# **S4 Table.** **Details of sources of case ascertainment and death identification of included studies and description of a comparison group.**

| **Author, publication year, ref, country** | **Congenital anomaly (CA) types (ICD codes)** | **Sources of case ascertainment** | **Sources of death identification** | **Comparison group included, if any** |
| --- | --- | --- | --- | --- |
| Agha, 2006 [1], Ontario, Canada | All anomalies and by group (ICD-9 codes 740.0-759.9) | Canadian CA Surveillance System (CCASS) | CCASS data linked to the Registrar General of Ontario Death File | Children without CAs (n=45,200) matched by birth year, maternal age, birth order, mother’s marital status, and parent’s birthplace |
| Bakker, 2019 [2] 8 European and 3 USA registries | Spina bifida | Congenital anomaly registries | Linkage with death certificates for 8 registries and FU by a clinician or registry staff for 4 registries | No reference group |
| Bell, 2016 [3], Western Australia (WA) | Orofacial clefts (OFC) (BPA-ICD9 (749.00–749.29) | WA Data Linkage System, including WA Register of Developmental Anomalies (WARDA) | Death registration data | Group without OFC (n=6603) |
| Berger, 2003 [4], Michigan, USA | All anomalies (ICD-9 codes 740-759) | Michigan Birth Defects Registry (MBDR) | MBDR linked to death files to the end of 2000 | All singleton live births without CA born to Michigan mothers in 1992-98 (n=902,807) |
| Borgstedt-Bakke, 2017 [5], Western Denmark | Spina bifida (myelomeningocele) | Western Denmark myelomeningocele database | University hospital’s charts based on the Danish Civil Registration System | Survival in the Danish general population plotted on the K-M survival curves as a reference, no formal tests performed |
| Brodwall, 2018 [6], Norway | Down syndrome | Medical Birth Registry of Norway | Linked to the Cause of Death Registry (CDR) data | Live births without chromosomal anomalies (n=943,477) were used for comparison in the analysis of associations with CHD and ECM, but not in the survival analysis |
| Burgos, 2017 [7], Sweden | Congenital diaphragmatic hernia (CDH) - ICD-9 756.6, ICD-10 Q79.0 and Q79.1 | Combination of Swedish NPR (<2% missing), MBR (0.5-3.9% missing), Register of Congenital Malformations (20% missing) | Linked with Swedish Register for Causes of Death (only 1.3% missing) | No reference group |
| Cassina, 2016 [8], North East Italy (NEI) | Oesophageal atresia | NEI Congenital Malformation Registry | Linked with vital records, medical records, and the regional registries of patients | No reference group |
| Cassina, 2019 [9], North East Italy | Anorectal malformations | NEI Congenital Malformation Registry and clinical databases of the Pediatric Surgery Units of the Veneto region | Linked with vital records, medical records, and the regional registries of patients | No reference group |
| Chardot, 2013 [10], France | Biliary atresia (BA) | Clinical charts of all 45 paediatric centres involved in management of BA patients | Follow up | No reference group |
| Chua, 2020 [11], Hong Kong | Down syndrome (ICD-9 code 758.0) | Hospital Authority Clinical Data Analysis and Reporting System (CDARS) containing health records of all local residents | Follow up using CDARS hospitalisation data | No reference group |
| Dastgiri, 2003 [12], Glasgow, Scotland | All anomalies and by group (ICD-9 codes 740-759) | Glasgow register of Congenital anomalies | Linked with death data by the registrar general for Scotland | No reference group |
| Davenport, 2011 [13], England & Wales | Biliary atresia | Prospective national data registry | Follow up of all identified BA cases | No reference group |
| De Carvalho, 2010 [14], Brazil | Biliary atresia | Medical records of patients with BA in 6 Brazilian reference centers | Follow up | No reference group |
| De Vries, 2011 [15], The Netherlands | Biliary atresia | Patients hospital records from one of the 6 Dutch university medical centres that specializes in paediatric surgery | Follow up | No reference group for survival |
| Eide, 2006 [16], Norway | All anomalies and by selected subgroup | Medical Birth Registry (MBR), 1967-79 | Statistics Norway (1967-1998) | Comparison with mortality in those without CAs (RR) |
| Folkestad, 2016 [17], Denmark | Osteogenesis Imperfecta (OI): | National Patient Register (NPR) | Linked with deaths in Danish CDR | Reference group – 5 persons randomly selected from Danish Civil registration System matched by gender, birth year and month |
| Frid, 1999 [18], northern Sweden | Down syndrome | Swedish Register of Congenital Malformations; Cytogenetic Register; MBR | Population Register; CDR and hospital medical records | No reference group |
| Garne, 2002 [19], Funen county, Denmark | Gastrointestinal anomalies (atresias, abdominal wall defects and CHD) | EUROCAT Registry for Funen County in Denmark | FU data from hospital records (Central database of hospital admissions) | No reference group |
| Glasson, 2016 [20], Western Australia (WA) | Down syndrome | 1) WA Intellectual Disability Exploring Answers database; 2) WA Register for Developmental Anomalies | WA death registrations (from 1969) and DSC records (from 1953). | No comparison group for survival, perinatal characteristic compared with the reference group (n=785,732) |
| Grizelj, 2010 [21], Croatia | Biliary atresia | Medical records of University Hospital Zagreb (care highly centralised) | FU data from hospital records | No reference group |
| Gudbjartsson, 2008 [22], only Iceland centre included | CDH | Central diagnosis- and operation-code registry | FU of all patients | No reference group |
| Halliday, 2009 [23], Victoria, Australia | Down syndrome | The Victorian Birth Defects Register (VBDR) | Linked VBDR cases with records from CCOPMM database | No reference group |
| Hayes, 1997 [24], Dublin, Ireland | Down syndrome | Dublin EUROCAT register, DCAR, hospital records of paediatric units, including leukaemia cardiac surgery registers. | Death Register | No reference group |
| Hinton, 2017 [25], Atlanta, USA | CDH | The Metropolitan Atlanta Congenital Defects Program (MACDP | Linked MACDP data and vital records from the state of Georgia; for deaths outside Georgia linkage with the NDI | Survival by ethnicity (White and Black) compared, no comparison with reference group |
| Jaillard, 2003 [26], France | CDH | Neonatal Intensive Care Unit, Lille, the only referral center for paediatric surgery (population 4.5 mln inhabitants) | FU of all patients | No reference group |
| Kucik, 2013 [27], 10 regions, USA | Down syndrome | 10 population-based birth defects monitoring programs | Linkage with medical records, state vital records, and the NDI | No reference group |
| Lampela, 2012 [28], Finland | Biliary atresia | Hospital patient database and cross-checked with the data of the Register of Congenital Malformations | Follow-up data obtained from patient records for all BA cases. | No reference group |
| Leonard, 2000 [29], Western Australia | Down syndrome | The Western Australian Birth Defects Register (BDR); Disability Services Commission (DSC) | BDR alone or linked with maternal and child health research database, questionnaire (children registered in DSC), Office of the Registrar-General | No reference group |
| Leonhardt, 2011 [30], Germany | Biliary atresia | European Biliary Atresia Registry (EBAR) and data from 4 German paediatric centers | Follow up of BA patients | No reference group |
| Lionti, 2012 [31], Victoria, Australia | Prader-Willi syndrome | Victorian Prader-Willi syndrome (PWS) Register | Linkage through the Australian NDI in September 2006 and June 2010 and through searches of the Victorian DI for deaths prior to 1980 | No reference group |
| Löf Granström, 2017 [32], Sweden | Hirschsprung disease (HSCR) | Swedish NPR | Linked to Swedish National CDR | Unexposed cohort (10 per case - n=7390) matched for birth year and sex from the Swedish National Population Register |
| McKiernan, 2000 [33], UK & Ireland | Biliary atresia | Cases identified by BPSU (reporting compliance 90%) | FU questionnaires sent to notifying paediatricians 1 year and 2 years after the end Feb 1995 | No reference group, compared survival by hospital caseload and other factors |
| McKiernan, 2009 [34], UK & Ireland | Biliary atresia | Cases identified by BPSU and reported in McKiernan, 2000 [33] (reporting compliance 90%) | Prospective FU | No reference group, compared survival by hospital caseload and other factors |
| Meyer, 2016 [35], 9 States USA | Trisomy 13 and trisomy18 | State-based birth defect surveillance programs | Matched cases to birth certificates and linked to death certificate files | No reference group |
| Nelson, 2016 [36], Ontario, Canada | Trisomy 13 and trisomy18 | Multiple health and demographic datasets (e.g. RPD) linked by encoded identifiers | Ontario Vital Statistics Death File and the RPD | No reference group |
| Nembhard, 2010 [37], Texas, USA | All CAs, not stratified by group ((ICD-9 codes 740.00-758.090) | Texas BDR, with active surveillance system, 100% resident coverage since 1999 (35% in 1996, 56% in 1997, 85% in 1998) | Linked to Texas birth and death certificates (Vital Statistics Unit) and NDI for out of state deaths. | No reference group |
| Nio, 2003 [38], Japan | Biliary atresia | Japanese Biliary Atresia Registry | Japanese Biliary Atresia Registry (2.6% n=19 lost to FU) | No reference group |
| Oddsberg, 2012 [39], Sweden | Oesophageal atresia | Swedish NPR, MBR and Register of Congenital Malformations | Linked with data from Total Population Register | Reference group from Total Population Register matched by calendar year, sex and age used for calculation of SMRs |
| Pakarinen, 2018 [40], Nordic countries | Biliary atresia | Data collected from all Nordic centers involved with the treatment of BA according to an agreed survey and data extraction sheet. | FU in participating paediatric centres | No reference group |
| Rankin, 2012 [41], Northern England | Down syndrome (ICD-10 Q90.0, Q90.1, Q90.2) | Northern Congenital Abnormality Survey (NorCAS) | NorCAS records matched to hospital and national mortality records | Life tables on the background population used |
| Rasmussen, 2006 [42], Metropolitan Atlanta, USA | Down syndrome  ICD-9-CM (758.000-  758.090) | Metropolitan Atlanta Congenital Defects Program (MACDP) - active ascertainment | MACDP records linked with NDI and with Georgia vital records | No reference group |
| Risby, 2017 [43], Southern Denmark | Gastroschisis | Identified from the electronic hospital patient registration system of the tertiary centre (Odense University hospital) | Survival status determined by the national personal number Registry (obtained for all children) | No reference group |
| Schneuer, 2019[44], New South Wales (NSW), Australia | All anomalies, by group and subtype | Identified from the NSW Register of Congenital Conditions | Record linkage to death registrations | No reference group |
| Schreiber, 2007 [45], Canada | Biliary atresia | Identified through the health records department at each institution from 12 Canadian University centres (standard coding system for BA) | FU from birth to death or last follow-up (up to 31 Dec 2002) | No reference group |
| Shin, 2012 [46], 10 regions, USA | Spina bifida (ICD-9 741.0 and 741.9) | 10 state-based birth defects surveillance programs; birth years varied from 1979-2003 in Georgia to 1996-2003 in Texas. | Linked state vital records, medical records, and the NDI | No reference group |
| Siffel, 2003 [47], Atlanta, USA | Encephalocele | MACDP records | MACDP records linked with Georgia vital records and with NDI for deaths outside the State | No reference group |
| Simmons, 2014 [48], Texas, USA | Achondroplasia | Cases identified from the Texas BDR (active surveillance) | All BDR data linked with death certificate data from the Texas Bureau of Vital Statistics | Age-adjusted mortality rates standardised to the 2005 U.S. population calculated |
| Sutton, 2008 [49], Dublin, Ireland | Neural tube defects (spina bifida, encephalocele) | Hospital medical records (4 Dublin maternity hospitals) | Vital status ascertained from a combination of medical records and/or parental interview. | No reference group |
| Tennant, 2010 [50], Northern England | All anomalies, by group and subtype | NorCAS database | Infant death data available in NorCAS; longer term survival status traced by the National Strategic Tracing Service | Life tables on the background population used |
| Tu, 2015 [51], South Australia | Biliary atresia | Medical records coding system and the histopathology database, also cross checked with the records of the South Australian Birth Defects Register | FU data obtained retrospectively from case notes | No reference group |
| Wang, 2011 [52], New York State, USA | All anomalies and by group | The CMR data matched with birth certificates | CA data linked to death certificates | No reference group; Risk of death (HR) compared between isolated vs non-isolated CAs by type |
| Wang, 2015 [53], 12 states, USA | All anomalies and by group | 12 state-based birth defects surveillance programs | Matched cases to birth certificates and linked to death certificate files; also NDI, hospital records for some states | No reference group; Risk of death (HR) for selected CA types compared by maternal ethnicity |
| Wildhaber, 2008 [54], Switzerland | Biliary atresia | All 7 paediatric surgery centres involved in the management of patients with BA contributed to the study | Follow up in all the 7 participating centres | No reference group |
| Wong, 2001 [55], Atlanta, USA | Spina bifida: | MACDP - active ascertainment | MACDP records and linked with NDI for deaths outside the State. | No reference group |

**Note:**

BA, biliary atresia, BDR, Birth Defects Registry; BPSU, British Paediatric Surveillance Unit; CA, congenital anomaly, CDR, Cause of Death Registry/Register; CDH, Congenital diaphragmatic hernia; CCOPMM, Consultative Council of Obstetric and Pediatric Morbidity and Mortality database; CMR, Congenital Malformations Registry; CNS, central nervous system; DCAR, Domiciliary Care Allowance register; DSC, Disability Services Commission; EUROCAT, European Surveillance of Congenital Anomalies; FU, follow up; HSCR, Hirschsprung disease; ICD, International Classification of Disease (ICD); K-M, Kaplan-Meier; LT, liver transplantation; MACDP, Metropolitan Atlanta Congenital Defects Program; MBR, Medical Birth Registry; NDI, National Death Index; NorCAS=Northern Congenital Abnormality Survey; NPR=National Patient Register; OFC=orofacial clefts; RPD=Registered Persons Database; SMR=standardized mortality ratio; WARDA=Western Australian Register of Developmental Anomalies.

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