**Supplementary Table 3: Identification of study participants, case definitions, and source of mortality data for studies on Intellectual Disability**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Author & Year of publication** | **Identification of people with Intellectual Disability (ID)** | **Definition/classification of Intellectual Disability**  | **Level of Intellectual Disability** | **Determination of mortality and causes of death** |
| (Arvio et al., 2016) | The national social insurance institution (KELA) provided a list of individuals who received disability benefits due to ID | ID defined based on the ICD-10 criteria (WHO 1996): an IQ< 70; presence of age-inappropriate adaptive skills; and a clinical manifestation during the developmental stages | Mild (IQ 50-69); severe (IQ<50) | Finnish population Register Centre delivered mortality data to KELA determined by the termination of benefits due to death  |
| (Bourke et al., 2017) | Population-based register of all live births linkedto the Intellectual Disability Exploring Answers (IDEA)database to identify children with ID  | IQ<70 or deficits in adaptive behavior occurring before the age of 18 years or having a known condition consistent with ID e.g. Downs syndrome | Mild (IQ 55-69); moderate (IQ 40-54); severe (IQ <40) | Western Australian Mortality Database (ICD-10 classification) and Australian Bureau of Statistics; autopsy reports used to determine the cause of death among ID cases |
| (Florio and Trollor, 2015) | New South Wales Department of Ageing, Disability and Home Care (ADHC) service register for people with ID was used | DSM-IV criteria in the definition and classification of ID | - | Mortality data were obtained from the registry of births, deaths and marriages in the New South Wales |
| (Forsgren et al., 1996) | Prevalence study of all cases with mental retardation | ID defined as people with IQ<70; present before the age of 18  | Mild mental retardation (MR) IQ 50-55 to 70; moderate IQ 35-40 to 50-55; severe IQ 20-25 to 35-40; and profound IQ<20-25 (DSM-III) | The Swedish National Central Bureau of Statistics, underlying and contributory cause of death; death certificates were also evaluated. |
| (Lauer and McCallion, 2015) | US state intellectual and developmental disabilities service systems used to identify study participants  | Definition of ID Varied by state and environments: The ICD-9 was used in medical environments & DSM-IV in mental health environments. ICD-9: the presence of neurodevelopmental disorders associated with ID and IQ<70; the DSM-IV used a combination of criteria involving IQ<70, age at onset <18 years and presence of functional impairments  | ICD-9 code used to classify ID as mild, moderate, severe or profound. | An external data system e.g. US Social Security Death Index; internal systems such as billing systems; and State Departmentof Health death certificates were used in the determination of death. |
| (McCarron et al., 2015) | Data from national intellectual disability database of Ireland (NIDD) provided ID cases | Not explained  | Not explained  | Central Statistics Office provided dataon deaths. |
| (Tyrer et al., 2007) | LeicestershireLearning Disability Register was used to identify adults having moderate-severe Intellectual Disability (ID) excluding mild cases of ID | Enrolment to the register was based on a moderate, severe or profound developmentalintellectual impairment (WHO 1992) with adaptive behavior problems, and the likely need for long-term support. | Moderate IQ 35-49; severe IQ 20-34; and profound IQ <20.  | People enrolled on the register and died were identified using mortality datafrom the Office of National Statistics.  |
| (Shavelle et al., 2014)  | Database of the California department services for people with ID, US identified people using the services; ID cases with significant physical impairment, comorbidity, or underlying degenerative conditions were excluded | ID was defined as the presence of limitations in intellectual functioning and adaptive behavior before the age of 18 years  | Mild IQ 50-70, moderate 35-50, severe 20-35, profound <20 | Mortality data were obtained from the California Departmentof Health Services, Bureau of Vital Statistics |
| (Cooper et al., 2020) | Participants identified through general practitioners’ registered patients, health and social work services, health board registers, payment records by social services | ID defined and classified according to the ICD-10 criteria | Classified as mild, moderate, severe and profound; specific IQ values for classification not provided  | Mortality data obtained through data linkage of existing data with the National Records for Scotland death certification data.  |
| (Smith et al., 2020) | Educational data from Scotland’s annual pupil census between 2008 and 2013 where children with additional support needs due to intellectual disability were identified.  | Not defined  | Not classified  | Individual data linkage with the National Records of Scotland deaths register. |