | Annual report published every year, accessible of the RHEOP website Scientific publications |
| | Scientific publications |
| Access to aggregated data | Access on specific project only |