BMC Cancer

SYSTEMATIC REVIEW Open Access

Cancer in adults with intellectual disability: a systematic review of prevalence and incidence

Martin McMahon[1,2*], Andrew Wormald[2], Shauna Walsh[1,2], Jessica Eustace-Cook[1], Mary McCarron[1,2], Philip McCallion[2,3], Valerie Smith[4], Alyson Mahar[5] and Louise Lynch[1,2]

Abstract

Background The epidemiology and pattern of cancer in people with an intellectual disability is poorly documented. Emerging evidence reports that a different profile and trajectory of cancer burden is experienced in this population. The prevalence and incidence of cancer in this group have not been systematically synthesised. This review will address a significant gap in the evidence base.

Methods The Joanna Briggs Prevalence and Incidence methodology was used to guide the conduct of this review. Reporting the review adheres to the PRISMA checklist. Observational studies reporting prevalence and incidence of cancer and cancer subtypes in adults with intellectual disability were identified through searches of Embase, MEDLINE, CINAHL, PsycINFO, Web of Science, and grey literature from database inception dates to May 2025. A modified JBI Critical Appraisal Checklist was used to assess study quality. Meta-analyses were completed using Meta-XL., with pooled estimates reported where appropriate and narrative synthesis provided for heterogeneous results.

Results Two articles reported cancer prevalence and ten reported cancer incidences. The pooled prevalence was 2% (95% CI: 1–3%). Incidence estimates varied from 1.0 to 4.7% but were from studies with different designs and follow-up periods, limiting direct comparability. Overall, findings tentatively suggest a similar to lower overall cancer prevalence and incidence to the general population, but some studies reported higher rates of ovarian, testicular and unknown primary cancers. The methodological quality of most ($n=11$) studies was high. Meta-analyses showed substantial statistical heterogeneity for included incidence studies reflecting methodological and clinical differences.

Conclusions Comparisons across studies are limited by heterogeneity in definitions of intellectual disability, study settings and cancer case identification. Challenges in synthesising cancer data in this population highlight the urgent need to identify people with intellectual disabilities at a population level and in cancer registries to help develop evidence that supports policy and practice in this area. Robust evidence is needed to inform clinical decision-making and policy development as the current epidemiological evidence is currently insufficient for this purpose.

Keywords Intellectual disability, Cancer, Prevalence, Incidence, Mortality, Systematic review

*Correspondence:
Martin McMahon
mcmahomj@tcd.ie

Full list of author information is available at the end of the article

Background

Intellectual disability (ID) comprising of 1–3% of the population [1] is a lifelong neurodevelopmental condition that originates during the developmental period with significant deficits in intellectual functioning, and adaptive behaviour, consisting of conceptual, social, and practical skill [2]. People with intellectual disability have a complex health profile, with a higher prevalence of certain conditions, including epilepsy, sensory issues, cerebral palsy, obesity, osteoporosis, congenital heart defects, and thyroid disorders [3–6]. They experience health inequalities and inequities [7, 8], and die at much younger ages than the general population [9–12] often from conditions which would have been amenable to good quality healthcare [3, 13].

Cancer is one of the most characterised diseases in the general population with well documented data on incidence, prevalence and outcomes across high income countries [14–17]. However, despite increasing attention to health inequities for people with intellectual disability the descriptive epidemiological cancer evidence is lacking and inconsistent. Emerging evidence signals that people with intellectual disability have a higher likelihood of developing cancer [18, 19], developing cancer at younger ages [20–22], and dying from cancer [21–23]. More recent evidence also highlights some specific disorders (e.g., Down's syndrome) and certain genetic mutations (e.g. neurofibromatosis type 1) potentially elevating the risk for developing particular cancers [24].

Recent population-based studies in people with intellectual disability are reporting that people with intellectual disability are more likely to be diagnosed with metastatic breast and colorectal cancer [20], cancer of the female uterus and male genital cancers [21]. Concerningly, in these studies, people with an intellectual disability are commonly diagnosed with cancer at advanced stages which supports an English study that found that over a third of all cancers in a population of people with intellectual disability were diagnosed at late stages in emergency presentations [25]. These inequalities with the general population are potentially exacerbated by lower screening rates. Diverse barriers exist which inhibit cancer screening for those with intellectual disability such as unpreparedness, fear, communication issues from both health professionals and patients, and a lack of knowledge [26].

Despite these concerning trends, the overall body of available epidemiological evidence provides mixed findings of cancer in adults with intellectual disability. Overall, the data on the prevalence and incidence of cancer in this population is inconclusive with existing studies varying widely and as far as we are aware, no study has to date undertaken a detailed prevalence and incidence evidence synthesis. Such reviews are important as they provide information on cancer burden, trends and geographical distributions while allowing healthcare professionals and policymakers to understand disease burden in populations. To address this gap the aim of this review is to estimate the prevalence and incidence of cancer in adults with intellectual disability and where possible, identify any trends in subgroups based on age, sex and severity of intellectual disability.

Materials and methods

Intellectual disability definition

Intellectual disability begins before adulthood and is characterised by having a significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence and mental capacity) which results in a reduced ability to cope independently (impaired social functioning) and has a lifelong effect on development [27]. An IQ of less than 75 is indicative of limitations in intellectual functioning and those with an intellectual disability e.g. Down Syndrome typically learn more slowly and may not grasp abstract concepts [28].

The authors are committed to inclusive and respectful content upholding the principle that language shapes perceptions and influences discourse. Therefore, we do not condone the use of derogatory, offensive, or discriminatory language in any of our articles and any reference to derogatory language has been removed from studies included in this review.

Registration and reporting

This systematic review followed the JBI guidance for Systematic reviews of prevalence and incidence [29]. Reporting the review adheres to the PRISMA (Preferred Reporting of Items for Systematic Reviews and Meta-Analyses) [30] reporting guidelines. The review protocol was published in 2024 [31]. The protocol is registered at the International Prospective Register of Systematic Reviews (PROSPERO; registration number: CRD42023423584). Supplementary methodological files are hosted on Open Science Framework (OSF) (available here https://osf.io/ruaq5/.)

Eligibility criteria

Types of studies

Eligibility criteria included quantitative studies that were observational (retrospective and cross sectional), and/or longitudinal with published baseline data that had estimated or presented data on the prevalence or incidence of cancer in adults with intellectual disability. No geographical, date or language restriction was applied. Studies were only included if the numerator and denominator of the prevalence and incidence estimation fraction was reported.

Types of participants

Adults (≥ 18 years) of any sex, ethnicity or socioeconomic status who are identified as having intellectual disability e.g. by self-report or administrative data were included in this review. Differences in reporting across countries and jurisdictions were considered. Studies reporting on chromosome abnormalities were assessed for the presence of intellectual disability and where specific conditions where intellectual disability could not be assumed (for example cerebral palsy) those were excluded unless the presence of intellectual disability could be determined.

Outcomes

The primary outcome measures were: (1) the prevalence of any type of cancer, (2) the incidence of any type of cancer. The secondary outcomes were the prevalence and incidence of cancer subtypes. The underlying information for these outcomes were cancer diagnoses, which were made in different ways. All cancer types reported in the included studies had to be diagnosed by an appropriately qualified medical professional with or without classification, self-reported or obtained from appropriate cancer registries.

Search strategy

Database search

The Condition Context Population (CoCoPop) framework [32] was used to frame the search strategy, and a subject librarian undertook all database searches and imported the results into Covidence. Embase (Elsevier; 1947-), MEDLINE (EBSCO; 1879-), CINAHL Ultimate (EBSCO; 1937-), PsycINFO (EBSCO; 1967-) and Web of Science – Core Collection (Clarivate; 1945-) were searched with no limits or filters placed on the search. Each database was searched from inception to May 2025. The reference lists from included full-text articles were hand searched and forward citation searching undertaken. To increase the sensitivity of the search, NEAR proximity operators were applied to the keyword search. The search strategy was peer-reviewed by two additional Subject Librarians and the Peer Review of Electronic Search Strategies (PReSS) checklist to improve quality of the literature search was followed [33]. Supplementary searches for grey literature were also undertaken. Full details of the search strategy are detailed in McMahon et al. (2024). Supplementary file 1.

Study selection and quality assessment

Screening of titles and abstracts Three reviewers screened (SW, AW, LL) the title and abstracts and retrieved articles independently based on eligibility criteria. Any conflicts were resolved through discussion and moderation with an independent researcher not included in the screening process (MMcM). The primary discussion points at this stage were studies that did not report on the presence of intellectual disability. The online reviewer tool COVIDENCE (https://www.covidence.org/) was used to manage the screening process and EndNote X20 by PDF Tron™ Systems Inc was used to manage bibliographies.

Screening of full text reports Three independent reviewers (LL, AW, SW) reviewed the full text of all articles and conflicts were resolved through discussion with the lead author (MMcM).

Assessment of methodological quality To assess the methodological quality of included studies a modified version of the JBI Critical Appraisal Checklist for Studies Reporting Prevalence Data was used for all studies [29]. This nine-question tool addresses the: appropriateness of the sampling frame and study participants; the adequacy of the sample size; the description of study subjects and setting; sufficiency of data analysis; validity of identification of condition; reliable measurement of condition; appropriate statistical analysis; and, response rate. For each question there is a 'yes', 'no', 'unclear' or 'not applicable' response. Two reviewers [AW, LL] independently determined the strength of each included study where 'yes' and 'not applicable' are scored '2', unclear scored '1'and 'no' scored '0'. This left a range of scores of '0–18' with 18 being the highest quality.

Data synthesis Meta-analyses of overall prevalence and incidence data from the included studies were conducted using MetaXL. Due to the level of heterogeneity, results are presented narratively, with pooled estimates provided where appropriate. Full meta-analytic outputs are available as supplementary files.

Data extraction A comprehensive data extraction form was predesigned and piloted on five records to assess suitability for the review. No changes were required after the pilot. Data extracted to the form included: Authors and year; Country of study; Study design; Sample origin; Age range (mean (SD); median); Sex (male/female as reported) (%); Measurements (ID = IQ < 70); Cancer diagnosis method; Subtype of cancer(s) as per ICD-Classification system; Death (%);Sample size N; and Cancer prevalence or incidence % (95% CI) which included comparative and subgroups if available. One reviewer (LL) extracted data and a second reviewer (SW) reviewed extraction to corroborate accuracy and comprehensiveness.

Results

Search and selection results

Database search

Figure 1 (PRISMA Flow Diagram) illustrates the results of the search and selection process. The database search

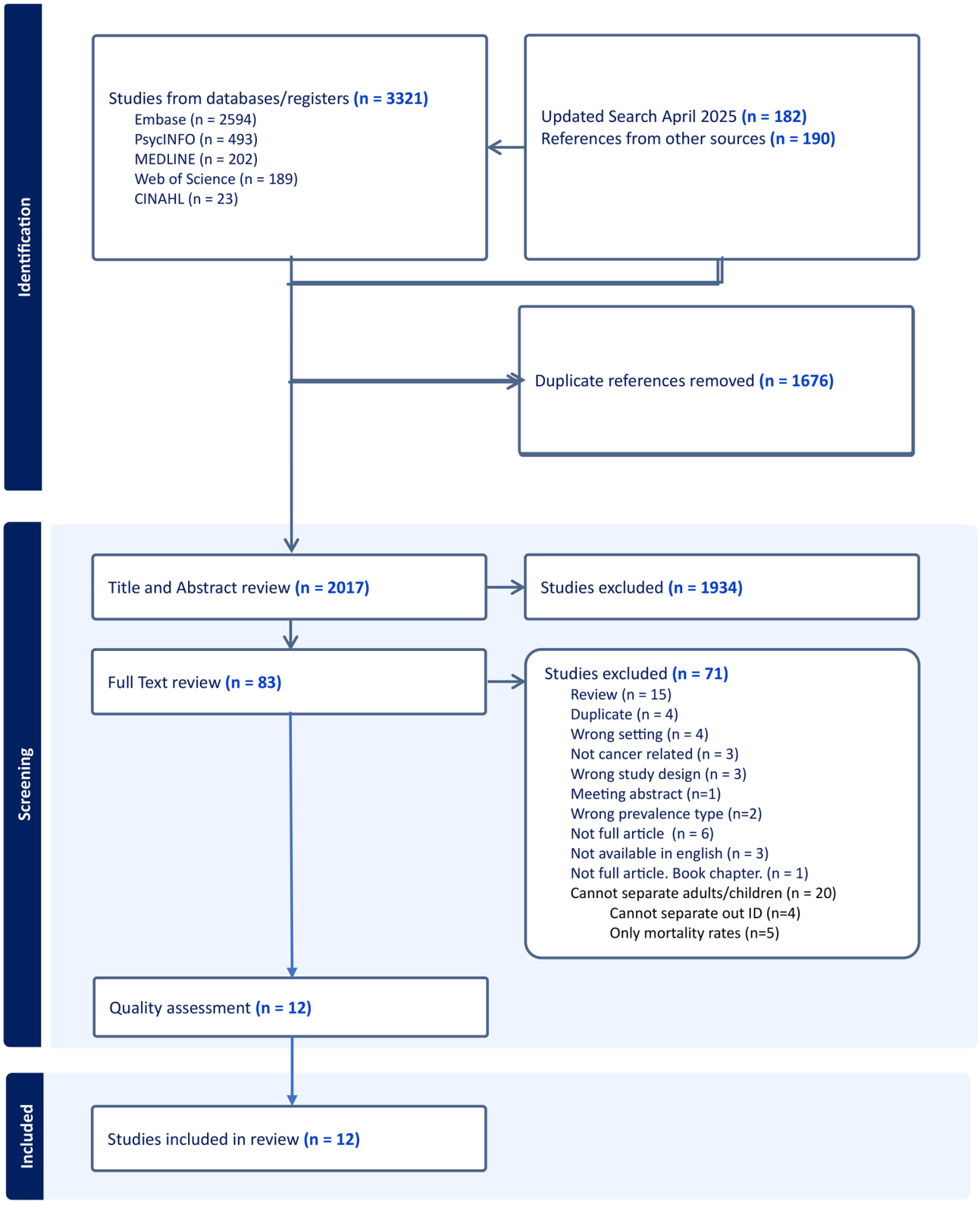

Fig. 1 Preferred Reporting Items for Systematic Reviews and Meta-Analyses for Cancer in adults with intellectual disability: a systematic review of prevalence and incidence

for prevalence and incidence studies identified 3,321 records for consideration and a further 190 records were identified from other sources (e.g. citation searching). Two additional studies that were included at this stage were preprints [34] the first that was subsequently published in July 2024 [21] and the second is in print as of May 2025 [35]. A rerun of the search in May 2025 resulted in 182 additional articles. The total number of articles include for review was 3,693. Following removal of duplicates ($n = 1,676$), 2,107 records were screened, of which 1,934 were excluded after title and abstract review. In total, 83 full text records were reviewed. At this stage 71 total records were excluded for example children and adults could not be separated in 20 studies, only mortality rates were available in five studies, full text was unavailable for three articles, one article could not be translated into English and in four studies intellectual disability could not be established. This resulted in 12 studies that were quality appraised and subsequently included in the review.

Main results

Description of included studies

Included studies were conducted in various countries, including the UK [36] Australia [37, 38], France [39, 40] Denmark [41] Germany [42] Sweden [43], Finland [41], Scotland [21] and the Netherlands [35]. Most studies used national or regional health registries [35, 44] and/or relied on – linked – administrative, survey [38], or institutional data [43]. The age of participants varied widely from 18 years to over 85 years. Overall, gender was in general balanced apart from two studies [37, 40] who included only female participants. Level of intellectual disability was not reported in most studies with two studies [36, 37] only reporting it. Study results were very diverse, with low consistent measures. Of the 12 studies included in this review, two studies reported Odds ratio (OR) or ORs could be calculated from overall population data reported [38, 45] for prevalence. Most incidence studies [35, 41, 43, 44, 46–48] reported cancer counts and overall population with four studies using SIR for incidence studies [21, 42, 46, 47]. Using the modified version of the JBI Critical Appraisal Checklist for Studies Reporting Prevalence Data ([29], most studies had a medium to high quality score (Appendix). Characteristics of all included studies are summarised in Table 1.

Key findings

Prevalence of cancer

Of the two studies that reported prevalence, one study [36] compared the likelihood of cancer in individuals with intellectual disability versus the general population using effect sizes (ES) expressed as ORs. McMahon and Hatton (2021) [36] (OR = 0.39, 95% CI [0.16, 0.97]) reported a lower odds of reporting cancer in comparison to the general population. One study [47] also reported on prevalence proportions within the intellectual disability population who had cancer, independent of direct comparison to a control population. Reported cancer prevalence ranges from approximately 1 to 2.3% [38, 45].

A meta-analysis of the two prevalence studies was conducted (Fig. 2). Heterogeneity was low ($I^2 = 9\%$), supporting the appropriateness of combining the study results. The pooled prevalence was 2% (95% CI: 1–3%), indicating a small but statistically significant overall estimate across the included studies.

Incidence of cancer

Incidence and sex-stratified meta-analyses are available in Supplementary File 2, with the key findings reported narratively below. High heterogeneity in this analysis reflects variation in study methods, populations and measurement and as a result, cautious interpretation is warranted. Ten studies [21, 35–50] reported on the incidence of cancer in adults with intellectual disabilities. Hasle et al. (2000) [46], Sullivan et al. (2003, 2004) [37, 38] and Patja et al. (2006) [41] all reported consistently low estimates of around of 1–2% while Krieg et al. (2024) [42], Cuypers et al. 2025 [35] and Ward et al. (2024) [21] reported higher incidence rates ranging from 2.9 to 4.7% respectively. As with prevalence rates, the incidence of cancer in adults with intellectual disability ranged widely across studies. Meta-analysis was completed for the nine studies that used percentage of cases.

Incidence stratified by gender

Analysis of cancer incidence stratified by gender, comparing the ORs for females and males with intellectual disabilities was undertaken. Ward et al. (2024) [21] indicated a statistically significant lower risk of cancer in both males and females with intellectual disabilities (Total SIR = 0.76, 95%CI 0.7–0.82). Furthermore, Krieg et al. (2024) [42], (OR = 0.79, 95%CI 0.57–1.09, $p = 0.144$), and Sullivan et al. (2004) [38] (Males SIR = 0.29, 95%CI 0.24–0.36; females SIR = 0.45, 95%CI 0.36–0.55) reported a lower but not statistical difference in cancer incidence. In the most recent study Cuypers and colleagues [35] reported that cancer incidence was slightly higher in females (OR = 0.82 95% CI 0.79–0.86) with intellectual disability than in males with intellectual disability (OR = 0.78 95% CI 0.75–0.81) but significantly lower than the general population.

Subtypes of cancer, age and severity of intellectual disability

Due to significant variability in cancer subtypes among people with intellectual disabilities we were unable to undertake meta-analysis. Overall, the studies revealed a distinct pattern of cancer subtypes in adults with

Table 1 Summary characteristics of included studies reporting prevalence and incidence ($n=12$)

Author(s), year	Country	Study design	Sample origin	Age range (mean (SD); median)	Gender (%)	Measurements (ID = IQ < 70)	Cancer diagnosis method	Cancer(s) subtype (per ICD-Class)	Death (%)	Sample size (*N*)	Cancer prevalence or incidence % (95% CI)
Bourgarel, S., Trétarre, B., Satgé, D. and Stoebner-Delbarre, A., 2016.	France	Cross-sectional	Adults with intellectual disability living in an institution who answered the HSI survey	Mean age = 43years	Male = 54%, female = 46%	NA		Colorectal cancer only	NA	2,123	SIR = 3 (0.6–8.76)
Hasle, H., Clemmensen, I.H. and Mikkelsen, M., 2000.	Denmark	Retrospective cohort	Danish Cytogenetic Register based on reports from cytogenetic labs. assumed to provide almost complete coverage of constitutional chromosomal abnormalities diagnosed in Denmark since 1961.	Age range not specified.	Male: $n=1536$ (54.6%). Female: $n=1278$ (45.4%).	Not specified. All participants have DS diagnosis.	Not specified. All clinical and pathological departments give notifications of malignancies to the Danish Cancer Registry.	ICD7 Codes. Digestive system, Stomach, Colon, Peritoneum, Respiratory, Lung, Breast, Uterus, Ovary, testis, Urinary tract, Kidney, Bladder, Non-melanoma, Other specified sites, Brain, Secondary and unspecified sites, Non-hodgkin lymphoma, Hodgkin's disease, All solid tumours, Leukaemia, Acute unspecified leukaemia	Not specified.	2814	$n=60$ (2.1%). 1968 to 1995, 27 year period.

Table 1 (continued)

Author(s), year	Country	Study design	Sample origin	Age range (mean (SD); median)	Gender (%)	Measurements (ID = IQ < 70)	Cancer diagnosis method	Cancer(s) subtype (per ICD-Class)	Death (%)	Sample size (*N*)	Cancer prevalence or incidence % (95% CI)
Krieg, S., Krieg, A., Loosen, S.H., Roderburg, C. and Kostev, K., 2024	Germany	Retrospective cohort	1284 general practices in Germany between January 2005 and December 2021. Based on data from the Disease Analyzer database used in GP and specialist practices. Database covers 3% of all private practices in Germany.	DS population: Range (Mean, SD) = 41.8 (15.3). Non-DS population: Range (Mean, SD) = 41.8 (15.3). Median for either group not specified.	DS population: Female: *N* = 1171, 48.0%. Male: *N* = 1267, 52%. Non-DS population: Female: *N* = 5855, 48.0%. Male = *N* = 6335, 52%.	Not specified. All have a diagnosis of DS, but no other specifics given.	Not specified. Data from the Disease Analyzer database used, which contains diagnoses data from computer systems used in practices of GPs & specialists. Shown to be representative of general & specialist practices in Germany. used.	ICD10 Codes not supplied, but cancer subtypes outlined. See Table in Appendix, page 6 of 11.	NA	2438 with DS, 12,190 no DS.	Cancer rate of 3.1% DS compared to 3.9% non-DS. 5 year cumulative incidence of cancer for DS versus non-DS. Incidence is per 1,000 patient years. Cancer total all patients: 3.89 5.53 0.79 (0.57–1.09) 0.144. Over 16 years (2005–2021)
McMahon, M. and Hatton, C., 2021	UK	Administrative population	Adults with ID receiving/received support from ID services in Jersey. The general population random stratified sample approach; addresses drawn at random from list of residential, active addresses for each parish on the Jersey Land Property Index	Age range 18–85	Male = 56.2% (*n* = 122), female = 43.8% (*n* = 95)	Mild = 50% (*n* = 108), Moderate = 25.8% (*n* = 56), severe = 15.7% (*n* = 34), profound = 8.8% (*n* = 19)	Self-report. For the ID sample, all electronic health and nursing notes held on Care Partner (electronic health & social care database) by Jersey's Health and Community Services were reviewed		NA	217	0.39 [0.16–0.97]

Table 1 (continued)

Author(s), year	Country	Study design	Sample origin	Age range (mean (SD); median)	Gender (%)	Measurements (ID = IQ < 70)	Cancer diagnosis method	Cancer(s) subtype (per ICD-Class)	Death (%)	Sample size (*N*)	Cancer prevalence or incidence % (95% CI)
Patja, K., Pukkala, E., Sund, R., Iivanainen, M. and Kaski, M., 2006.	Finland	Population cohort	Finnish registry on persons with ID, data on ID populations. Dates of death obtained from National Population Registry. Follow-up for cancer incidence was performed in the Finnish Cancer Registry, with personal identifier as linkage keys.	Age range not specified. 10 year age intervals provided, can not determine range.	Males: *n* = 1888 (52.7%). Female: *n* = 1693 (47.3%).	Not specified. All participants have DS diagnosis.	Not specified. Finnish Cancer Registry is a population-based registry covering the whole country. Receives information from all levels of healthcare. Various surveys have confirmed that coverage is > 99% complete.		Not specified.	*N* = 1783. Male: *n* = 936. Female: *n* = 847. 0–9 and 10–19 age ranges excluded.	*n* = 41 (2.3%). Period 1978–1986, 8 years.
Pellikaan, K., Nguyen, N.Q., Rosenberg, A.G., Coupaye, M., Goldstone, A.P., Høybye, C., Markovic, T., Grugni, G., Crinò, A., Caixàs, A. and Poitou, C., 2023.	Netherlands, UK, France, Spain, Italy, Australia	Retrospective cohort	Centers participating in the INfoRMEd-PWS network in the Netherlands, United Kingdom, France, Spain, Italy and Australia.	Range: 18–73 years. Median: 28 years. Mean and SD not specified.	Males only mentioned on table. *N* = 251 (46%). Presume Female: *n* = 295 (54%).	Not specified. All have a diagnosis of PWS, attending or have attended services of a center.	Not specified. Local investigators collected data from patients on malignancies. Self-report?		*n* = 3 (0.55%)	546	1.3%. 95% CI not specified.
Satgé, D., Axmon, A., Trétarre, B., Sandberg, M. and Ahlström, G., 2020.	Sweden	Retrospective cohort	3 Swedish National registers from 2001–2012	NA	4327 (54.5%) = men, 3609 (45.5%) = women	N/A	Data from National Patient Register were used to determine the presence of each investigated cancer type for each person in the study.		NA	7936	OR = 0.63 [0.57–0.7]. ID population compared to general population.

Table 1 (continued)

Author(s), year	Country	Study design	Sample origin	Age range (mean (SD); median)	Gender (%)	Measurements (ID = IQ < 70)	Cancer diagnosis method	Cancer(s) subtype (per ICD-Class)	Death (%)	Sample size (*N*)	Cancer prevalence or incidence % (95% CI)
Sullivan, S.G., Glasson, E.J., Hussain, R., Petterson, B.A., Slack-Smith, L.M., Montgomery, P.D. and Bittles, A.H., 2003.	Australia	Retrospective cohort	Identified through Disability Services Commission of Western Australia (WA), which maintained a database of all persons referred with ID since 1953. Entry to the study commenced at 01/01/1982 or on the participant's 25th birthday	674 aged 50 to 69 years between 1989–2001, 380 of whom were active clients & included for linkage with BreastScreen Mean age at diagnosis = 49 (range 27–86)	100% female	11 with mild ID, 4 moderate & 5 with severe were diagnosed with breast cancer	WA cancer Registry		NA	2,370	Period 1982–2000, 19 years or when the person turned 25. 25–39yrs 18,668.69 person-years *n* = 4, SIR 0.70 [0.19–1.81], 40–49yrs 7,323.03, *n* = 7 SIR 0.69 [0.28–1.42], 50–59yrs 3,281.57, *n* = 6 SIR 0.82 [0.30–1.79], 60–69yrs 1,385.72, *n* = 2 SIR 0.51 [0.06–1.85], 70 + yrs 575.20, *n* = 1 SIR 0.0.57 [0.01–3.20].
Sullivan, S.G., Hussain, R., Threlfall, T. and Bittles, A.H., 2004.	Australia	Retrospective cohort	Subjects were identified through the Disability Services Commission of WA	30.8 (SD = 16.3), median age = 30.7	5490 (58.3%) = males, 3919 (41.7%) = females		Cases of cancer were identified by linkage of the DSC database with the WA Cancer Registry.		NA	9409	All cancers: Males SIR = 0.29 (0.24–0.36), females SIR = 0.45 (0.36–0.55). Period 1982–2001, 19 years.

Table 1 (continued)

Author(s), year	Country	Study design	Sample origin	Age range (mean (SD); median)	Gender (%)	Measurements (ID = IQ < 70)	Cancer diagnosis method	Cancer(s) subtype (per ICD-Class)	Death (%)	Sample size (*N*)	Cancer prevalence or incidence % (95% CI)
Trétarre, B., Bourgarel, S., Stoebner-Delbarre, A., Jacot, W., Bessaoud, F. and Satge, D., 2017.	France	Cross-sectional	A random, representative sample of institutions & residents in various establishments in metropolitan France and French overseas territories. 1519 institutions randomly selected. 3 types of institutions included; specialised residential institutions, medicalised residential institutions & community-style residential accommodation.	Range: Not specified. Mean: 42.8 years. SD not specified.	*N* = 978. All female participants.	Not specified. Subjects were considered to have ID if they selected 'mental retardation' among a list of 12 psychological disorders proposed in the questionnaire. Three types of residential institutions i.e. residential, medicalised residential & community style residential accommodation, each housing people with various levels of autonomy.	Self-report. Disabled persons healthcare survey. Caregiver in institute assisted if individual was unable to be interviewed directly. Cumulative incidence rate was the sum of specific incidence rates from birth to age 50.		Not specified.	978	1.4%. Breast cancer only looked at. Period covered 1991–2009, 10 years.

Table 1 (continued)

Author(s), year	Country	Study design	Sample origin	Age range (mean (SD); median)	Gender (%)	Measurements (ID = IQ < 70)	Cancer diagnosis method	Cancer(s) subtype (per ICD-Class)	Death (%)	Sample size (*N*)	Cancer prevalence or incidence % (95% CI)
Cuypers, M., Naaldenberg, J., Banda, A., Oost LJ., Bloemendal HJ., Leusink, GL.	Netherlands	Retrospective cohort	Data from the 26 Netherlands Cancer Registry & linked to population data from Statistics Netherlands	18–75 + years. Mean & SD not specified	57.4% males, 42.6% females	Not specified. Assumed to have ID if entitled to long-term care or supportive services or received income benefits due to a diagnosis of mild ID only	Obtained from the NCR for individuals both with and without ID	Subchapters of ICD-10 Chapter II on malignant neoplasms including most prevalent tumour sites and cancers included in the national screening programme(i.e. breast, cervical, and colon cancer)	NA	187,149 individuals with ID & 760,907 individuals without ID	Overall cancer adj.OR 0.79 [0.76–0.81]. Unknown primary adj. OR 1.60 [1.29–1.98]. Oesophageal adj.OR 1.26 [1.06–1.49). All female genital cancers (C51-C58)OR 1.33 [1.13–1.56].
Ward, L.M., Cooper, S.A., Sosenko, F., Morrison, D., Fleming, M., McCowan, C., Robb, K., Hanna, C., Hughes-McCormack, L., Dunn, K. and Conway, D., 2024.	Scotland	Retrospective cohort	Population data from Scotland's 2011 Census linked to the National Records of Scotland (NRS) death certificate data and Scottish Cancer Registry (Scottish Morbidity Records 06, SMR06) held by National Services Scotland were used	Mean age = 43.9yrs (16.8). 18–24 2,720 (15.8%), 25–34 2,976 (17.3%), 35–44 3,277 (19.1%), 45–54 3,664 (21.3%), 55–64 2,494 (14.5%), 65–74 1,330 (7.73%), 75 + 742 (4.3%)	Male = 9,565 (55.6%), female = 7,638 (44.4%)	NA	Scotland's 2011 census data, Scottish Cancer Registry & National Records of Scotland. Covers 8 year 9 month period		2.5% (435)	The number of records in the Linked analysis dataset was 583,264. 17,203 with an ID, 566,061 with no ID	Total SIR = 0.76[0.7–0.82], Female SIR = 0.79[0.71–0.88], Male SIR = 0.71 [0.64–0.80]. 8 year 9 month period

Follow-up periods ranged from 8 to 27 years across studies reporting incidence. Cancer incidence was variably reported as cumulative proportion over time or as crude/standardised rates per person-years

SD Standard deviation, *ID* Intellectual disability, *IQ* Intelligence quotient, *CI* Confidence interval, *SIR* Standardised incidence ratio, *OR* Odds ratio, *DS* Down Syndrome, *NCR* National Cancer Registry

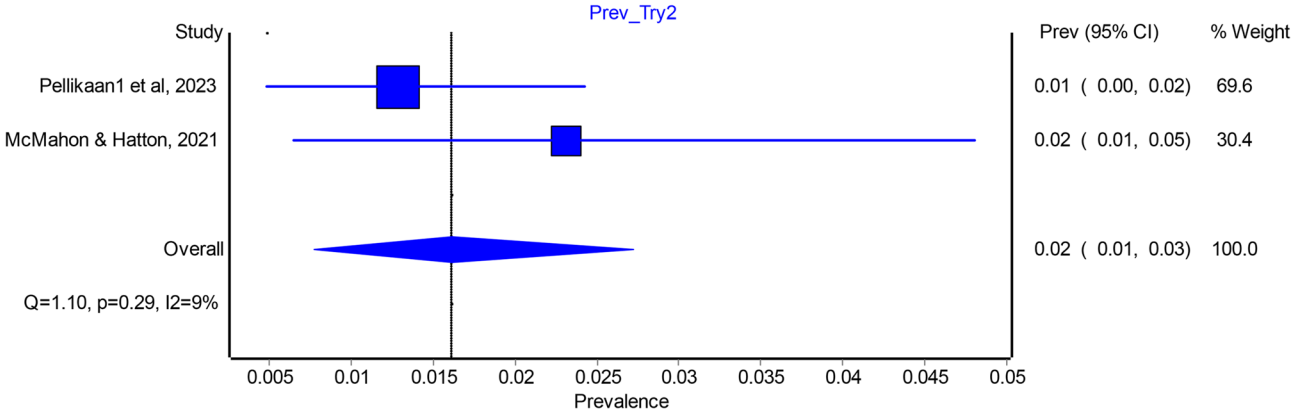

Fig. 2 Meta-analysis of prevalence studies

intellectual disability. Haematological malignancies, particularly leukaemia was prominently reported in people with Down Syndrome [42, 46]. Conversely, Krieg et al. (2024) [42] reported lower incidence rates of digestive, respiratory, and genital cancers in people with Down syndrome. Cancers of the digestive system including colorectal cancer were reported [21, 42] with Ward et al. (2024) [21] also reporting elevated risks for ovarian and uterine cancers in women with intellectual disability, and higher rates of testicular cancer in males. Patja et al. (2005) [41] reported increased risks of testicular cancer in men with Down syndrome. Trétarre et al. (2017) [40] found the incidence of breast cancer was similar to that of the general population (standardised incidence ratio, SIR 0.857, 95% CI 0.42–1.53). Other cancers, for example melanoma and other skin cancers were comparatively rare but still reported, with Pellikaan et al. (2023) [47] noting occasional unique subtypes, such as intracranial hemangiopericytoma in Prader-Willi Syndrome with low rates of malignancies associated with this syndrome. Sullivan et al. (2004) [38] reported that the age-standardised incidence of all cancers in people with intellectual disability was not significantly different from the general population. Similarly, Trétarre et al. (2017) [40] found the age risk was not significantly different from that of the general population. Hasle et al. (2000) [46] reported the unique situation of no leukaemia after the age of 29 years along with no significant increase in solid tumours in people with Down syndrome. The most recent study [35] from Cuypers and colleagues reported an overall lower incidence of combined cancer types in adults with intellectual disability compared to the general population, but there were higher incidences of unknown primary, oesophageal and all female genital cancers, with lower rates of skin cancer. People living in residential care - potentially reflecting increased severity of intellectual disability - had the lowest overall cancer incidence and interesting, this study reported that those with intellectual disabilities were diagnosed with cancer nearly 10 years earlier on average than the general population, with incidence peaking between ages 55–64 years.

Discussion

Our systematic review yielded quantitative findings indicating wide variability in the prevalence and incidence of cancers in adults with an intellectual disability. An inconsistent and complex summary of cancer burden in this population is presented. Overall, while studies here show a trend of lower rates of overall cancers [36, 43], there is evidence of an increase in specific cancer subtypes from other studies, such as ovarian, unknown primary, oesophageal and testicular cancer [21, 35]. Reported prevalence ranged from 1 to 2% [38, 45] while, there was significant divergence in cancer incidence, ranging from 1–3% [37, 46] to higher incidence in recent studies (Ward et al., 2024: 5%) [21]. Importantly, the Ward et al. (2024) [21] study uses population-level data to identify an overall lower incidence of cancer in the intellectual disability population compared to the general population but reports higher rates of metastatic cancer of unknown primary origin (female SIR = 1.70, male SIR = 2.08), cancer of the uterus (female SIR = 1.63), ovarian cancer (female SIR = 1.59), kidney cancer (female SIR = 1.85), and testicular cancer (male SIR = 2.49). Similarly, the Cuypers et al., 2025 study reports higher rates of unknown primary (OR 1.60), and oesophageal cancer (OR 1.26). Concerningly, despite the lower overall incidence reported, the Ward et al. [21] study also reports that people with intellectual disability are more likely to die from cancer than the general population. Similar findings by Cuypers et al. (2022; 2025) [23, 35], reported that people with intellectual disability die from cancer at younger ages. This demonstrates a clear trend of higher cancer deaths despite a lower comparable incidence to the general population. When the results of the recent Mahar et al. (2024) [20] study, which reported the prevalence of intellectual disability among people diagnosed with cancer, is considered where people with intellectual disability were more

likely to be diagnosed with breast and colorectal cancer at later stages—a worrying picture emerges and highlights the urgent need for greater understanding of cancer epidemiology in this population, particularly with the need to influence and inform in four primary areas: cancer disease burden with a particular focus on subgroup differences; identifying inequalities and inequities that exist across the diagnostic spectrum; improving cancer detection using a pre-emptive health surveillance approach and addressing research gaps and informing policy and clinical guidance.

The meta-analyses indicate substantial heterogeneity for cancer incidence and sex-stratified analysis across the included studies, due to clinical and methodological heterogeneity. It is therefore important that the findings in the supplementary files are interpreted with caution, as these summary estimates may lead to unreliable and misleading conclusions [45]. They do however also help illustrate the scale of the challenge and the extent of the cancer burden in adults with intellectual disability.

On one level, the lower prevalence and incidence rates may be attributable to the non-identification of people with an intellectual disability in the population, referred to as the 'hidden majority' in administrative data [44, 48]. For example, the majority of people with an intellectual disability are not known to services, making them difficult to identify in health and social care registries and therefore prohibit the linkage to national cancer registries. However, the Scottish study from Ward et al. (2024) [21], bridges this gap by linking census data with National Cancer Registry data, making it more likely to capture those not known to health and social care services and, theoretically, reflecting the population of people with intellectual disability more broadly. There are, however, limitations—with low absolute case numbers for some cancers limiting the study's power to detect differences. From this perspective, coupled with older data identified in this review [41, 46, 47, 50] there needs to be concentrated and collaborative effort among research communities to identify and measure intellectual disability in a consistent manner and engage in data linkages to identify people with intellectual disability who have cancer and to unite to explore better use of data sharing and integration.

Additionally, the concept of diagnostic overshadowing [51]— arising from a cognitive bias where presenting symptoms are attributed to the intellectual disability rather than investigated as potential signs of other conditions—may overshadow cancer diagnoses. In this situation, cancer rates will continue to appear low because they are not identified and recorded. There is a wealth of evidence that supports this theory [3, 49, 52], and the Mahar et al. (2024) [20] and Cuypers et al. (2025) [35] studies highlights the late-stage diagnosis of cancers in people with an intellectual disability. Additionally, the high prevalence of multimorbidity [4, 53, 54] in this population also complicates diagnosis with the added burden of complex clinical presentations and the reduced ability to self-report symptoms in many cases. It is therefore reasonable to question how common it is for people with intellectual disability to have cancer but never receive a diagnosis and die from cancer or issues secondary to cancer due to factors such as communication barriers and healthcare access issues.

Furthermore, national cancer screening programmes are also an important public health intervention. However, if cancers are occurring in this population at younger ages, then policy makers and national cancer screening programmes should consider if they need be adapted to meet their needs [55]. This should be considered a human rights issue under the United Nations Rights of Persons with Disabilities (2006) [56]. Nevertheless, as far as we are aware, there is no evidence that explores the effectiveness of cancer screening programmes for people with an intellectual disability. However, some evidence shows that those living in residential settings or have a higher intellectual disability level participate in less screening [52]. This requires attention, as does the recording of cancer diagnosis and staging in people with intellectual disability. For example, a recent study has reported an increased risk of missing stage data at diagnosis for adults with intellectual disability in Canada [57]. This creates problems at both an individual level, where treatment decisions are impacted for the person themselves and at a population level, where overall surveillance and reporting are compromised. These differences underscore a significant health inequality and inequity that also require attention [58].

It is critically important to discuss the heterogeneity observed between studies, which underscores the challenges in quantitatively synthesising cancer prevalence and incidence in this population. Differences in study populations, study design, methodology, sample size and outcomes were observed. While this limits generalisability, it highlights the challenges associated with undertaking such a review and underlines the urgent need to address these issues to improve future research. As attempts are made to reduce heterogeneity, future research should focus on the improved identification of people with an intellectual disability with more robust methodologies. Additionally, the concept of targeted screening for high-risk subtypes of cancer (for example, breast and colorectal cancer at younger ages) should be a focus of future research, as well as the evaluation of the implementation of educational training programmes for those involved in the care of people with an intellectual disability at primary, secondary, and tertiary care levels to help improve recognition of cancer symptoms in

this population. Furthermore, longitudinal studies with appropriate sample sizes and robust data-sharing practices should be undertaken to help track cancer incidence over time and measure the effectiveness of interventions. Addressing these gaps would go some way towards understanding the epidemiology and subtypes of cancer in people with an intellectual disability and addressing the health inequality and inequity gap that exists.

Although this review provides important insights into the prevalence and incidence of cancer in adults with intellectual disabilities, it is not without limitations, and the following need to be considered when assessing the value of these findings. The significant heterogeneity observed across studies indicates variability in study findings, which limits confidence in presenting reliable pooled estimates. The lack of subgroup stratification in studies prohibits detailed subgroup analysis, which would be helpful in terms of drawing more nuanced conclusions. All the studies come from high-income countries, and this geographical bias may not be representative of the cancer burden in people with intellectual disabilities in middle- and low-income countries. There is significant variation in sample sizes, which creates difficulty in detecting differences, especially when stratifying different subgroups to explore trends. Finally, studies did not typically differentiate gender from biological sex, and this may not capture gender diverse populations of adults with intellectual disability. These limitations highlight the complexity of conducting such a review in this population. Despite this, our review provides important findings that reinforce the complex and inconsistent picture of cancer burden in people with intellectual disability.

Conclusion

Due to the level of study differences observed, the findings present a complex picture of the prevalence and incidence of cancer in adults with intellectual disability and highlight the challenge of quantitatively measuring cancer burden in this population. Overall, the cancer prevalence and incidence appear to be lower than in the general population but higher for some specific subtypes of cancer. Findings from this review highlight the urgent need for robust evidence to support policy and clinical decisions to inform and influence efforts to improve cancer outcomes for this population. Key points to achieve this will include the following:

- Improvement in the identification and standardised measurement of people with intellectual disability across countries through data linkage with cancer registries.
- Examination of issues impeding cancer screening for those in residential settings and with more severe intellectual disabilities.

Appendix

Individual study quality scores (n=12)

Article number	Article name	Score [Yes, *N*/a = 2, unclear = 1, no = 0]	Quality Rating
1	Ward, L.M., Cooper, S.A., Sosenko, F., Morrison, D., Fleming, M., McCowan, C., Robb, K., Hanna, C., Hughes-McCormack, L., Dunn, K. and Conway, D., 2024. Population-based cancer incidence and mortality rates and ratios among adults with intellectual disabilities in Scotland. medRxiv, pp.2024-01. [21]	18	High
2	McMahon, M. and Hatton, C., 2021. A comparison of the prevalence of health problems among adults with and without intellectual disability: A total administrative population study. Journal of Applied Research in Intellectual Disabilities, 34(1), pp.316–325. [36]	17	High
3	Satgé, D., Axmon, A., Trétarre, B., Sandberg, M. and Ahlström, G., 2020. Cancer diagnoses among older people with intellectual disability compared with the general population: a national register study. Journal of Intellectual Disability Research, 64(8), pp.579–588. [43]	17	High
4	Sullivan, S.G., Hussain, R., Threlfall, T. and Bittles, A.H., 2004. The incidence of cancer in people with intellectual disabilities. Cancer Causes & Control, 15, pp.1021–1025. [38]	17	High
5	Sullivan, S.G., Glasson, E.J., Hussain, R., Petterson, B.A., Slack-Smith, L.M., Montgomery, P.D. and Bittles, A.H., 2003. Breast cancer and the uptake of mammography screening services by women with intellectual disabilities. Preventive medicine, 37(5), pp.507–512. [37]	17	High

Individual study quality scores (n=12)

Article number	Article name	Score [Yes, *N*/a = 2, unclear = 1, no = 0]	Quality Rating
6	Bourgarel, S., Trétarre, B., Satgé, D. and Stoebner-Delbarre, A., 2016. Frequency and screening of colorectal cancer in persons with intellectual disability living in institution in France. Oncologie, 18(4), pp.265–270. [39]	17	High
7	Patja, K., Pukkala, E., Sund, R., Iivanainen, M. and Kaski, M., 2006. Cancer incidence of persons with Down syndrome in Finland: a population-based study. International journal of cancer, 118(7), pp.1769–1772. [41]	17	High
8	Hasle, H., Clemmensen, I.H. and Mikkelsen, M., 2000. Risks of leukaemia and solid tumours in individuals with Down's syndrome. The Lancet, 355(9199), pp.165–169. [46]	17	High
9	Krieg, S., Krieg, A., Loosen, S.H., Roderburg, C. and Kostev, K., 2024. Cancer Risk in Patients with Down Syndrome—A Retrospective Cohort Study from Germany. Cancers, 16(6), p.1103. [42]	15	High
10	Pellikaan, K., Nguyen, N.Q., Rosenberg, A.G., Coupaye, M., Goldstone, A.P., Høybye, C., Markovic, T., Grugni, G., Crinò, A., Caixàs, A. and Poitou, C., 2023. Malignancies in Prader-Willi syndrome: results from a large international cohort and literature review. The Journal of Clinical Endocrinology & Metabolism, 108(12), pp.e1720-e1730. [47]	15	High
11	Trétarre, B., Bourgarel, S., Stoebner-Delbarre, A., Jacot, W., Bessaoud, F. and Satge, D., 2017. Breast cancer and screening in persons with an intellectual disability living in institutions in France. Journal of Intellectual Disability Research, 61(3), pp.266–278. [40]	12	Medium
12	Cuypers M, Naaldenberg, J., Banda, A., Oost, L., Bloemendal, H., & Leusink, G. Cancer incidence and diagnostic characteristics in people with intellectual disabilities in the Netherlands: A national registry-based cohort study. *BMJ Oncology Advance online publication* In press/2025 [35]	18	High

Abbreviations

IQ	Intelligence quotient
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
ES	Effect size
OR	Odds ratio

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12885-025-15014-x.

Supplementary Material 1.

Supplementary Material 2.

Acknowledgements
We acknowledge Greg Sheaf for reviewing the search criteria.

Authors' contributions
MMcM conceptualised and designed the study and AW, SW, JEC, MMcC, PMcC, VS, AM and LL all made substantial contributions to the conception and design of the study and its analysis and interpretation of the data. All the authors drafted the manuscript or revised it critically for important intellectual content. All authors reviewed, critiqued and approved the final version submitted for publication.

Funding
There was no funding received.

Data availability
Data will be available on request from the corresponding author.

Declarations

Ethics approval and consent to participate
Not applicable.

Consent for publication
Not applicable.

Competing interests
The authors declare no competing interests.

Author details
[1]School of Nursing & Midwifery, Trinity College Dublin, The University of Dublin, Dublin, Ireland
[2]Trinity Centre for Ageing with Intellectual Disability (TCAID), Trinity College Dublin, the University of Dublin, Ground Floor Chemistry Building Extension, Lincoln Gate, Dublin, Ireland
[3]School of Social Work (College of Public Health) Temple University, Philadelphia, PA, USA

[4]University College Dublin, School of Nursing Midwifery and Health Systems, Dublin, Ireland
[5]School of Nursing, Queens University Canada, Ontario, Canada

Received: 25 February 2025 / Accepted: 8 September 2025
Published online: 12 December 2025

References

1. Maulik PK, Mascarenhas MN, Mathers CD, Dua T, Saxena S. Prevalence of intellectual disability: a meta-analysis of population-based studies. Res Dev Disabil. 2011;32(2):419–36.
2. American Psychiatric Association D-TF. Diagnostic and statistical manual of mental disorders: DSM-5™. 5th ed. Arlington, VA, US: American Psychiatric Publishing, Inc.; 2013. pp. 947–xliv.
3. Heslop P, Blair PS, Fleming P, Hoghton M, Marriott A, Russ L. The confidential inquiry into premature deaths of people with intellectual disabilities in the UK: a population-based study. Lancet. 2014;383(9920):889–95.
4. Liao P, Vajdic C, Trollor J, Reppermund S. Prevalence and incidence of physical health conditions in people with intellectual disability – a systematic review. PLoS ONE. 2021;16(8):e0256294.
5. Cooper S-A, Hughes-McCormack L, Greenlaw N, McConnachie A, Allan L, Baltzer M, et al. Management and prevalence of long-term conditions in primary health care for adults with intellectual disabilities compared with the general population: A population-based cohort study. J Appl Res Intellect Disabil. 2018;31(S1):68–81.
6. Robertson J, Hatton C, Emerson E, Baines S. Prevalence of epilepsy among people with intellectual disabilities: a systematic review. Seizure. 2015;29:46–62.
7. Chapman HM, McMahon M, Kaley A, Mafuba K, Donovan M-A. The Case for More Action and More Research into Health Care Provision and Health Inequalities for People with Intellectual Disabilities. 2024. 52(3).
8. Emerson E, Hatton C. Health inequalities and people with intellectual disabilities. New York: Cambridge University Press; 2014. vii, 167-vii, p. https://doi.org/10.1017/CBO9781139192484
9. O'Leary L, Cooper S-A, Hughes-McCormack L. Early death and causes of death of people with intellectual disabilities: a systematic review. J Appl Res Intellect Disabil. 2018;31(3):325–42.
10. Doyle A, O'Sullivan M, Craig S, McConkey R. People with intellectual disability in Ireland are still dying young. J Appl Res Intellect Disabil. 2021;34(4):1057–65.
11. McCarron M, Carroll R, Kelly C, McCallion P. Mortality rates in the general Irish population compared to those with an intellectual disability from 2003 to 2012. J Appl Res Intellect Disabil. 2015;28(5):406–13.
12. Cooper SA, Allan L, Greenlaw N, McSkimming P, Jasilek A, Henderson A, et al. Rates, causes, place and predictors of mortality in adults with intellectual disabilities with and without Down syndrome: cohort study with record linkage. BMJ Open. 2020;10(5):e036465.
13. Glover G, Williams R, Heslop P, Oyinlola J, Grey J. Mortality in people with intellectual disabilities in England. J Intellect Disabil Res. 2017;61(1):62–74.
14. (CDC). CfDCaP. United States cancer statistics 2025 [Available from: https://www.cdc.gov/cancer/data/index.html?utm_source=chatgpt.com.
15. (AIHW). AIoHaW. Cancer data in Australia. 2025 [Available from: https://www.aihw.gov.au/reports/cancer/cancer-data-in-australia/contents/overview.
16. (OECD). OfEC-oaD. EU cancer profiles. 2024 [Available from: https://web-archive.oecd.org/temp/2024-02-06/649817-eu-cancer-profiles.htm.
17. Society CC. Canadian cancer statistics. 2025 [Available from: https://cancer.ca/en/research/cancer-statistics/canadian-cancer-statistics?utm_source=chatgpt.com.
18. Liu Q, Adami H-O, Reichenberg A, Kolevzon A, Fang F, Sandin S. Cancer risk in individuals with intellectual disability in Sweden: a population-based cohort study. PLoS Med. 2021;18(10):1–18.
19. Maarten C, Deborah C, Kathryn AR. Identifying the deficits in cancer care for people with intellectual disabilities. BMJ Oncol. 2024;3(1):e000171.
20. Mahar AL, Biggs K, Hansford RL, Derksen S, Griffiths R, Enns JE, et al. Stage IV breast, colorectal, and lung cancer at diagnosis in adults living with intellectual or developmental disabilities: a population-based cross-sectional study. Cancer. 2023;130(5):740–9.
21. Ward LM, Cooper SA, Sosenko F, Morrison D, Fleming M, McCowan C, et al. Population-based cancer incidence and mortality rates and ratios among adults with intellectual disabilities in scotland: a retrospective cohort study with record linkage. BMJ Open. 2024;14(8):e084421.
22. Hansford R, Ouellette-Kuntz H, Bourque MA, Decker K, Derksen S, Hallet J, et al. Investigating inequalities in cancer staging and survival for adults with intellectual or developmental disabilities and cancer: a population-based study in Manitoba, Canada. Cancer Epidemiol. 2024;88:102500.
23. Cuypers M, Schalk BWM, Boonman AJN, Naaldenberg J, Leusink GL. Cancer-related mortality among people with intellectual disabilities: a nationwide population-based cohort study. Cancer. 2022;128(6):1267–74.
24. Banda A, Naaldenberg J, Timen A, van Eeghen A, Leusink G, Cuypers M. Cancer risks related to intellectual disabilities: a systematic review. Cancer Med. 2024;13(9):e7210.
25. Heslop P, Cook A, Sullivan B, Calkin R, Pollard J, Byrne V. Cancer in deceased adults with intellectual disabilities: English population-based study using linked data from three sources. BMJ Open. 2022;12(3):e056974.
26. Chan DNS, Law BMH, Au DWH, So WKW, Fan N. A systematic review of the barriers and facilitators influencing the cancer screening behaviour among people with intellectual disabilities. Cancer Epidemiol. 2022;76:102084.
27. American Association of Intellectual and Developmental Disabilities (AAIDD). Defining Criteria for Intellectual Disability 2023 [Available from: https://www.aaidd.org/intellectual-disability/definition.
28. Shree A, Shukla PC. Intellectual disability: definition, classification, causes and characteristics. Learn Community-An Int J Educational Social Dev. 2016;7(1):9–20.
29. Munn Z, Moola S, Lisy K, Riitano D, Tufanaru C. Methodological guidance for systematic reviews of observational epidemiological studies reporting prevalence and cumulative incidence data. International Journal of Evidence-Based Healthcare. 2015. https://doi.org/10.1097/XEB.0000000000000054.
30. Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ. 2021;372.
31. McMahon M, Lynch L, Wormald A, Eustace-Cook J, McCarron M, McCallion P, et al. Prevalence and incidence of cancer amongst adults with intellectual disability—a systematic review and meta-analysis protocol. HRB Open Res. 2024;6:51.
32. Munn Z, Moola S, Lisy K, Riitano D, Tufanaru C. Systematic reviews of prevalence and incidence. Joanna Briggs Institute reviewer's manual Adelaide: The Joanna Briggs Institute.; 2017.
33. McGowan J, Sampson M, Salzwedel DM, Cogo E, Foerster V, Lefebvre C. PRESS peer review of electronic search strategies: 2015 guideline statement. J Clin Epidemiol. 2016;75:40–6.
34. Ward LA, Cooper S-A, Sosenko F, Morrison D, Fleming M, McCowan C et al. Population-based cancer incidence and mortality rates and ratios among adults with intellectual disabilities in Scotland. MedRxiv. 2024:2024.01.18.23300433.
35. Cuypers M, Naaldenberg J, Banda A, Oost L, Bloemendal H, Leusink G. Cancer incidence and diagnostic characteristics in people with intellectual disabilities in the Netherlands: A national registry-based cohort study. BMJ Oncology. 2025;4:e000686.
36. McMahon M, Hatton C. A comparison of the prevalence of health problems among adults with and without intellectual disability: a total administrative population study. J Appl Res Intellect Disabil. 2021;34(1):316–25.
37. Sullivan SG, Glasson E, Hussain R, Petterson B, Slack-Smith L, Montgomery P, et al. Breast cancer and the uptake of mammography screening services by women with intellectual disabilities. Prev Med. 2003;37(5):507–12.
38. Sullivan SG, Hussain R, Threlfall T, Bittles AH. The incidence of cancer in people with intellectual disabilities. Cancer Causes Control. 2004;15:1021–5.
39. Bourgarel S, Trétarre B, Satgé D, Stoebner-Delbarre A. Le cancer colorectal et son dépistage Chez les personnes déficientes intellectuelles vivant En institution En France. Oncologie. 2016;18(4):265–70.
40. Trétarre B, Bourgarel S, Stoebner-Delbarre A, Jacot W, Bessaoud F, Satge D. Breast cancer and screening in persons with an intellectual disability living in institutions in France. J Intellect Disabil Res. 2017;61(3):266–78.
41. Patja K, Pukkala E, Sund R, Iivanainen M, Kaski M. Cancer incidence of persons with Down syndrome in Finland: a population-based study. Int J Cancer. 2006;118(7):1769–72.
42. Krieg S, Krieg A, Loosen SH, Roderburg C, Kostev K. Cancer risk in patients with down syndrome—a retrospective cohort study from Germany. Cancers (Basel). 2024;16(6):1103.
43. Satgé D, Axmon A, Trétarre B, Sandberg M, Ahlström G. Cancer diagnoses among older people with intellectual disability compared with the general population: a national register study. J Intellect Disabil Res. 2020;64(8):579–88.

44. Lin E, Balogh R, Cobigo V, Ouellette-Kuntz H, Wilton AS, Lunsky Y. Using administrative health data to identify individuals with intellectual and developmental disabilities: a comparison of algorithms. J Intellect Disabil Res. 2013;57(5):462–77.
45. Deeks JJ, Higgins JP, Altman DG, Group CSM. Analysing data and undertaking meta-analyses. Cochrane handbook for systematic reviews of interventions. 2019:241 – 84.
46. Hasle H, Clemmensen IH, Mikkelsen M. Risks of leukaemia and solid tumours in individuals with Down's syndrome. Lancet. 2000;355(9199):165–9.
47. Pellikaan K, Nguyen NQC, Rosenberg AGW, Coupaye M, Goldstone AP, Høybye C, et al. Malignancies in Prader-Willi syndrome: results from a large international cohort and literature review. J Clin Endocrinol Metab. 2023;108(12):e1720–30.
48. McMahon M, McCallion P, McCarron M. An invisible population: late-stage cancer diagnosis for people with intellectual or developmental disability. Cancer. 2024;130(5):668–70.
49. Hosking FJ, Carey IM, Shah SM, Harris T, DeWilde S, Beighton C, et al. Mortality among adults with intellectual disability in England: comparisons with the general population. Am J Public Health. 2016;106(8):1483–90.
50. Higgins JP, Thompson SG, Deeks JJ, Altman DG. Measuring inconsistency in meta-analyses. BMJ. 2003;327(7414):557–60.
51. Mason J, Scior K. Diagnostic overshadowing'amongst clinicians working with people with intellectual disabilities in the UK. J Appl Res Intellect Disabil. 2004;17(2):85–90.
52. Javaid A, Nakata V, Michael D. Diagnostic overshadowing in learning disability: think beyond the disability. Prog Neurol Psychiatry. 2019;23(2):8–10.
53. Cooper SA, McLean G, Guthrie B, McConnachie A, Mercer S, Sullivan F, et al. Multiple physical and mental health comorbidity in adults with intellectual disabilities: population-based cross-sectional analysis. BMC Fam Pract. 2015;16:110.
54. Kinnear D, Morrison J, Allan L, Henderson A, Smiley E, Cooper SA. Prevalence of physical conditions and multimorbidity in a cohort of adults with intellectual disabilities with and without Down syndrome: cross-sectional study. BMJ Open. 2018;8(2):e018292.
55. Vukovic V, Banda A, Carneiro L, Dogan S, Knapp P, McMahon M et al. The importance of cancer prevention policies to inform and guide preventative and screening measures for people with intellectual disabilities: the COST project Cancer-Understanding prevention in intellectual disabilities. J Intellect Disabil. 2023:17446295231213752.
56. Convention on the Rights of Persons with Disabilities. (2006).https://www.un.org/disabilities/documents/convention/convoptprot-e.pdf
57. Biggs K, Ouellette-Kuntz H, Griffiths R, Hansford R, Hallet J, Kelly C, et al. Frequency of missing TNM stage data for adults with intellectual or developmental disabilities in a provincial cancer registry-a brief report. Cancer Med. 2025;14(1):e70579.
58. M McMahon, J O'Reilly. Cancer in people with intellectual disability: lower incidence, later-stage diagnosis - Who counts? Who cares? BMJ Oncol. 2025;4(1):e000845. https://doi.org/10.1136/bmjonc-2025-000845.

Publisher's Note