Respiratory-associated deaths in people with intellectual disabilities: a systematic review and meta-analysis

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INTRODUCTION

People with intellectual disabilities account for approximately 1%-3% of the global population. The World Health Organisation (WHO) defines intellectual disabilities as impairments in adaptive functioning, social functioning and intellectual functioning (IQ<70), requiring a need for daily support, with the onset in the developmental phase (<18 years). While some heterogeneity is to be expected in the definition of intellectual disabilities across studies drawing on administrative data sets, the WHO definition can be applied to all studies included in this review. Life expectancy and mortality rates are important indicators of health inequality. People with intellectual disabilities die up to 20 years earlier than the general population. Respiratory disorders are a leading cause of death among people with intellectual disabilities. The range of standardised mortality ratios (SMRs) due to respiratory disorders for people with intellectual disabilities are very high in some studies, and much lower in others. Despite this, SMRs due to respiratory disorders for people with intellectual disabilities differ widely across studies. Respiratory cause of mortality in people with intellectual disabilities has not been systematically examined. Previous studies have focused on either children and young people (4-19 years) or older adults (55-years) on average. This systematic review and meta-analysis aims to investigate and quantify the risk of, and factors associated
with, respiratory-associated deaths in people with intellectual disabilities.

METHODS

The Preferred Reporting Items for Systematic Reviews and Meta-Analyses checklist was followed. This review was prospectively registered with the International Prospective Register of Systematic Reviews.

Eligibility

This systematic review included studies which analysed and presented data on people who were ascertained as having intellectual disabilities and a comparison group of individuals in the general population, with respiratory disorders included as a separate cause of death. For studies that included multiple disabilities, at least 70% of participants had to have intellectual disabilities, if results were not reported separately. Studies also had to be full-text, peer-reviewed and published in English. To be included in the meta-analysis, studies had to report SMRs with 95% CIs for respiratory-associated deaths based on external comparison group or to have presented data allowing such outcomes to be derived. Studies were excluded if they focused on specific etiologies of intellectual disabilities, such as Down syndrome, as these are associated with different health and mortality profiles compared with other people with intellectual disabilities. Studies were excluded if the full paper was not available in English. Studies focussing on postoperative and post-treatment deaths were excluded as these are not representative of the wider population with intellectual disabilities. Studies with small samples (<20 participants) or case series designs were also excluded as these papers are less representative.

Search strategy and selection criteria

We searched Ovid Embase, ISI Web of Science (all databases), CINAHL and PsycINFO from 1 January 1985 to the 27 April 2020, using comprehensive terms related to ‘intellectual disabilities’, ‘mortality’ and ‘respiratory disease’ (full search strategy in online supplemental appendix 1). In addition, a manual bibliography and citation search of included studies was conducted using Google Scholar and key researchers in the field of mortality in individuals with intellectual disabilities were emailed to identify any additional relevant papers. The aforementioned eligibility criteria were used. After duplicates were removed, all records were imported into Covidence software (www.covidence.org) for title and abstract and full-text screening. All titles, abstracts (CM and AMcG) and full-texts (CM, AMcG and ER) were double-screened with inter-rater reliability (Cohen’s kappa) of $\kappa = 0.57$ and $\kappa = 0.58$, respectively.

DATA EXTRACTION

Data extraction was conducted using a structured database created in Excel. Five researchers (GSS, LAH-M, DK, KD and AMcG) each extracted data from 25% of the included studies and, to check reliability, one other researcher (CM) independently extracted data from 20% of included studies. Extracted data were compared in meetings and discrepancies resolved through consensus discussion. Researchers did not extract data on included papers where they were a listed author.

Assessment of study and outcome quality

Study quality was appraised using the Standard Quality Assessment Criteria for Evaluating Primary Research Papers from a Variety of Fields. Quality ratings were calculated in percentage form using the standard method and categorised as weak (<55%), moderate (55%–75%) or strong (>75%) quality. Each paper had quality appraisals completed by two researchers, who then agreed a consensus score for each item (table 1). Researchers did not evaluate quality of papers where they were a listed author. Risk of bias score was not used to exclude any studies from either the systematic review or meta-analysis. We evaluated the quality of our own systematic reviews using the Measurement Tool to Assess Systematic Reviews checklist.

Summary of outcomes and statistical analysis

Findings of all included studies were combined in a narrative synthesis. The primary goal of the meta-analysis was to investigate if the SMRs of respiratory-associated deaths differ for individuals with and without intellectual disabilities. If SMRs were reported by specific respiratory causes, sex, age group, level of intellectual disability, socioeconomic status or ethnicity, these were collected and presented for potential analysis (see table 2). Random-effects meta-analysis was undertaken using RevMan. Included studies reported either:

- an SMR or HR

OR

- The observed number of deaths or expected deaths necessary to calculate a SMR. These were calculated using STATA V.14 by dividing the observed number of deaths in a cohort study group by the expected mortality based on age and gender-specific death rates in the general population comparison group.

Random-effects models were selected for all meta-analyses due to the different populations and measures in the included studies. Inverse of the variance method was used to calculate the weighted mean respiratory mortality log-SMR across studies, as well as for subgroup meta-analyses. As the SMR is a ratio, log transformation was needed to maintain symmetry in the analysis. SMRs and HRs from each study were transformed to log values for computations and back transformed for presentation of the results. Weighted mean log-SMRs and their 95% CIs were reported separately for individuals with and without...
Table 1  Characteristics of studies reporting mortality rates for respiratory disorders and pneumonia in people with intellectual disabilities (ID)

| Author               | Country | Study design, setting and follow-up | Data sources                                           | ID sample (n, % female, age, level of ID) | Deaths in ID sample (n, % female, age at time of death, level of ID) | Comparison sample (n, % female, age and deaths (n, % female, age) | Respiratory disorder definition (eg, ICD codes or other definitions) | Quality percentage (assessment) |
|----------------------|---------|-------------------------------------|-------------------------------------------------------|------------------------------------------|---------------------------------------------------------------|--------------------------------------------------------------|---------------------------------------------------------------|---------------------------------|
| Brameld et al (2018) | Australia | Retrospective matched cohort study of adults 20 years old and over. Follow-up 2009–2013 | Intellectual Disability Exploring Answers (IDEA) Database. Death certificate data | Total sample characteristics not available | n=591; 43.8% female; mean age* and level of ID not available | Total sample characteristics not available. Number of deaths=62 917; 47.4% female; mean age not available | ICD 10-chapter codes for respiratory disorders | 95.45% (strong) |
| Cooper et al (2020)  | UK      | Population-based cohort study. Follow-up 2001–2018 | Primary care records and health check data; death certificate data. Comparison data from Health Board statistics | n=962; 45.4% female; mean age=44.1 years (range 16–83); ID mild=382 (39.7%), moderate=236 (24.5%), severe=180 (18.7%), profound=163 (17.0%) | n=294/961 (30.6%); 47.5% female; mean age=52.4 (SD 13.6) | Not available | ICD 10-chapter codes for respiratory disorders | 86.36% (strong) |
| Dupont et al (1987)  | Denmark | Population-based cohort study of adults with mild ID. Follow-up 1976–1984 | Danish National Service for the Mentally Retarded. Death certificate data | n=7134; gender, age and level of ID not available | n=446; 37.9% females; age and level of ID not available | Not available | Not described | 40.90% (weak) |
| Durvasula et al (2002) | Australia | Population-based cohort study of children and adults. Follow-up 1989–1999 | ID prevalence study. Death certificate data, medical records and postmortem data. Australian Bureau of Statistics | n=693; 44.6% female; mean age=N/A; ID 40% mild, 35% moderate, 25% severe/profound | n=40 (6%); 45% female; median age=32 (range 10–59); level of ID not available | n=1 25 848; 51% female; mean age not available. Number of deaths=2154; 37.8% female; mean age not available | Not described | 90.91% (strong) |

Continued
| Author(s) | Country | Study design, setting and follow-up | Data sources | ID sample (n, % female, age, level of ID) | Deaths in ID sample (n, % female, age at time of death, level of ID) | Comparison sample (n, % female, age) and deaths (n, % female, age) | Respiratory disorder definition (eg, ICD codes or other definitions) | Quality percentage (assessment) |
|-----------|---------|----------------------------------|--------------|-----------------------------------------|---------------------------------------------------------------|---------------------------------------------------------------|---------------------------------------------------------------|-----------------------------|
| Forsgren et al. (1996) | Sweden | Population-based cohort study of adults with ID. Follow-up 1986–1992 | Board for Provision and Services to the Mentally Retarded. Death certificate data from Swedish National Bureau of Statistics | n=1478; 44.5% female; age and level of ID not available | n=247; 42.1% female; median age=64 years (IQR 52–75 years); ID 39.7% mild, 31.2% moderate, 21.5% severe, 7.7% profound | Not available | ICD 9-chapter codes for respiratory disorders | 81.82% (strong) |
| Glover et al. (2017) | UK | Population-based case–control study in primary care. Follow-up 2010–2014 | Primary care records (Clinical Practice Research Data, CPRD). Death certificate data | n=664 deaths; 44.1% female | Total sample characteristics not available | Total sample characteristics not available. Number of deaths=97 379; 52.3% female; mean age not available | ICD 10-chapter codes for respiratory disorders | 81.82% (strong) |
| Heslop et al. (2014) | UK | Population-based audit of deaths of children and adults with ID aged 4 and over. Audit period 2010–2012 | Medical records. Death certificate data from UK Office of National Statistics | n=247; 42.1% female; median age=64 years (IQR 52–75 years); ID 39.7% mild, 31.2% moderate, 21.5% severe, 7.7% profound | Total sample characteristics not available. Number of deaths=480 467; 51.6% female; median age not available | Total sample characteristics not available. Number of deaths=480 467; 51.6% female; median age not available | 81.82% (strong) |
| Hollins et al. (1998) | UK | Cohort study of adults on an ID register. Follow-up 1982–1990 | Learning disability register. Death certificate data. | n=2026; gender, age and ID level not available | n=268 deaths; gender and age not available; 51.5% mild–moderate, 48.5% severe–profound | Not available | Not described | 81.82% (strong) |
Table 1  Continued

| Author | Country | Study design, setting and follow-up | Data sources | ID sample (n, % female, age, level of ID) | Deaths in ID sample (n, % female, age at time of death, level of ID) | Comparison sample (n, % female, age and level of ID) | Respiratory disorder definition (eg, ICD codes or other definitions) | Quality percentage (assessment) |
|--------|---------|-----------------------------------|--------------|----------------------------------------|---------------------------------------------------------------|-------------------------------------------------|-------------------------------------------------------------|-------------------------------|
| Hosking et al (2016) | UK | Population-based case-control study in primary care. Follow-up 2009–2013 | Primary care records (CPRD linkage). Death certificate data | n=16 666; 58.1% female; mean age 39.9 (SD: 16.2). 19.6% of sample had high support needs | n=656 (3.9%); 55.6% female; age and level of ID not available | n=113 562; 58.1% female; mean age not available. Number of deaths=1358 (1.2%); 60.4% female; mean age not available | ICD 10-chapter codes for respiratory disorders | 90.91% (strong) |
| Janicki et al (1999) | USA | Cohort of adults with ID 40 years old and over. Follow-up 1984–1993 | Data from state agency with responsibility for reviewing deaths of disabled persons. Health department data | Total sample characteristics not available | Total sample characteristics not available | Total sample characteristics not available. Number of deaths=149, 980; gender not available, mean age=70.0 | ICD 9-chapter codes for respiratory disorders | 77.27% (strong) |
| Ng et al (2017) | Sweden | Population-based case-control study of adults with ID 55 years old and over. Follow-up 2002–2015 | National database of hospital admissions and outpatient care. National disability register. Swedish National Cause of Death register | n=15 289; 45.5% females; mean age not available; level of ID not available | n=4728; 44.9% female; age and ID level not available | n=4728; 44.9% female; age and ID level not available | ICD 10-chapter codes for respiratory disorders | 95.45% (strong) |
| Oppewal et al (2018) | Netherlands | Cohort study of adults with ID 50 years old and over living in three care organisations. Follow-up November 2013–March 2018 | Medical case notes of participants with ID who died during study period. Cause specific mortality statistics for 50+ population in the Netherlands | n=1050; 48.7% female; mean age=61.6 (SD: 8.0, range 50–94); ID level=2.9% borderline, 21.2% mild, 48.2% moderate, 16.4% severe, 8.7% profound | n=207 deaths (19.7%) but only 159 with cause of death available. 60.7% female; mean age not available; ID level=5.7% borderline, 18.9% mild, 54.7% moderate, 13.2% severe, 7.5% profound | Not available | ICD 10-chapter codes for respiratory disorders | 50.0% (weak) |
| Author          | Country  | Study design, setting and follow-up | Data sources                                                                 | ID sample (n, % female, age, level of ID) | Deaths in ID sample (n, % female, age at time of death, level of ID) | Comparison sample (n, % female, age and deaths (n, % female, age) | Respiratory disorder definition (eg, ICD codes or other definitions) | Quality percentage (assessment) |
|-----------------|----------|------------------------------------|-------------------------------------------------------------------------------|------------------------------------------|--------------------------------------------------------------------|------------------------------------------------------------------|---------------------------------------------------------------------|-----------------------------|
| Patja et al     | Finland  | Population-based, nationwide cohort study. Follow-up 1963–1997 | Original 1962 population-based study (Amnell et al 1964). Death certificate data | n=2369; gender, age and level of ID not available | 1111 deaths with death certificates available for 1095–51.0% female, mean age=57.7; ID level: 40.3% mild, 29.4% moderate, 11.5% severe, 18.0% profound, 0.7% unknown | Not available | ICD 9-chapter codes for respiratory disorders | 81.82% (strong) |
| Raitasuo et al  | Finland  | Cohort study of adults living in an institution. Follow-up 1972–1993 | Medical case notes and death certificate data. General population mortality statistics for population in Finland | N = 2000; gender, age and level of ID not available | 216 deaths, 42.6% female; mean age 26.7 (1–86 years); ID level: 2.0% borderline, 15.0% mild, 18.0% moderate, 20.0% severe, 45.0% profound, 20.0% unknown | Not available | ICD 9-chapter codes for respiratory disorders | 54.55% (weak) |
| Smith et al     | UK       | Nationwide, population-based cohort study of children aged 4–19. Follow-up 2008–2015 | Scottish pupils census: death certificates data | n=18 278; 35% female; mean age not available | n=106; mean age=14.3 (95% CI: 13.4 to 15.1); level of ID not available | n=7 779 12; 50% female; mean age not available. Number of deaths=458; mean age=16.1 years (95% CI: 15.8 to 16.5) | ICD 10-chapter codes for respiratory disorders | 100% (strong) |
| Trollor et al   | Australia| Population-based cohort study of adults 20 years old and above registered with disability services. Follow-up 2005–2011 | Disability Services Minimal Data set. Australian Bureau of Statistics. Death records | n=19 362; 44% female, mean age=37 (range 27–48); ID not available | n=732 (4%); 41% female; median age=54 (42–64), level of ID not available | Total sample characteristics not available. Number of deaths=305 050; 49% female; median age=81 (70–92). | ICD 10-chapter codes for respiratory disorders | 95.45% (strong) |
Table 1  Continued

| Author          | Country | Study design, setting and follow-up | Data sources                                                                 | ID sample (n, % female, age, level of ID) | Deaths in ID sample (n, % female, age at time of death, level of ID) | Comparison sample (n, % female, age) and deaths (n, % female, age) | Respiratory disorder definition (eg, ICD codes or other definitions) | Quality percentage (assessment) |
|-----------------|---------|-------------------------------------|------------------------------------------------------------------------------|-----------------------------------------|---------------------------------------------------------------------|------------------------------------------------------------------|------------------------------------------------------------------|---------------------------------|
| Tyrer and McGrother (2009) 23 | UK      | Population-based cohort study of individuals with moderate- profound ID on a register. Follow-up 1993–2006 | Leicestershire learning disability register. Death certificate data. National Statistics 1993–2006 | n=2995; 41.9% female; Age and level of ID not available | Total sample characteristics not available. Number of deaths≈126 000 | ICD 9 and ICD 10-chapter codes for respiratory disorders | 72.73% (moderate) |

*Individuals in the ID cohort died at a significantly younger age than the comparison cohort.

ICD, International Classification of Diseases; ID, intellectual disabilities; N/A, not available.

Definition of respiratory disorder

Thirteen out of 17 (76%) studies defined the respiratory disorder using International Classification of Diseases (ICD) codes or other definitions. The magnitude of the back-transformed ratio and associated CI were also reported.
| Author         | All-cause mortality | Deaths from respiratory disorders | Between group comparison of deaths from respiratory disorders | Deaths from individual respiratory disorders | Between group comparison of deaths from individual respiratory disorders | Variables associated with risk of death from respiratory disorders |
|---------------|---------------------|-------------------------------|-------------------------------------------------|--------------------------------------------|------------------------------------------------|----------------------------------------------|
| Brameld et al (2018) | 591 had ID/63,508 out of all deaths (0.93%) | 62/591 (10.5%) deaths | Not available | Emergency Department presentations in the last year of life: influenza and pneumonia RR=2.6 (95% CI: 2.0 to 3.4, p<0.001) | Chronic obstructive pulmonary disease (COPD) RR=0.8 (95% CI: 0.5 to 1.6, p=0.596) | Decedents with ID had increased odds of dying of (relative odds of having condition listed as underlying cause of death), adjusted for comorbidity: influenza/pneumonia (OR=5.3, 95% CI: 2.4 to 11.8) |
|               |                     |                               |                                                 | Asthma RR=4.7 (95% CI: 2.1 to 10.4, p<0.001) | Ear, nose and throat infections RR=1.9 (95% CI: 0.8 to 4.0, p=0.122) | Pneumonitis due to solids/liquids RR=17.9 (95% CI: 11.3 to 28.3, p<0.001) |
|               |                     |                               |                                                 | Pneumonitis due to solids/liquids RR=17.9 (95% CI: 11.3 to 28.3, p<0.001) | Hospital admissions in the last year of life: influenza and pneumonia RR=2.3 (95% CI: 1.0 to 5.3, p=0.044) | Asthma (OR=2.3, 95% CI: 1.0 to 5.2) (not significant) |
|               |                     |                               |                                                 | Hospital admissions in the last year of life: influenza and pneumonia RR=2.3 (95% CI: 1.0 to 5.3, p=0.044) | COPD RR=1.4 (95% CI: 0.9 to 2.4, p=0.164) | No difference for COPD as cause of death |
|               |                     |                               |                                                 | Asthma RR=4.6 (95% CI: 1.4 to 15.0, p=0.011) | Ear, nose and throat infections RR=0.0 (95% CI: 0.0, p=0.972) | |
|               |                     |                               |                                                 | Pneumonitis due to solids/liquids RR=17.6 (95% CI: 11.7 to 26.5, p<0.001) | |

Continued
Table 2 Continued

| Author            | All-cause mortality | Deaths from respiratory disorders | Between group comparison of deaths from respiratory disorders | Deaths from individual respiratory disorders | Between group comparison of deaths from individual respiratory disorders | Variables associated with risk of death from respiratory disorders |
|-------------------|---------------------|-----------------------------------|-------------------------------------------------------------|---------------------------------------------|-------------------------------------------------------------|---------------------------------------------------------------|
| Cooper et al. (2020) | 294/961 (30.6%) deaths | SMR=2.24 (95% CI: 1.98 to 2.49) | Underlying cause of death: Down syndrome (DS): 8/57 (14.0%) deaths | SMR=6.78 (95% CI: 5.02 to 8.54) (adjusted for age and sex) | All-contributing factors in death: Respiratory infection=27.1% deaths | Aspiration/reflux/choking=19.8% deaths |
|                    |                     |                                   | Without DS: 49/205 (23.9%) deaths                          |                                             | Underlying cause of death: DS: | Not available |
|                    |                     |                                   | Respiratory infection=<5/57 deaths                          |                                             | Aspiration/reflux/choking=<5/57 deaths | Respiratory infection=<5/57 deaths |
|                    |                     |                                   | Other respiratory conditions=<5/57 deaths                  |                                             | Other respiratory conditions=<5/57 deaths | Other respiratory conditions=<5/57 deaths |
|                    |                     |                                   | Without DS: Aspiration/reflux/choking=22/205 (10.8%) deaths |                                             | Without DS: Respiratory infection=49/205 (23.9%) deaths | Respiratory infection=49/205 (23.9%) deaths |
| Dupont et al. (1987) | n=446 deaths/7134 (5.9%) people with mild ID | n=277 males n=169 females | Respiratory deaths common cause of death in people with ID (all ages) | Not available | Not available | Not available |
|                    |                     |                                   | Tests of significance only; respiratory deaths were more common for males with ID (all ages), and females aged 35-64, vs population of Denmark 1977 | Not available | Not available | Not available |
|                    |                     |                                   | Other respiratory conditions=31/205 (15.1%) deaths | | | |

Continued
### Table 2 Continued

| Author                  | All-cause mortality | Deaths from respiratory disorders | Between group comparison of deaths from respiratory disorders | Deaths from individual respiratory disorders | Between group comparison of deaths from individual respiratory disorders | Variables associated with risk of death from respiratory disorders |
|-------------------------|---------------------|-----------------------------------|-------------------------------------------------------------|---------------------------------------------|-------------------------------------------------------------------------|------------------------------------------------------------------|
| Durvasula (2002)<sup>34</sup> | 40/693 (6%) deaths  | 14/40 (35%) deaths               | For people under 40, respiratory and external deaths were most common, for people over 40, cancer and respiratory deaths were most common. Age: 7/14 deaths in under 25-year olds and 6/14 deaths in 40+ year olds. | Not available                                                                           | Age, gender, DS, myelodysplastic syndrome                                    |
| Forsgren et al (1996)<sup>35</sup> | n=124/1478 (8.4%) people with ID (all ages), over 9992 person-years | n=13/124 (10%) deaths were respiratory disease for people with ID vs n=3.9 expected. SMR=3.3 (95% CI: 2.0 to 5.5) (adjusted for age and sex) | Respiratory disease was common cause of death for people with ID and epilepsy but SMR was not possible due to small sample size. | Not available | Epilepsy (active seizures) |
| Glover et al (2017)<sup>36</sup> | n=664 deaths for people with ID (all ages) over 59 279.7 person-years | n=114 deaths from respiratory causes for people with ID vs 23.3 expected | SMR=4.9 (4.0, 5.9) (adjusted for age and sex) | Not available | Not available | Not available |
| | | | | | | | |

Additional: SMRs for severity of ID, epilepsy and cerebral palsy are available in online supplemental appendix.
### Table 2  Continued

| Author                  | All-cause mortality | Deaths from respiratory disorders | Between group comparison of deaths from respiratory disorders | Deaths from individual respiratory disorders | Between group comparison of deaths from individual respiratory disorders | Variables associated with risk of death from respiratory disorders |
|-------------------------|---------------------|-----------------------------------|-------------------------------------------------------------|---------------------------------------------|------------------------------------------------------------------------|------------------------------------------------------------------|
| Heslop et al (2014)⁵    | n=247 deaths in people with ID aged 4+ Rate of death 16.2 per 1000 person years Median age of death: 64 (52, 75). Additional: all-cause mortality for sex, ID severity, amenable mortality, patient care, and accommodation available online supplemental appendix | n=37 (15%) deaths had underlying cause due to respiratory diseases, vs 14.0% England and Wales deaths (p=0.66) | Not available | Not available | Not available | Reduced smoking in ID group p=0.02 |
| Hollins et al (1998)¹¹  | 270/2026 (13.3%) deaths 116/1081 (10.7%) deaths on Wandsworth register 154/945 (16.3%) deaths on Kensington register | Not available | Not available | Bronchopneumonia: n=56 (48%) (Wandsworth) n=69 (45%) (Kensington) COPD emphysema: n=1 (Wandsworth) n=1 (Kensington) Asphyxia: n=4 (Wandsworth) n=1 (Kensington) Respiratory other: n=4 (Wandsworth) n=4 (Kensington) | Not available | Not available |
| Hosking et al (2016)²⁴  | 656/16 666 (3.9%) deaths HR=3.62 (95% CI: 3.33 to 3.93) | 123/16 666 (18.8%, rate=24.8) deaths HR=6.68 (95% CI: 5.38 to 8.29) (adjusted for age, sex and general practice) | Down syndrome=24/1793 (20.3%) deaths General population: 135/13 562 (rate=3.9) deaths | Pneumonia; n=67/16 666 (rate=13.9) Aspiration pneumonitis; n=21/16 666 (rate=4.2) | General population: Pneumonia: 39/113 562 (rate=1.1) Aspiration pneumonitis: n=6/113 562 (rate=0.2) | Not available |

Continued
Table 2  Continued

| Author          | All-cause mortality                                                                 | Deaths from respiratory disorders | Between group comparison of deaths from respiratory disorders                                                                 | Deaths from individual respiratory disorders | Between group comparison of deaths from individual respiratory disorders | Variables associated with risk of death from respiratory disorders |
|-----------------|--------------------------------------------------------------------------------------|------------------------------------|--------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------|------------------------------------------------------------------------|------------------------------------------------------------------|
| Janicki et al   | 2752 deaths in the group aged 40+/4183 all-age deaths (66%)                         | 40+ year olds; n=548 (20%), rate: 201 per 100 000 | Increasing by age decade: aged 40s: 343 per 100 000 (16% of those who died) aged 50s: 793 per 100 000 (20%) aged 60s: 1660 per 100 000 (25%) aged 70+: 3441 per 100 000 | Males with ID rate of death: 257 per 100 000 Females with ID rate of death: 331 per 100 000 respiratory causes did not vary over the 10-year study period. Deaths due to respiratory diseases increased, with increasing age. Gender: breathing obstructions were more prevalent among males. Gender x age: respiratory disease was increased in the oldest groups, for males particularly while respiratory disease remained static as a cause of death for females across ages | Breathing obstructions: 2.7% average deaths per year across 10 years, n=75, rate=27.5 per 100 000 Respiratory disease types: pneumonia was the most prevalent type of respiratory cause of death, with 43% of respiratory disease deaths in ID group | Not available |
| Ng et al (2017) | 4738/15 289 deaths in people aged 55+ (31%)                                          | 807/4738 (17%) respiratory deaths for those with ID HR=12.5 (10.9, 14.2) (adjusted for sex, year of birth and year of access to services) | ID rate: 423 per 100 000 DS rate: 3187 per 1000 ID group (excludes DS) Pneumonitis due to solids and liquids: 10%, rate 25 per 100 000 Pneumonia: 50%, rate 129 per 100 000 Other COPD: 20%, 49 per 100 000 DS group Pneumonitis due to solids and liquids 31.4%, 181 per 100 000 Pneumonia 20%, 113 per 100 000 Asthma 8%, 45 per 100 000 Bronchitis 8%, 45 per 100 000 Other respiratory disorders 8%, 45 per 100 000 | Not available                                 | Not available                                                                 | Age, gender |

Continued
| Author               | All-cause mortality | Deaths from respiratory disorders | Between group comparison of deaths from respiratory disorders | Deaths from individual respiratory disorders | Between group comparison of deaths from individual respiratory disorders | Variables associated with risk of death from respiratory disorders |
|----------------------|---------------------|----------------------------------|-------------------------------------------------------------|---------------------------------------------|------------------------------------------------------------------|---------------------------------------------------------------|
| Oppewal et al (2018) | 207/1050 ID=19.7%;  | 69/159 ID=44.3%; 33/45 DS=73.3% | 5-year age bands: P50–P54 ID=100%GP=3.3%; P55–P59 ID=26.5%GP=4.7%; P60–P64 ID=51.4%GP=6.0%; P65–P69 ID=30.4%GP=6.7%; P70–P74 ID=23.8%GP=8.6%; P75–P78 ID=12.5%GP=9.4%; P80–P84 ID=26.3%GP=9.4%; P85–P90 ID=10%GP=9.9%; P90–P95 ID=40%GP=10.4%; P95+ ID=100%GP=10.9% | Pneumonia ID=80.4%; COPD ID=17.6% | Not available | Not available |
| Patja et al (2001)   | 1111/2369 ID=46.9%  | Immediate cause 322/1093 ID=29%;  | Male: age 2–19 SMR=5.8 (4.4–15.6); age 20–39 SMR=5.4 (2.9–8.0); age 40–49 SMR=5.5 (3.5–7.5); age 60+ SMR=2.7 (2.7–4.8) Female: age 2–19 SMR=4.3 (0.3–4.7); age 20–39 SMR=3.2 (1.1–5.1); age 40–59 SMR=6.2 (4.1–8.2); age 60+ SMR=3.3 (1.7–3.0) | Pneumonia ID=83%; COPD ID=11% | Pneumonia deaths (%): profound ID=29%; severe ID=13%; moderate ID=33%; mild ID=25%; Risk ratios compared with general population: Mild ID 2.6 times higher; profound ID 5.8 times higher. ID men higher risk than women in younger age groups (<39 years), but at lower risk from 60 years of age onwards | Age, gender (all respiratory) ID severity (with pneumonia) |
| Raitauso et al (1997) | 216 deaths | Immediate cause of death 97/216 ID=45%; Primary cause 14/216 ID=6%. Respiratory diseases were the dominant causes of ID death. SMR=2.15 (CI: 1.18 to 3.61) | age 0–14 SMR=0.48; age 15–44 SMR=3.46; age 45–74 SMR=2.35; age 75 SMR=0 | Bronchopneumonia (immediate cause) ID=43% | Not available | Age (all respiratory) |

Table 2 Continued
### Table 2

| Author                        | All-cause mortality | Deaths from respiratory disorders | Between group comparison of deaths from respiratory disorders | Deaths from individual respiratory disorders | Between group comparison of deaths from individual respiratory disorders | Variables associated with risk of death from respiratory disorders |
|-------------------------------|---------------------|------------------------------------|-------------------------------------------------------------|---------------------------------------------|---------------------------------------------------------------------|-------------------------------------------------------------------|
| **Smith et al (2020)**        | n=106 (0.6%) deaths | SMR=11.6 (95% CI: 9.6 to 14.0)     | Underlying cause of death: General population: n=55, CMR=81.7 (95% CI: 62.7 to 106.4) deaths SMR=55.3 (95% CI: 42.5 to 72.1) (adjusted for age and sex) | Underlying cause of death: Pneumonia including influenza: n=5, SMR=55.3 (95% CI: 42.5 to 72.1) (adjusted for age and sex) | General population: All-contributing factors in death: Pneumonia including influenza: n=5, SMR=55.3 (95% CI: 42.5 to 72.1) (adjusted for age and sex) | Not available                                                   |
| **Trollor et al (2017)**      | 732/19 362 ID=4%    | SMR=1.3 (1.2 to 1.5)               | Not available                                               | Not available                                | Not available                                                       | Not available                                                   |
| **Tyver and McGrother (2009)**| 503/2995 (17%) deaths | SMR=5.46 (95% CI: 4.58 to 6.46) (adjusted for age and sex) | Not available                                               | Bronchopneumonia: SMR=6.47 (95% CI: 5.00 to 8.23), O=66, E=10.2. Other respiratory: SMR=4.64 (CI: 3.58 to 5.91), O=65, E=14.0 | Male: SMR=2.28 (95% CI: 2.02 to 2.56), O=278, E=121.8. Female: SMR=3.24 (95% CI: 2.83 to 3.69), O=225, E=69.4 | Gender                                                          |

*Only where adjusted specifically for respiratory mortality. CMF, comparative mortality figure; E, expected death calculated by authors using data from the study; O, observed deaths; RR, rate ratio; SMR, standardised mortality ratio.
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Figure 1 PRISMA flow diagram of systematic search and selection. A total of 2286 records were retrieved through a search of Embase, ISI Web of Science (all databases), CINAHL and PsycINFO with an additional nine records identified through other sources. After removing 241 duplicates, 2025 records were excluded due to ineligible types, the remaining 29 were retrieved as full-texts. From these, 17 were included in the narrative review and 10 included in the meta-analysis. PRISMA, Preferred Reporting Items for Systematic Reviews and Meta-Analyses.

ICD 9-chapter codes and ICD 10-chapter codes for respiratory disorders. The remaining four studies included in the systematic review did not define respiratory disorders.

Causes of death from respiratory disorders
Thirteen papers reported on cause of deaths from respiratory disorders. Pneumonia was reported as a cause of death in 12 studies, five studies reported deaths from pneumonitis related to aspiration, five studies reported on chronic obstructive pulmonary disease (COPD), one study reported on asthma and one reported respiratory cancer deaths.

EVIDENCE SYNTHESIS
Respiratory-associated mortality
Five papers reported that respiratory disorders were the dominant cause of death in people with intellectual disabilities. A further three studies found that deaths from respiratory disorders were the second most common cause of death. Respiratory-associated deaths were in the top five main causes of deaths for a further four papers. Comparative results (intellectual disabilities vs general population) for deaths due to respiratory disorders were reported in 10/17 (59%) of the studies. In the majority of these studies, rates of death from respiratory disorders were higher for people with intellectual disabilities than for people in
the general population. However, Troller et al reported that respiratory-associated deaths in the general population were (9%) similar to the population with intellectual disabilities (12%). Hollins et al also reported that respiratory disorders were the most commonly cited cause of death for both groups.

**Individual respiratory disorders and mortality**

Pneumonia was reported as the most common cause of respiratory death in people with intellectual disabilities. Contributors to pneumonia deaths included influenza and injury from inhalation and aspiration events. Pneumonitis featured as an underlying or contributing cause for between 8% and 21% of disabilities. Crude comparison data showed people (between 10 and 20 times) to die from pneumonitis. Two studies reported tests of significance. While one study reported proportions of respiratory deaths between males and females, while two reported separate SMRs for different age-bands which varied widely. Group-level analysis was not possible. Level of intellectual disabilities was only reported as associated with respiratory related deaths in one study with 35-year follow-up using relative risk but failed to report confidence or p-values. This study found that, when compared with the general population, the relative risk of respiratory related deaths was 2.6 times higher for people with mild intellectual disabilities and 5.8 times higher for people with profound and multiple intellectual disabilities.

**Factors associated with respiratory-associated deaths experienced by people with intellectual disabilities**

Age, gender and severity of intellectual disability have been found to be associated with risk of respiratory cause of death. Only four out of 17 (23.5%) papers directly reported on factors associated with the risk of respiratory-associated deaths (see table 2). Two reported SMRs separately for males and females, while two reported proportions of respiratory deaths between males and females. None directly compared males versus females or reported tests of significance. While one study reported higher respiratory SMRs among females, another study reported separate SMRs for different age-bands which varied widely. Group-level analysis was not possible. Level of intellectual disabilities was only reported as associated with respiratory related deaths in one study with 35-year follow-up using relative risk but failed to report confidence or p-values. This study found that, when compared with the general population, the relative risk of respiratory related deaths was 2.6 times higher for people with mild intellectual disabilities and 5.8 times higher for people with profound and multiple intellectual disabilities.

**Respiratory mortality among children and young people**

Respiratory deaths among children and young people with intellectual disabilities were reported in five studies and found to be a common cause of death across all studies. Four studies included comparison with the general population for respiratory causes of death, while one included the national population without intellectual disabilities. All analyses were limited by the small numbers of death. Raitasuo et al reported only one death. Patja et al reported higher SMR for males aged 2–19 years but not females. Smith et al reported 8% deaths had respiratory disease as the underlying cause but the SMR for underlying cause was not reported.

**Meta-analytical outcomes**

Ten studies reported the necessary data to calculate (SMR, HR or data necessary to calculate these) and were included in the meta-analysis of respiratory mortality of people with intellectual disabilities and the general population. As Hollins et al reported the SMR of two separate cohorts, these were displayed separately in the relevant forest plots. The pooled SMRs for respiratory mortality between people with intellectual disabilities and the general population was 10.86 (95% CI: 5.32 to 22.18). The results indicate that respiratory mortality occurs almost 11 times more frequently in the intellectual disabilities group than in the general population group. At the individual study level, this was adjusted for age in all studies and for sex in all studies except for two of these studies, where this was not clear. There was evidence of considerable statistical heterogeneity between studies in the meta-analyses, with I²=99.0%. Results are displayed in figure 2.

As five studies focused on adults only, one study focused on children only and six included people of all ages, a subanalysis was conducted of studies which reported data on an adult only population. The results of this subanalysis are displayed in figure 3. The pooled SMR reduced slightly from 10.86 (95% CI: 5.32 to 22.18) to 6.53 (95% CI: 4.29 to 9.96), after one study with a sample of primarily children was excluded. Studies which included both adults and children in their sample were removed one at a time. First, both cohorts from Hollins et al were removed and the pooled SMR was reduced by around half, from 915 to 4.80. The further removal of studies by Glover et al, Patja et al and Raitasuo et al resulted in a final pooled SMR for adults of 5.85 (95% CI: 4.73 to 7.22, p<0.001). Heterogeneity between studies was also reduced from I²=99% to I²=56% by the exclusion of samples which included children.

A subanalysis was conducted of studies which reported an SMR for pneumonia. The pooled SMR for pneumonia mortality for people with intellectual disabilities compared with the general population was 26.65 (95% CI: 5.63 to 126.24, p<0.001). These results, displayed in figure 4, indicate that pneumonia-related mortality occurs much more frequently in people with intellectual disabilities than in the general population group. Evidence of considerable statistical heterogeneity between studies was also present in this subanalysis with I²=99.0%. SMRs were recalculated excluding the only study to include an adult only sample, Tyrer and McGrother, resulting in a substantial increase in pooled SMR (95% CI: 26.65 to 42.70).

**Sensitivity analysis**

Sensitivity analysis in relation to quality assessment was run for the 10 studies included in the meta-analysis (online supplemental appendix 3). Studies which were rated as weak or moderate were removed from the analysis. The pooled SMR for mortality ratios changed slightly as Raitasuo et al (from 10.81 to 12.67) and then Tyrer...
DISCUSSION

This systematic review and meta-analysis highlights that people with intellectual disabilities experience excess respiratory-associated deaths, with a respiratory mortality of almost 11 times greater than for the general population. Respiratory mortality was more prevalent among studies which include children, and pneumonia was a major contributor to the higher respiratory mortality reported in this study. Clinical guidelines have contributed to a reduction in mortality from community-acquired pneumonia. We believe the evidence presented here highlights the need for clinical guideline development groups to make recommendations on reducing the risks of premature death due to community-acquired pneumonia among people with intellectual disabilities. Vaccination programmes for influenza can help to reduce respiratory mortality in children and adults. Although there is a relatively low uptake of influenza vaccine among people with intellectual disabilities, annual health-checks for people with intellectual disabilities have been reported to increase uptake of influenza immunisation. People with intellectual disabilities should be identified as a high-risk group and immunisation providers should prioritise the improvement of vaccine uptake, for example through the roll-out of health checks. People with intellectual disabilities are at increased risk of recurrent chest infections which are secondary to dysphagia with a high proportion of aspiration pneumonia-related deaths occurring among individuals with severe and profound intellectual disabilities. Increased recognition of the link between dysphagia and respiratory disorders among caregivers and practitioners is critical to ensuring the early identification of individuals with respiratory disorders. The higher risk of death from respiratory disorders, such as pneumonia, for people with intellectual disabilities is a significant concern in relation to the rapidly developing COVID-19 pandemic. Urgent action to
Overall, mortality in childhood is very low relative to adulthood, and in the paediatric age group, chronic disabling conditions such as intellectual disability, epilepsy and cerebral palsy all have a marked impact on SMR. Comorbidity with epilepsy and cerebral palsy are likely to be significant modifiers of the relationship between intellectual disability and respiratory mortality. Children with more severe intellectual disability are more likely to have epilepsy and cerebral palsy, both of which are independent risk factors for respiratory mortality.

**Study strengths and limitations**

Our study has several strengths. The meta-analysis included mortality ratios from 10 observational studies covering 1844 respiratory deaths in people with intellectual disabilities, which has improved the power and precision to answer this important research question. A rigorous and systematic analysis process was undertaken, and we minimised the risk of bias, errors and omissions by having two or more reviewers conduct comprehensive searches, assess study quality and extract descriptive data. Due to the low prevalence (~1%) of intellectual disabilities among the general population, low sample size was a considerable limitation, relative to other patient groups. However, our meta-analysis included two national,10 12 and five regional intellectual populations in their respective countries.11 15 23 28 While heterogeneity was found, due to methodological and clinical diversity including study design, age and study nationality, this is common in meta-analyses and statistical heterogeneity was inevitable.20 We have not included assessment of non-reporting or publication bias. Most of the research was conducted in Western countries, thus limiting the extent to which the findings may generalise to non-Western countries. Furthermore, ethnicity was not reported widely which prevented further analysis. There was variation among studies on how mortality was examined and how deaths were reported. There is a general lack of evidence on factors associated with the increased risk of respiratory-related deaths in people with intellectual disabilities. As a consequence, we were not able to perform meta-regression on predictors or factors reported in studies which increase SMRs for respiratory deaths (age, sex, place of death or severity of intellectual disabilities). This should be a priority for future research in order to inform the development of targeted interventions to prevent respiratory-related deaths. Although the meta-analysis enables synthesis of data from a large sample, many of the individual studies reported on small samples and are at increased risk of bias. It is encouraging that there have been several larger studies in recent years and future research should focus on reporting respiratory mortality in representative, population-based samples. Furthermore, the majority of the studies included for review relied on death certificate data. One the most reported causes on the death certificate of people with intellectual disabilities is the intellectual disability itself. Given that this problem only
exists within this population, true causes of death remain underestimated.\textsuperscript{41, 42} As reporting has improved over the years, and many counties implemented automated coding systems, it is likely that older paper have more bias than more recent studies.

These findings signify the urgent need to develop and implement evidence-informed strategies to reduce premature mortality among people with intellectual disabilities. Respiratory disorders are a major cause of death for people with intellectual disabilities, many of which are avoidable with improved public health initiatives and access to good quality health and social care. However, further research is required to understand both the multifactorial causes of this heightened risk as well as the most effective approaches for the multiprofessional clinical management of these risks.

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