BMJ Open

Rates, causes and predictors of all-cause and avoidable mortality in 514,878 adults with and without intellectual disabilities: a record linkage national cohort study

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2024-089962
Article Type:	Original research
Date Submitted by the Author:	14-Jun-2024
Complete List of Authors:	Rydzewska, Ewelina; The University of Edinburgh Nijhof, Dewy; University of Glasgow Hughes-McCormack, Laura; University of Glasgow School of Health and Wellbeing, Mental Health and Wellbeing Melville, Craig; University of Glasgow Cairns, Deborah; University of Glasgow Callander, Ruth; Scottish Comission for People with Learning Disabilities Fleming, Michael ; University of Glasgow, Public Health Mackay, Daniel; University of Glasgow Sosenko, Filip; University of Glasgow College of Medical Veterinary and Life Sciences, Institute of Health and Wellbeing Ward, Laura; University of Dundee School of Medicine, Health Informatics Centre; University of Glasgow School of Health and Wellbeing, Mental Health and Wellbeing Dunn, Kirsty; University of Glasgow, Institute of Health and Wellbeing Truesdale, Maria; University of Glasgow College of Medical Veterinary and Life Sciences, Mental Health and Wellbeing Pell, Jill; University of Glasgow Wyper, Grant; NHS Health Scotland Jani, Bhautesh; University of Glasgow Barlow, Fiona; University of Glasgow College of Medical Veterinary and Life Sciences, Mental Health and Wellbeing Henderson, Angela; University of Glasgow, Institute of Health and Wellbeing Cooper, Sally-Ann; University of Glasgow, Institute of Health and Wellbeing
Keywords:	Mortality, PUBLIC HEALTH, Primary Care < Primary Health Care

I, the Submitting Author has the right to grant and does grant on behalf of all authors of the Work (as defined in the below author licence), an exclusive licence and/or a non-exclusive licence for contributions from authors who are: i) UK Crown employees; ii) where BMJ has agreed a CC-BY licence shall apply, and/or iii) in accordance with the terms applicable for US Federal Government officers or employees acting as part of their official duties; on a worldwide, perpetual, irrevocable, royalty-free basis to BMJ Publishing Group Ltd ("BMJ") its licensees and where the relevant Journal is co-owned by BMJ to the co-owners of the Journal, to publish the Work in this journal and any other BMJ products and to exploit all rights, as set out in our licence.

The Submitting Author accepts and understands that any supply made under these terms is made by BMJ to the Submitting Author unless you are acting as an employee on behalf of your employer or a postgraduate student of an affiliated institution which is paying any applicable article publishing charge ("APC") for Open Access articles. Where the Submitting Author wishes to make the Work available on an Open Access basis (and intends to pay the relevant APC), the terms of reuse of such Open Access shall be governed by a Creative Commons licence – details of these licences and which Creative Commons licence will apply to this Work are set out in our licence referred to above.

Other than as permitted in any relevant BMJ Author's Self Archiving Policies, I confirm this Work has not been accepted for publication elsewhere, is not being considered for publication elsewhere and does not duplicate material already published. I confirm all authors consent to publication of this Work and authorise the granting of this licence.

Title: Rates, causes and predictors of all-cause and avoidable mortality in 514,878 adults with and without intellectual disabilities: a record linkage national cohort study

Authors:

Ewelina Rydzewska,[1,2] Dewy Nijhof,[2] Laura Hughes,[2] Craig Melville,[2] Michael Fleming,[2] Daniel Mackay,[2] Filip Sosenko,[2] Laura Ward,[3] Kirsty Dunn,[2] Maria Truesdale,[2] Deborah Cairns,[2*] Jill P. Pell,[2] Grant M. A. Wyper,[2,4] Bhautesh D. Jani,[2] Fiona Barlow,[2] Angela Henderson,[2] Ruth Callander,[4] Sally-Ann Cooper[2]

1. School of Health in Social Science, University of Edinburgh, Edinburgh, Scotland, UK
2. School of Health and Wellbeing, University of Glasgow, Glasgow, Scotland, UK
3. School of Medicine, University of Dundee, Dundee, Scotland, UK
4. Population Health and Wellbeing, Public Health Scotland, Edinburgh, Scotland, UK
5. Scottish Commission for People with Learning Disabilities, Glasgow, Scotland, UK

*Corresponding author:

Professor Deborah Cairns
School of Health and Wellbeing
University of Glasgow
Glasgow
Scotland, UK
deborah.cairns@glasgow.ac.uk

Abstract

Background: Studies on avoidable mortality in adults with intellectual disabilities are limited, as are studies on causes of death.

Objectives: We aimed to quantify mortality rates, and causes, and identify factors (i.e., age, sex, Scottish Index of Multiple Deprivation [SIMD]) related to avoidable mortality in adults with intellectual disabilities.

Design: a record linkage national cohort study.

Setting: A cohort of adults with intellectual disabilities with or without co-occurring autism, aged 25+ years and a randomly selected comparison group aged 25+ years without intellectual disabilities or autism identified from Scotland's Census, 2011. Census records were linked to the National Records of Scotland Statutory Register of Deaths database to ascertain all deaths in 2011-2019.

Participants: We analysed data on 14,477 adults with intellectual disabilities aged 25+ years and a randomly selected comparison group of 506,207 adults aged 25+ without intellectual disabilities identified from Scotland's Census 2011.

Primary and secondary outcome measures: We ran χ^2 tests and t-tests to investigate individual characteristics and differences in age at death for adults with intellectual disabilities compared to peers in the general population. Cox proportional hazard models were fitted to calculate risk of mortality (all-cause, avoidable, treatable, preventable) unadjusted and adjusted for age, sex and SIMD. We then calculated mortality rates, using crude and indirect standardisation methods.

Results: During the 8.5-year-follow-up, 23.7% of adults with intellectual disabilities died compared to 13.8% of controls. Median age at death among adults aged 25+ with intellectual disabilities was 65.0 years compared to 80.0 years for adults without intellectual disabilities. For all-cause mortality, the age-standardised SMR in the population with intellectual disabilities was 3.1 [95% CI 3.0-3.2]. The SMRs were higher for the youngest age groups, women and in the most affluent areas. This was also the case for SMRs for avoidable, treatable, and preventable deaths. For the population of adults with intellectual disabilities, 31.7% of recorded deaths were considered avoidable, 21.1% were treatable and 19.9% were preventable. In the controls, 18.2% of deaths were considered avoidable, 8.8% treatable and 14.7% preventable. Down syndrome and dementia were the two most commonly recorded underlying causes of death for people with intellectual disabilities while malignant neoplasm of bronchus and lung and acute myocardial infarction were most commonly recorded in the general population.

Conclusions: Risks of all-cause, avoidable, treatable, and preventable mortality were higher for adults with intellectual disabilities than their peers. The highest SMRs were observed for youngest adults, women, and individuals living in the most affluent areas.

Keywords: avoidable mortality, intellectual disabilities, adults, data linkage

Strengths and limitations of this study:

- Unique study of avoidable mortality in adults with intellectual disabilities in a whole country population
- High response rate of 94%, and systematic enquiry of everyone regarding intellectual disabilities
- Results of the study are generalisable to other adult populations in high-income countries
- The records of death were taken from death certificates, and not verified at post-mortem

Introduction

On average, people with intellectual disabilities have been reported to die 20 years younger than those without intellectual disabilities, including dying from causes considered to have been avoidable[1]. In recent years, there have been several studies of deaths in adults with intellectual disabilities, that have attempted to reduce the limitations of previous studies such as small sample sizes, or non-representative populations. These studies have typically used record-linkage methods, and reported Standardised Mortality Ratios (SMRs) in the region of 2-4, higher in women than men, and at younger ages, though some report SMR to be only slightly above 1[1]. Direct comparisons between studies are difficult though due to differences in methods, reporting, and ages studied; a tabulated overview is provided in Cooper et al.[2]

There is much less information on the most common underlying causes of death in adults with intellectual disabilities, and less consistency in how these are reported (for example, grouping by ICD-10 categories, or by individual causes of death) which limits comparisons between studies. One study reported the most common causes of death to be pneumonia, other respiratory diseases, and diseases of the nervous system.[3] Another reported diseases of the circulatory and respiratory systems to be the most common cause of death.[4] A third reported that mortality rates due to influenza and pneumonia, septicaemia and aspiration pneumonia substantially exceeded the adult mortality rates in the general population.[5] A fourth reported diseases of the circulatory system, neoplasm, and the nervous system to be the most common cause of death.[6] A fifth noted that people with intellectual disabilities had increased odds of presentation, admission or death from conditions defined as ambulatory care sensitive, which are potentially preventable, specifically vaccine-preventable respiratory disease, asthma, cellulitis and convulsions and epilepsy.[7] Three studies reported cause-specific SMRs to be higher across most groups of disorders than in the general population.[2-4]

Avoidable mortality has also been little studied in adults with intellectual disabilities. Its definition includes preventable mortality (deaths which are preventable through public health interventions, for example, deaths from infectious diseases that can be prevented by vaccination, or alcohol or drug related deaths), and treatable (previously known as 'amenable') mortality (deaths amenable to timely and effective healthcare, for example, deaths due to epilepsy, diabetes, or respiratory infections) while some causes of death can be both preventable and treatable.[8,9] Recent studies that have reported on avoidable deaths suggest that up to 40% of deaths of adults with intellectual disabilities may be avoidable, compared to 28% of deaths in the general adult population.[2,4,10,11]

Specifically, one study in which 961 adults aged 16–83 years with intellectual disabilities had clinical examinations in 2001–2004 found that 102 (38.9%) of the 262 deaths were avoidable, 78 (29.8%) were treatable and 51 (19.5%) were preventable, while 27 (10.3%) were classed as both treatable and preventable.[2] In a study of 16,666 adults with intellectual disabilities from 343 general practices in the UK, 37.0% of all deaths among adults with intellectual disabilities were classified as being treatable, compared with 22.5% in the general population (Hazard Ratio (HR) 5.9; 95% CI 5.1, 6.8).[4] A study of 732 deaths in 19,362 adults aged 20+ years registered for intellectual disability services from 2005 to 2011 in New South Wales found that 31% of deaths were avoidable; higher than in the general population (17%).[6] Two further studies reported data on children, young people and adults combined.[10,11] Heslop et al.[10] undertook a population-based Confidential Inquiry of the deaths of 247 people with intellectual disabilities aged 4 years and older in southwest England who died between June 1 2010 and May 31 2012. Treatable deaths were more common in people with intellectual disabilities (37%) than in the general population (13%).[10] Glover et al.[11] used general practice data for people with and without intellectual disabilities of all ages, and reported that 44.7% of deaths were avoidable, with a higher proportion of deaths from causes classified as treatable, but a lower proportion from preventable causes compared with people without intellectual disabilities (actual figures not reported).[11] These studies demonstrated that rates of avoidable mortality are high in adults with intellectual disabilities, and higher than in the general population, suggesting that pervasive health inequalities may be contributing, and that further investigation is necessary.

The aim of this study was to investigate deaths in adults with intellectual disabilities, compared with controls, for an entire country's population from 2011-2019. For adults with intellectual disabilities compared with other adults, we investigated (a) age- sex- and neighbourhood deprivation- standardised mortality ratios, (b) underlying cause of death, and all-contributory causes of death by ICD-10 chapters, and most common specific causes, and (c) the proportion of deaths considered avoidable, treatable, and preventable.

Methodology

Patient and public involvement

This study was undertaken by the XXXXXXXXXX due to the growing concern expressed by people with intellectual disabilities and their families about mortality. The XXXXXXXXXX's steering group includes people with intellectual disabilities and partners from third sector organisations. Results from this study will be disseminated to people with intellectual disabilities and their families in an easy-read version via the XXXXXXXXXX website and

newsletters and in collaboration with the Scottish Commission for People with Learning Disabilities.

Approvals

Approval was gained from Scotland's Public Benefit and Privacy Panel for Health and Social Care (reference: 1819-0051), Scotland's Statistics Public Benefit and Privacy Panel (reference: 1819-0051), and the University of Glasgow's College of Medical, Veterinary, and Life Sciences Ethical Committee (reference: 200180081). Data sharing agreements were put in place with the data controllers of all the linked datasets.

Study sample, setting and process

Ninety four percent of the Scottish population completed Scotland's Census, 2011. We used these data to create a cohort of adults with intellectual disabilities with or without co-occurring autism, aged 25+ years at the Census date (27th March 2011), and a randomly selected comparison group aged 25+ years without intellectual disabilities or autism from a 15% unmatched sample of the Scottish population also identified from Scotland's Census, 2011. Their records were linked to the National Records of Scotland Statutory Register of Deaths database to ascertain all deaths up to 31st December 2019. Access to the anonymised linked data was given to the approved members of the research team via Scotland's National Safe Haven. Full details on Scotland's Census 2011 are available at: https://www.scotlandscensus.gov.uk/about/2011-census/. Further information on the record linkage and the cohorts have previously been reported in detail.[12]

Variables

Intellectual disabilities: Scotland's Census 2011 provides information on the number and characteristics of Scotland's population and households on the Census day, 27th March 2011. The census is undertaken every 10 years. It includes people living in communal establishments (such as care homes and student halls of residence) as well as people living in private households. In 2011, the census in Scotland was estimated to have achieved a 94% response rate.[13] The Census team required the form to be completed by the head of household or joint head of household on behalf of all occupants in private households, and the manager was responsible on behalf of all occupants in communal dwellings. It was a legal requirement to complete the census, and non-compliance or supplying false information could result in a fine of £1,000. The Census team followed up non-responders and also provided help in responding when it was needed; hence, the high 94% completion rate.

Scotland's Census is probably one of few country censuses, which identifies people with intellectual disabilities and distinguishes these from specific learning disabilities such as dyslexia; indeed, it may be unique in this regard. Self-/proxy reporting was used to identify people with intellectual disabilities from the Census questionnaire, question 20: 'Do you have any of the following conditions which have lasted, or are expected to last, at least 12 months? Tick all that apply'. Respondents were given a choice of 10 response options, with option number (3) 'learning disability (e.g., Down's syndrome)' being synonymous in the UK with the international term 'intellectual disabilities'. The remaining response options were as follows: (1) deafness or partial hearing loss, (2) blindness or partial sight loss, (4) learning difficulty (e.g., dyslexia), (5) developmental disorder (e.g., autistic spectrum disorder or Asperger's syndrome), (6) physical disability, (7) mental health condition, (8) long-term illness, disease or condition, (9) other condition, (10) no condition. Importantly, the question distinguished between intellectual disability (for which the term 'learning disability' is used in the UK), learning difficulty (which in the UK is synonymous with the international term 'specific learning disability' such as dyslexia) and autism.

Age: Age was grouped into six categories of 1) 25-34 years, 2) 35-44 years, 3) 45-54 years, 4) 55-64 years, 5) 65-74 and 6) 75+ years, based on the Census data.

Sex: Sex was coded in two categories of male and female, based on the Census data.

Scottish Index of Multiple Deprivation (SIMD)*:* SIMD was grouped in population quintiles where SIMD 1 included the most deprived neighbourhoods and SIMD 5 corresponded with the most affluent neighbourhoods. SIMD was identified from postcodes, based on the Census data, and calculated at datazone level.

Deaths: We used data from death certificates registered at National Records of Scotland, to identify date of deaths, and underlying causes and all contributing factors in deaths for adults with intellectual disabilities and the general population comparison group. For cause of death analyses, we analysed the underlying cause of death; defined as the disease or injury which initiated the chain of morbid events leading directly to death, or the accident/act which produced the fatal injury.[14] We also analysed a broader composite outcome of all contributing factors in death, defined as a cause listed as either the underlying cause, secondary cause or a contributing factor. We used the Tenth Revision of the International Statistical Classification of Diseases and Related Health Problems (ICD-10)[15] to group causes of death into categories. The cancer codes included C00.0-D48.9 inclusive. The analyses were restricted to deaths recorded between the 28th March 2011 and the 31st December 2019.

We defined treatable and preventable deaths as per avoidable mortality outcomes outlined in the guidance of the Office for National Statistics,[8] noting that some causes of death are both treatable and preventable. As per the ONS guidance, avoidable mortality analyses excluded any deaths at the age of 75+, thus the following cases were excluded from the avoidable mortality analyses: 1) anyone who was 75+ years at the start of the study (i.e., Census day the 27th March 2011); 2) anyone who died at the age of 75+ years during the study duration; 3) anyone who turned 75+ years at any point during the study period.

Data processes

All follow-up/censoring: Adults aged 25+ years were followed up from the Census date (27th March 2011), and all models were censored on death or the study end date (31st December 2019), whichever came first, unless stated otherwise. Cases of individuals who died either before or on the day of Census (i.e., any deaths prior to the 28th of March 2011) were excluded from the analyses, as participants were expected to spend at least one day in the study to enable us to run survival analysis. Furthermore, in the comparison group, we also excluded individuals who subsequently died during the study period and had their cause of death recorded as a form of an intellectual disability/autism (ICD-10 codes: F70, F71, F72, F73, F78, F79, F84).

Missing data: Data linkage was conducted by the National Records of Scotland (NRS). All data provided to us for this study included complete cases only, i.e., no observations were included who had missing or imputed cells for any variable. We included all cases provided from NRS in the analysis apart from the exclusions mentioned above. Any errors in cause of death records such as omission, use of abbreviations, or ambiguous deaths were listed as an unknown cause.

Analyses

Information on age, sex, and SIMD was recorded on the Census day, i.e., the 27th March 2011. Explorative statistical analyses including t-tests and χ^2 tests were used to investigate characteristics of adults with intellectual disabilities compared to peers in the general population. Differences in mean age at death were explored using t-tests.

Crude mortality rates per 100,000 were calculated using the censor date/date of death. For indirect standardisation, observed deaths were assumed to be independent and vary with the Poisson distribution. The mortality rates were indirectly standardised for both men and women, using the expected age-specific mortality rates per 1-year age group, using Stata's 'strate'

command, to calculate age-SMRs for adults with versus without intellectual disabilities. The 95% CIs were calculated based on the quadratic approximation of the log likelihood. Expected rates were calculated using fixed age and sex-specific rates from the large control population. The SMRs were subsequently calculated stratified by age category (25-34, 35-44, 45-54, 55-64, 65-74 and 75+ years), sex and SIMD.

For all-cause mortality, Kaplan-Meier survival curves were plotted for the study period for both groups and the proportional hazards assumption was tested.

For the underlying causes of death and all contributing factors in death, the total numbers of deaths in each ICD-10 chapter were collated. We then collated the number of deaths for the top 20 most commonly recorded underlying causes and all contributing factors in death. For cause-specific SMRs, indirect sex-standardisation was also performed (using 10-year age bands). The rates and age-standardised SMRs for avoidable, treatable, and preventable mortality were calculated using robust errors.

Cox proportional hazard models were fitted to the data to calculate risks of mortality (all-cause, avoidable, treatable, preventable) unadjusted and adjusted for age, sex, and SIMD. For categories which had fewer than 10 deaths, no calculation was attempted due to lack of reliability. Furthermore, in keeping with the Office of National Statistics mortality methodology, all mortality rates between 10 and 20 deaths were labelled as unreliable.[8] Two researchers (D.N. and E.R.) carried out the main analyses. All analyses were conducted in Stata version 17.

Results

The study cohort included 14,477 adults with intellectual disabilities aged 25+ and 506,207 adults without intellectual disabilities nor autism aged 25+, following exclusion of 71 individuals with a record of death before or on the date of the Census and exclusion of 51 cases without intellectual disabilities or autism who died during the study but had their cause of death recorded as a form of intellectual disability/autism.

Demographic information

Table 1 presents demographic information on the population of adults with and without intellectual disabilities, at the time of Scotland's Census, 2011. Compared with their peers, adults with intellectual disabilities had a higher proportion of men (n=7,927, 54.8% vs. n=238,036, 47.0%; p<0.001), were more likely to be living in more deprived neighbourhoods (p<0.001) and were overall younger (p<0.001).

All-cause mortality

Crude mortality: The study period (27th March 2011 – 31st December 2019) resulted in the equivalent of 4,272,853 person years of follow up. This included 113,044 person years contributed by the intellectual disabilities population and 4,159,809 person years for the population without intellectual disabilities. The median age at death for adults with intellectual disabilities was younger at 65 years (SD=14.1, IQR=56.0-76.0) compared with 80 years (SD=12.9, IQR=71.0-87.0) for adults without intellectual disabilities.

Of the 14,477 adults with intellectual disabilities 3,429 (23.7%) died during the 8.5 years of follow up. In the population without intellectual disabilities, 69,641/506,207 (13.8%) adults died during the same follow up period. Crude mortality over the study period was 3033.3 (95% CI 2933.5-3136.6) per 100,000 person years of follow up (Supplemental Table 1) among adults with intellectual disabilities, and 1674.1 (95% CI 1661.8-1686.6) per 100,000 for adults without intellectual disabilities (Supplemental Table 2). The proportional hazards assumption was visually assessed and met. Kaplan-Meier survival curves for the overall time period were run (Supplemental Figure 1).

Standardised mortality ratios (SMRs):

For all-cause mortality, compared with adults without intellectual disabilities, the age-standardised SMR in the population with intellectual disabilities was 3.1 (95% CI 3.0-3.2). The sex-standardised SMR was 1.8 (95% CI 1.7-1.9) and SIMD-standardised SMR was 1.7 (95% CI 1.6-1.7) (Table 2).

The age-stratified SMR was highest in the youngest age group (25-34 years old) at 6.4 (95% CI 5.5-7.5) and gradually decreased with age, with the lowest SMR recorded for the oldest age group of 75+ year old at 1.6 (95% CI 1.5-1.8). The sex-stratified SMR was higher for women (SMR 2.0, 95% CI 1.9-2.1) than men (SMR1.7, 95% CI 1.6-1.8). SMR was also highest in the most affluent areas (SMR=2.5, 95% CI 2.2-2.7) and gradually decreased with rising deprivation level, with SMR in the most deprived areas recorded at 1.4 (95% CI 1.3-1.5).

Cause-specific mortality

Table 3 reports the crude mortality rates for underlying causes of death and all contributing causes of death by ICD-10 chapters.

Underlying cause of death: The most common underlying causes of death in the adults with intellectual disabilities were: diseases of the circulatory system (n=692; Crude Mortality Rate (CMR)=612.2, 95% CI 568.2-659.5); neoplasms (n=489; CMR=432.6, 95% CI 395.9-472.7) diseases of the respiratory system (n=484, CMR=428.2, 95% CI 391.7-468.0), and diseases of the nervous system (n=442; CMR=391.0, 95% CI 356.2-429.2). In the control group without intellectual disabilities, the most common underlying causes of death were: neoplasms (n=20,667; CMR=496.8, 95% CI 490.1-503.6); diseases of the circulatory system (n=19,093; CMR=459.0, 95% CI 452.5-465.5), diseases of the respiratory system (n=8,716; CMR=209.5, 95% CI 205.2-214.0), then mental and behavioural disorders (n=5,084; CMR=122.2, 95% CI 118.9-125.6).

All contributing factors in death: In the group with intellectual disabilities, the most common all contributing factors in death were: diseases of the respiratory system (n=1,616; CMR=1,429.5, 95% CI 1,361.5-1,501.0); diseases of the circulatory system (n=1,271; CMR=1,124.3, 95% CI 1,064.2-1,187.9); mental and behavioural disorders (n=944; CMR=835.1, 95% CI 783.5-890.1) and diseases of the nervous system (n=943; CMR=834.2, 95% CI 782.6-889.2). In the control group without intellectual disabilities, the most common were diseases of the circulatory system (n=35,223; CMR=846.7, 95% CI 837.9-855.6), the respiratory system (N=24,834; CMR=597.0, 95% CI 589.6-604.5), and neoplasms (n=23,717; CMR=570.1, 95% CI 562.9-577.4).

Most common causes of death: Table 4 reports the most common individual underlying causes and all contributing factors. Based on pre-specified groupings of specific ICD-10 codes, among adults with intellectual disabilities the most commonly recorded underlying causes of death were Down syndrome, dementia and acute myocardial infarction. For all contributing factors in death, pneumonia due to organism unspecified, Down syndrome and pneumonitis due to solids and liquids were the most commonly recorded. In the population of adults without intellectual disabilities, the most commonly recorded underlying causes of death were malignant neoplasm of bronchus or lung, acute myocardial infarction and dementia. For all contributing factors in death, chronic ischemic heart disease, pneumonia due to organism unspecified and other chronic obstructive pulmonary disease were most commonly recorded.

Avoidable mortality

Incidence: Of the 3,429 deaths recorded for the population of adults with intellectual disabilities 1,087 (31.7%) were considered avoidable. Of all deaths, 722 (21.1%) were treatable and 681 (19.9%) were preventable. In the population of adults without intellectual disabilities, 12,673 (18.2%) of the 69,641 deaths were considered avoidable; 6,110 (8.8%) treatable and 10,207 (14.7%) preventable (Table 5).

Crude avoidable mortality in adults with intellectual disabilities was 1,061.4 (95% CI 1,000.1-1126.4) per 100,000 person years of follow up and 375.9 (95% CI 369.4-382.5) for adults without intellectual disabilities. Treatable mortality in the intellectual disabilities group was 705.0 (95% CI 655.4-758.3) per 100,000 person years of follow up and 181.2 (95% CI 176.7-185.8) for adults without intellectual disabilities. Preventable mortality for the intellectual disabilities cohort was 665.0 (95% CI 616.9-716.8) per 100,000 person years of follow up and 302.8 (95% CI 296.9-308.7) for adults without intellectual disabilities. Further details are provided in Supplemental Tables 1 and 2.

Standardised mortality ratios: Table 2 shows that SMRs for individual age groups were highest in the youngest age groups, for all avoidable deaths as well as for treatable and preventable mortality. SMRs for avoidable, treatable and preventable deaths were higher for females (avoidable: 3.5, 95% CI 3.2-3.8; treatable: 4.7, 95% CI 4.2-5.3; preventable: 2.7, 95% CI 2.4-3.1) than males (avoidable: 2.4, 95% CI 2.2-2.6; treatable: 3.3, 95% CI 3.0-3.6; preventable: 1.8, 95% CI 1.7-2.0). There was a gradient of increasing SMRs for avoidable, treatable and preventable mortality as the extent of the neighbourhood deprivation decreased.

Table 5 reports underlying cause of death with the Cox proportional hazards, unadjusted (HR) and adjusted for age, sex and SIMD (aHR). For all deaths: HR=3.3 (95% CI 3.2-3.4) and aHR=3.0 (95% CI 2.9-3.1). For avoidable deaths: HR=3.3 (95% CI 3.1-3.6), treatable deaths: HR=4.7 (4.3-5.0) and preventable deaths: HR=2.6 (2.4-2.8), and aHRs were: avoidable deaths: aHR=2.7 (95% CI 2.5-2.9), treatable deaths: aHR=3.9 (95% CI 3.6-4.2) and preventable deaths: aHR=2.0 (95% CI 1.9-2.2) (Table 5).

Discussion

Summary of principal findings

For all-cause mortality, compared with adults without intellectual disabilities, the age-standardised SMR in the population with intellectual disabilities was 3.1. The SMRs were higher for the youngest age groups, women and in the most affluent areas. This gradient in

increase in the SMRs in more affluent neighbourhoods is likely caused by the difference in the general population across extent of neighbourhood deprivation, rather than a difference across neighbourhoods in the population with intellectual disabilities, i.e., the general population experience higher rates of deaths in the more deprived areas whereas for adults with intellectual disabilities this trend is not as pronounced. Adults with intellectual disabilities also died younger than adults without intellectual disabilities (median age at death: 65.0 years vs. 80.0 years).

Avoidable deaths were substantially more common in people with intellectual disabilities than other people; particularly due to deaths from conditions that could have been treated by high quality care. Our paper is novel in investigating avoidable deaths in detail, including reporting SMRs for avoidable, treatable, and preventable deaths by the socio-demographic features of age, sex, and extent of neighbourhood deprivation. SMRs for avoidable deaths ranged from 4.2 to 2.0, being higher at younger age groups, in women, and the more affluent the neighbourhood.

For those with intellectual disabilities, the most common underlying causes of death were diseases of the circulatory system, neoplasms, diseases of the respiratory system and diseases of the nervous system, with fairly similar rates between each. This differs from the controls, where neoplasms were markedly more common, followed by diseases of the circulatory system, and then, though much less common, diseases of the respiratory system and mental and behavioural disorders. All contributing factors in death for adults with intellectual disabilities were most commonly diseases of the respiratory system, followed by diseases of the circulatory system, and equally mental and behavioural disorders and diseases of the nervous system. In the control group, the most common all contributing factors in death were diseases of the circulatory system by far. Sex-standardised SMRs for underlying causes of deaths ranged from 259.5 (congenital malformations, deformations and chromosomal abnormalities) to 1.4 (neoplasms). For all contributing factors in deaths, the range was 238.3 (congenital malformations, deformations and chromosomal abnormalities) to 1.4 (neoplasms).

Comparison with existing literature

We are aware of only three studies on avoidable mortality in adults with intellectual disabilities. These covered shorter periods of time and/or included smaller sample sizes, limiting opportunities for comparison.[2,4,6] We report that 31.7% of deaths of adults with intellectual disabilities were avoidable, compared to 46.3%,[4] 38.9%[2] and 31.0%[6]. Compared to the general population, we found much higher rates of avoidable (SMR=3.2), treatable

(SMR=4.5), and preventable (SMR=2.5) deaths. The Incidence Rate Ratio (IRR) for avoidable deaths reported by Trollor et al.[6], whilst raised, showed a much lesser difference than in our study (IRR 1.47; 95% CI 1.54 to 1.99; p<0.001). Hosking et al.[4] reported hazard ratios that were more similar to our findings: avoidable (3.44), treatable (5.86), and preventable (1.69) deaths. Cooper et al.[2] did not calculate comparisons with the general population. We are not aware of any previous studies that have reported on avoidable, treatable, and preventable mortality in relation to socio-demographic factors such as age, sex, or neighbourhood deprivation with which we can compare our findings.

The high rate of SMR (3.1) we report for all-cause mortality is consistent with previous literature, as is the higher SMR in females, and at younger ages. However, we are not aware of previous studies of SMR in adults with intellectual disabilities in relation to the extent of neighbourhood deprivation. One Australian study reported contrary results to ours and other studies, with regards to the sex, and age findings.[6]

Few studies have reported causes of death by ICD-10 chapter, and reports are contradictory. By ICD-10 chapter, we found the most common underlying causes of death to be diseases of the circulatory system, neoplasms, diseases of the respiratory system and diseases of the nervous system, similarly to the report by Cooper et al.[2] whilst others reported the most common to be circulatory,[4] vascular,[16] heart disease,[17] and jointly circulatory and neoplasm[6]. With regard to findings from the analysis of pre-specified groupings of specific ICD-10 codes, we have found that Down syndrome was the most commonly recorded cause of death for adults with intellectual disabilities. This suggests that there may still exist prevailing uncertainty in relation to underlying causes of death in people with intellectual disabilities and there is continued conflation of disability and health among attending medical practitioners responsible for recording causes of death in Scotland.[18]

Implications for policy and practice

The higher risk of all-cause, avoidable, treatable, and preventable mortality, and earlier age at death for adults with intellectual disabilities than their peers without intellectual disabilities demonstrates a clear need for improvements in the early detection, prevention, care and treatment of health problems experienced by people with intellectual disabilities. This is essential at all ages, and for people living in all areas; more so than for the general population, these are not issues related to older age nor neighbourhood deprivation. Recording of Down syndrome as a cause of death in adults with intellectual disabilities is still common among attending medical practitioners in Scotland. It is, therefore, crucial that we better understand how individual health conditions impact on the health and mortality of adults with intellectual

disabilities. Research efforts should be directed particularly towards the management of epilepsy and pneumonia to reduce premature mortality due to the diseases of the nervous and respiratory systems, which are one of the leading causes of death in this population. Our findings on mortality caused by cardiovascular diseases and neoplasms in adults with intellectual disabilities also suggest that public health interventions aimed at circulatory diseases and cancer screening may need appropriate adaptation and tailoring for this population. Clinical and health training initiatives should be introduced across all age groups and all neighbourhoods, given that our findings suggest that mortality risk is highest in the most affluent areas for adults with intellectual disabilities.

Strengths and Limitations

A major strength of this study is that it includes a whole country population of adults with intellectual disabilities and a representative proportion of people in the general population, with a high response rate of 94% for Scotland's Census 2011,[13] thereby reducing the study bias. Whether each individual had intellectual disabilities was enquired about, and intellectual disabilities was specifically distinguished from specific learning disabilities, and from autism. Prior to the Census, these questions were field tested, to check their utility and acceptability, using cognitive question testing with 70 respondents on the whole questionnaire, and 102 respondents specifically on the health questions. Additionally, the prevalence of intellectual disabilities in the Census data (0.5%) is the same as that found in Scottish GP registers, and in other large data sources, which have been used to identify adults with intellectual disabilities.[19]

Limitations include the fact that the Census data do not specify whether a record of intellectual disabilities was reported by a person with intellectual disabilities or their proxy (e.g., a parent/carer, spouse etc.). Moreover, respondents reported whether or not each person was known to have intellectual disabilities rather than each person having an assessment for intellectual disabilities, so some reporting error is possible. Further, our death data was taken from death certificates, and not verified at post-mortem. The death certificates will have been completed by numerous clinicians, and there may be some error in reporting, including between underlying causes and all contributing factors in death, but such error in reporting mostly poses limitations only when investigating more granular outcomes. Some data repression was necessary where very small numbers were identified to mitigate the risk of disclosure. In keeping with the ONS methodology for investigating avoidable mortality,[8] all crude mortality rates per 100,000 people based on fewer than 20 deaths were labelled as unreliable to warn users of their low reliability. It is also important to note that the ONS list of avoidable deaths is based on general population data and is, therefore, possibly an

underestimate of avoidable deaths in the population with intellectual disabilities due to differing health and death profiles.

Given the strengths of the study, we believe the results will be generalisable to other high-income countries, as well as filling a significant gap in existing research on avoidable mortality in adults with intellectual disabilities, and contradictory reports on causes of death. However, this needs to be determined by replication of our findings.

Acknowledgements: We would like to acknowledge the support of the eDRIS Team (Public Health Scotland), particularly David Clark, for their involvement in obtaining approvals, provisioning and linking data, and for the use of the secure analytical platform within the National Safe Haven.

Contributors: DN and ER analysed the data and interpreted findings. ER wrote the first draft of the manuscript. S-AC developed the record linkage, conceived the study, analysed and interpreted the data and contributed to the manuscript. CM, AH, and DK conceived the study, analysed and interpreted the data and contributed to the manuscript. DN, LH, MF, DM, KD, LW, FS, FB, JM, J-DS, B-DJ, MT, GW and JP interpreted findings and contributed to the manuscript. All authors approved the final version of the manuscript.

Funding: This work was supported by the UK Medical Research Council, grant number: MC_PC_17217), Baily Thomas Charitable Fund and the Scottish Government via the XXXXXX.

Disclaimer: The funders had no role in the study design, collection, analyses or interpretation of data, writing the report nor the decision to submit the article for publication.

Competing interests: None declared.

Ethics approval: NHS Scotland Public Benefit and Privacy Panel for Health and Social Care (reference: 1819-0051), Scottish Government's Statistics Public Benefit and Privacy Panel (reference: 1819-0051), and the University of Glasgow's College of Medical, Veterinary, and Life Sciences Ethical Committee (reference: 200180081).

Data availability statement: No data are available. This study linked patient information held across several administrative health datasets within Information Services Division (ISD) of NHS National Services Scotland (NSS), with data externally held by the Scottish Government (Scotland's Census 2011) and National Records of Scotland (Statutory Register of Deaths). Linkage and de-identification of data was performed by ISD. A data processing agreement between NHS NSS and University of Glasgow and a data sharing agreement between the Scottish Government and University of Glasgow were drafted. University of Glasgow was authorised to receive record-linked data controlled and held by ISD within NSS, via access through the National Safe Haven. The ISD Statistical Disclosure Control Protocol was followed in all described processes.

References:

1. O'Leary L, Hughes-McCormack L, Dunn K, Cooper S-A. Early death and causes of death of people with Down syndrome: A systematic review. J Appl Res Intellect Disabil [Internet]. 2018;31(5):687–708. Available from: http://dx.doi.org/10.1111/jar.12446
2. Cooper S-A, 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 [Internet]. 2020;10(5):e036465. Available from: http://dx.doi.org/10.1136/bmjopen-2019-036465
3. Tyrer F, McGrother C. Cause-specific mortality and death certificate reporting in adults with moderate to profound intellectual disability. J Intellect Disabil Res [Internet]. 2009;53(11):898–904. Available from: http://dx.doi.org/10.1111/j.1365-2788.2009.01201.x
4. 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 [Internet]. 2016;106(8):1483–90. Available from: http://dx.doi.org/10.2105/AJPH.2016.303240
5. Lauer E, Grossman G, Oxx S, Trafton W, Russell K, 2012 & 2013 Mortality Report. Commonwealth of Massachusetts Executive Office of health & Human Services. Department of Developmental Services. Centre for Developmental Disabilities Evaluation and Research (CDDER). 2014. Available from: https://www.mass.gov/doc/2012-2013-mortality-report/download.
6. Trollor J, Srasuebkul P, Xu H, Howlett S. Cause of death and potentially avoidable deaths in Australian adults with intellectual disability using retrospective linked data. BMJ Open [Internet]. 2017;7(2):e013489. Available from: http://dx.doi.org/10.1136/bmjopen-2016-013489
7. Brameld K, Spilsbury K, Rosenwax L, Leonard H, Semmens J. Use of health services in the last year of life and cause of death in people with intellectual disability: a retrospective matched cohort study. BMJ Open [Internet]. 2018;8(2):e020268. Available from: http://dx.doi.org/10.1136/bmjopen-2017-020268
8. Office for National Statistics (ONS). Avoidable mortality in the UK. Quality and methodology information. 2022. Available from: https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/causesofdeath/methodologies/avoidablemortalityinenglandandwalesqmi
9. Office for National Statistics (ONS). Consultation response: review of avoidable mortality definition. 2016. Available from: https://www.ons.gov.uk/aboutus/whatwedo/statistics/consultationsandsurveys/allconsultationsandsurveys/reviewofavoidablemortalitydefinition
10. 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 [Internet]. 2014;383(9920):889–95. Available from: http://dx.doi.org/10.1016/S0140-6736(13)62026-7
11. Glover G, Williams R, Heslop P, Oyinlola J, Grey J. Mortality in people with intellectual disabilities in England. J Intellect Disabil Res [Internet]. 2017;61(1):62–74. Available from: http://dx.doi.org/10.1111/jir.12314
12. Cooper S-A, Henderson A, Kinnear D, Mackay D, Fleming M, Smith GS, et al. Cohort profile: Scotland's record-linkage e-cohorts of people with intellectual disabilities, and autistic people (SCIDA). BMJ Open [Internet]. 2022;12(5):e057230. Available from: http://dx.doi.org/10.1136/bmjopen-2021-057230
13. National Records of Scotland (NRS). 2011 Census Release 1C - How the 2011 Census population estimates were obtained. Edinburgh: National Records of Scotland. 2013.

14. World Health Organization (WHO). International Statistical Classification of Diseases and Related Health Problems, 10th revision. Geneva: World Health Organization. 1992.
15. World Health Organization (WHO). International Statistical Classification of Diseases and Related Health Problems, 10th revision. 2010; Volume 2. Instruction manual. Available from: https://icd.who.int/browse10/Content/statichtml/ICD10Volume2_en_2010.pdf
16. Patja K, Mölsä P, Livanainen M. Cause-specific mortality of people with intellectual disability in a population-based, 35-year follow-up study: Cause-specific mortality. J Intellect Disabil Res [Internet]. 2001;45(1):30–40. Available from: http://dx.doi.org/10.1111/j.1365-2788.2001.00290.x
17. Arvio M, Salokivi T, Tiitinen A, Haataja L. Mortality in individuals with intellectual disabilities in Finland. Brain Behav [Internet]. 2016;6(2):e00431. Available from: http://dx.doi.org/10.1002/brb3.431
18. Landes SD, Turk MA, Finan JM. Factors associated with the reporting of Down syndrome as the underlying cause of death on US death certificates. J Intellect Disabil Res [Internet]. 2022;66(5):454–70. Available from: http://dx.doi.org/10.1111/jir.12926
19. Cooper S-A, Henderson A, Jacobs M, Smiley E. What Are Learning Disabilities? How Common Are Learning Disabilities? Scottish Learning Disabilities Observatory. 2016. Available from: https://www.sldo.ac.uk/media/1610/what-are-learning-disabilities-how-common-are-learning-disabilities.pdf

Table 1. Demographic information in 2011* for adults with and without intellectual disabilities

Demographic information*	Intellectual disabilities	Controls	P value †
Total, n (person-years)	14,477 (113,043.63)	506,207 (415,9808.6)	
Male sex, n (%)	7,927 (54.8%)	238,036 (47.0%)	<0.001
Co-occurring Autism			
Total n (%)	1,631 (11.3%)	-	
Male sex n (%)	1,017 (7.0%)	-	
Age, n (%) at time of Census			
25-34	2,974 (20.5%)	83,868 (16.6%)	<0.001
35-44	3,276 (22.6%)	97,881 (19.3%)	
45-54	3,663 (25.3%)	108,048 (21.3%)	
55-64	2,493 (17.2%)	92,693 (18.3%)	
65-74	1,330 (9.2%)	67,519 (13.3%)	
75+	741 (5.1%)	56,198 (11.1%)	
SIMD quintile, n (%) at time of Census			
1 (most deprived)	4,226 (29.2%)	91,378 (18.1%)	<0.001
2	3,781 (26.1%)	98,114 (19.4%)	
3	2,950 (20.4%)	104,062 (20.6%)	
4	2,209 (15.3%)	108,765 (21.5%)	
5 (least deprived)	1,311 (9.1%)	103,888 (20.5%)	
Deaths, crude rate per 100,000 (CI)**	3033.342 (2933.494-3136.588)	1674.140 (1661.752-1686.62)	

*Data taken from time of Census
**58 individuals aged 25+ had a record of death which occurred before the date of the Census and 13 individuals died on the day of the Census; both groups were removed
51 cases without intellectual disabilities or autism died during the study but had their cause of death recorded as a form of intellectual disability/autism and were subsequently removed from the study

† X^2 test for intellectual disabilities compared with control group (For age and SIMD, X^2 test was performed across all categories, overall *p* value)
Abbreviations: CI=Confidence interval; SIMD=Scottish Index of Multiple Deprivation

Table 2. Standardised Mortality Ratios (SMRs) for adults with intellectual disabilities compared to controls for age, sex, and deprivation (SIMD)

Demographic variables	All deaths SMR (95% CI)	Avoidable deaths SMR (95% CI)	Treatable deaths SMR (95% CI)	Preventable deaths SMR (95% CI)
Age				
Overall Age-SMR	3.130 (3.027-3.236)	3.227 (3.041-3.425)	4.490 (4.174-4.829)	2.511 (2.329-2.707)
25-34	6.400 (5.489-7.462)	4.196 (3.351-5.254)	8.685 (6.463-11.67)	2.781 (2.069-3.737)
35-44	5.139 (4.589-5.755)	3.818 (3.267-4.463)	5.676 (4.675-6.890)	2.540 (2.051-3.145)
45-54	5.299 (4.931-5.695)	3.414 (3.070-3.795)	4.480 (3.926-5.111)	2.715 (2.375-3.103)
55-64	4.143 (3.882-4.422)	3.015 (2.753-3.301)	4.214 (3.780-4.698)	2.422 (2.164-2.710)
65-74	2.522 (2.344-2.713)	1.980 (1.474-2.661)	2.652 (1.854-3.793)	1.946 (1.397-2.711)
75+	1.632 (1.506-1.767)	-	-	-
Sex				
Overall Sex-SMR	1.808 (1.748-1.869)	2.734 (2.576-2.901)	3.796 (3.529-4.083)	2.095 (1.943-2.258)
Male	1.682 (1.605-1.762)	2.362 (2.183-2.555)	3.269 (2.962-3.608)	1.822 (1.655-2.005)
Female	1.967 (1.875-2.065)	3.453 (3.153-3.780)	4.714 (4.229-5.255)	2.745 (2.433-3.097)
SIMD				
Overall SIMD-SMR	1.688 (1.632-1.745)	2.446 (2.305-2.596)	3.451 (3.209-3.713)	1.878 (1.743-2.025)
1 (most deprived)	1.380 (1.296-1.470)	1.850 (1.664-2.057)	2.565 (2.242-2.933)	1.462 (1.283-1.666)
2	1.587 (1.487-1.693)	2.488 (2.223-2.784)	3.573 (3.114-4.100)	1.889 (1.638-2.179)
3	1.907 (1.773-2.052)	3.075 (2.703-3.500)	4.172 (3.562-4.886)	2.354 (1.996-2.777)
4	2.031 (1.863-2.215)	2.941 (2.471-3.499)	4.298 (3.511-5.261)	2.316 (1.855-2.892)
5 (least deprived)	2.459 (2.206-2.741)	4.356 (3.517-5.395)	5.501 (4.253-7.116)	3.271 (2.458-4.354)

Abbreviations:
SMR=Standardised Mortality Ratio; CI=confidence interval

Table 3. Crude mortality rates per 100,000 person-years and standardised mortality ratios for underlying causes of death and all contributing factors in death by ICD-10 chapters for adults aged 25+ with and without intellectual disabilities

ICD-10 Chapter	Underlying cause of death						
	Intellectual disabilities		Controls		SMR (95% CI)		
	N (%)	CMR (95% CI)	N (%)	CMR (95% CI)	All	Men	Women
Ch. 1. Certain infectious and parasite diseases	53 (1.5%)	46.885 (35.819-61.369)	838 (1.2%)	20.145 (18.826-21.556)	2.324 (1.166-5.425)	4.434 (3.100-6.341)	3.728 (2.477-5.610)
Ch. 2. Neoplasms	489 (14.3%)	432.576 (395.886-472.667)	20,667 (29.7%)	496.826 (490.098-503.646)	1.206 (1.150-1.492)	1.234 (1.090-1.396)	1.510 (1.330-1.714)
Ch. 3. Diseases of the blood, blood-forming organs and immune mechanism	<10	-	135 (0.2%)	3.245 (2.742-3.842)		-	-
Ch. 4. Endocrine, nutritional and metabolic diseases	90 (2.6%)	79.615 (64.755-97.886)	1,389 (2.0%)	33.391 (31.680-35.194)	3.389 (2.331-6.605)	3.573 (2.715-4.701)	3.919 (2.863-5.364)
Ch. 5. Mental and behavioural disorders	243 (7.1%)	214.961 (189.564-243.761)	5,084 (7.3%)	122.217 (118.903-125.623)	3.989 (3.456-4.444)	3.961 (3.283-4.778)	3.833 (3.236-4.540)
Ch. 6. Diseases of the nervous system	442 (12.9%)	390.999 (356.196-429.204)	3981 (5.7%)	95.702 (92.774-98.721)	7.771 (7.080-8.531)	7.580 (6.631-8.664)	7.842 (6.885-8.931)
Ch. 7. Diseases of the eye and adnexa	<5	-	<5	-		-	-
Ch. 8. Diseases of the ear and mastoid process	<5	-	<5	-		-	-
Ch. 9. Diseases of the circulatory system	692 (20.2%)	612.1530 (568.201-659.505)	19093 (27.4%)	458.987 (452.523-465.544)	2.455 (2.278-2.645)	2.220 (2.006-2.456)	2.634 (2.360-2.941)
Ch. 10. Diseases of the respiratory system	484 (14.1%)	428.153 (391.659-468.048)	8716 (12.5%)	209.529 (205.176-213.974)	3.950 (3.695-4.296)	4.095 (3.628-4.622)	3.696 (3.240-4.215)
Ch. 11. Diseases of the digestive system	166 (4.8%)	146.846 (126.124-170.973)	3616 (5.2%)	86.927 (84.139-89.807)	2.538 (2.288-2.967)	2.328 (1.889-2.869)	2.732 (2.189-3.411)
Ch. 12. Diseases of the skin and subcutaneous tissue	12 (0.3%)[u]	10.615 (6.029-18.692)[u]	226 (0.3%)	5.433 (4.769-6.190)	3.453 (1.978-6.133)[u]	-	-
Ch. 13. Diseases of the musculoskeletal system and connective tissue	22 (0.6%)	19.461 (12.814-29.557)	449 (0.6%)	10.794 (9.840-11.840)	3.152 (2.075-4.787)	4.086 (2.263-7.378)[u]	2.631 (1.457- 4.751)[u]
Ch. 14. Diseases of the genitourinary system	98 (2.9%)	86.692 (71.121-105.673)	1364 (2.0%)	32.790 (31.095-34.577)	5.602 (4.595-6.828)	6.460 (4.896-8.523)	4.919 (3.707-6.527)

Ch. 15. Pregnancy, childbirth and puerperium	<5	-	<5	-	-	-	-
Ch. 16. Certain conditions originating in the perinatal period	<5	-	<5	-	-	-	
Ch. 17. Congenital malformations, deformations and chromosomal abnormalities	426 (12.4%)	376.846 (342.707-414.385)	65 (0.1%)	1.563 (1.225-1.993)	255 (224.0-285.4)	224.4 (196.9-255.8)	306.5 (267.0-351.8)
Ch. 18. Symptoms, signs and abnormal clinical and laboratory findings	56 (1.6%)	49.538 (38.124-64.371)	936 (1.3%)	22.501 (21.105-23.990)	3.20 (2.593-4.041)	2.240 (1.488-3.370)	4.002 (2.845-5.629)
Ch. 19. Injury, poisoning and certain other consequences of external causes	<5	-	<5	-	-	-	-
Ch. 20. External causes of morbidity and mortality	115 (3.4%)	101.731 (84.738-122.131)	2,571 (3.7%)	61.806 (59.462-64.242)	2.38 (2.264-2.543)	1.719 (1.353-2.185)	2.636 (1.986-3.498)
Unknown cause of death or error in underlying cause of death code	<5	-	<5	-	-	-	-
Total number of deaths	3,429 (100%)	3033.342 (2933.494-3136.588)	69,641 (100%)	1674.140 (1661.752-1686.62)	3.180 (3.127-3.236)	2.882 (2.751-3.019)	3.329 (3.172-3.494)
ICD-10 Chapter	All contributing factors in death						
	Intellectual disabilities		Controls		SMR (95% CI)		
	N	CMR (95% CI)	N	CMR (95% CI)	All	Men	Women
Ch. 1. Certain infectious and parasite diseases	241 (7.0%)	213.192 (187.906-241.881)	3,774 (5.4%)	90.725 (87.877-93.667)	3.999 (3.563-4.457)	3.848 (3.242-4.567)	3.915 (3.248-4.719)
Ch. 2. Neoplasms	572 (16.7%)	505.999 (466.186-549.213)	23,717 (34.1%)	570.146 (562.936-577.449)	1.482 (1.310-1.544)	1.298 (1.159-1.454)	1.554 (1.380-1.750)
Ch. 3. Diseases of the blood, blood-forming organs and immune mechanism	33 (1.0%)	29.192 (20.754-41.062)	1,001 (1.4%)	24.064 (22.618-25.601)	2.111 (1.529-3.025)	1.566 (0.909-2.696)[u]	2.783 (1.796-4.314)[u]
Ch. 4. Endocrine, nutritional and metabolic diseases	467 (13.6%)	413.115 (377.296-452.335)	8,672 (12.5%)	208.471 (204.129-212.905)	3.327 (3.029-3.643)	2.706 (2.381-3.076)	4.071 (3.581-4.629)
Ch. 5. Mental and behavioural disorders	944 (27.5%)	835.076 (783.469-890.082)	10,899 (15.7%)	262.007 (257.134-266.973)	6.380 (5.939-6.747)	6.151 (5.625-6.726)	6.281 (5.734-6.880)
Ch. 6. Diseases of the nervous system	943 (27.5%)	834.191 (782.612-889.170)	7,266 (10.4%)	174.672 (170.701-178.734)	8.880 (8.341-9.476)	8.473 (7.747-9.267)	9.112 (8.319-9.980)
Ch. 7. Diseases of the eye and adnexa	<5	-	41 (0.06%)	0.986 (0.726-1.339)	-	-	-

Ch. 8. Diseases of the ear and mastoid process	<5	-	11 (0.02%)	0.264 (0.146-0.477)	-	-	-
Ch. 9. Diseases of the circulatory system	1,271 (37.1%)	1124.345 (1064.201-1187.888)	35,223 (50.6%)	846.746 (837.948-855.635)	2.459 (2.328-2.598)	2.231 (2.069-2.406)	2.644 (2.440-2.865)
Ch. 10. Diseases of the respiratory system	1,616 (47,1%)	1429.537 (1361.51-1500.962)	24,834 (35.7%)	596.999 (589.620-604.47)	4.456 (4.191-4.731)	4.400 (4.118-4.702)	4.506 (4.193-4.842)
Ch. 11. Diseases of the digestive system	288 (8.4%)	254.769 (226.981-285.959)	6,824 (9.8%)	164.046 (160.200-167.985)	2.444 (2.255-2.664)	2.248 (1.926-2.624)	2.440 (2.051-2.904)
Ch. 12. Diseases of the skin and subcutaneous tissue	46 (1.3%)	40.692 (30.480-54.327)	727 (1.0%)	17.477 (16.251-18.795)	4.373 (3.226-5.572)	3.857 (2.515-5.916)	4.443 (3.002-6.575)
Ch. 13. Diseases of the musculoskeletal system and connective tissue	62 (1.8%)	54.846 (42.761-70.347)	1,791 (2.6%)	43.055 (41.106-45.096)	2.844 (2.722-2.981)	2.672 (1.845-3.870)	2.143 (1.531-3.000)
Ch. 14. Diseases of the genitourinary system	379 (11.1%)	335.269 (303.159-370.780)	8,911 (12.8%)	214.217 (209.815-218.711)	3.380 (3.348-3.484)	3.261 (2.840-3.744)	2.984 (2.576-3.456)
Ch. 15. Pregnancy, childbirth and puerperium	<5	-	<5	-	-	-	-
Ch. 16. Certain conditions originating in the perinatal period	<5	-	<5	-	-	-	-
Ch. 17. Congenital malformations, deformations and chromosomal abnormalities	742 (21.6%)	656.384 (610.814-705.353)	127 (0.2%)	3.053 (2.566-3.633)	238.3 (221.8-256.1)	207.5 (188.2-228.9)	275.2 (247.5-306.0)
Ch. 18. Symptoms, signs and abnormal clinical and laboratory findings	521 (15.2%)	460.884 (422.961-502.208)	9,745 (14.0%)	234.266 (229.660-238.963)	3.898 (3.694-4.149)	3.784 (3.342-4.284)	3.763 (3.341-4.237)
Ch. 19. Injury, poisoning and certain other consequences of external causes	194 (5.7%)	171.615 (149.088-197.546)	4,068 (5.8%)	97.793 (94.834-100.845)	2.586 (2.377-2.885)	2.309 (1.928-2.766)	2.585 (2.064-3.237)
Ch. 20. External causes of morbidity and mortality	234 (6.8%)	207.000 (182.106-235.296)	4,927 (7.1%)	118.443 (115.182-121.797)	2.565 (2.357-2.916)	2.313 (1.957-2.733)	2.749 (2.251-3.358)
Unknown cause of death or error in underlying cause of death code	<5	-	<5	-	-	-	-
Total number of deaths	3,429 (100%)	3033.342 (2933.494-3136.588)	69,641 (100%)	1674.140 (1661.752-1686.62)	3.160 (3.027-3.236)	2.882 (2.751-3.019)	3.329 (3.172-3.494)

*n<5 repressed due to statistical disclosure
CMR, crude mortality rate – reported for ≥ 10 deaths; ICD-10, International Classification of Diseases, Tenth Revision
CMR rates based on 10-20 deaths labelled “u” for unreliable

Table 4. Most common causes of death in adults with and without intellectual disabilities

	Underlying causes of deaths	
	Intellectual disabilities	Controls
1	Down Syndrome (n = 341) ICD code: Q90.0, Q90.1, Q90.2, **Q90.9**	Malignant neoplasm of bronchus and lung (n = 5,163) ICD code: **C34.0, C34.1, C34.2, C34.3, C34.8, C34.9**
2	Dementia (n = 227) ICD code: F00.0, F00.1, F00.2, F00.9, **F03, G30.0, G30.1**, G30.8, **G30.9**	Acute myocardial infarction (n = 4,907) ICD code: I21.0, I21.1, I21.2, I21.3, **I21.4, I21.9**
3	Acute myocardial infarction (n = 158) ICD code: I21.0, I21.1, I21.2, I21.3, I21.4, **I21.9**	Dementia (n = 4,857) ICD code: F00.0, F00.1, F00.2, F00.9, **F03, G30.0, G30.1**, G30.8, **G30.9**
4	Pneumonia, organism unspecified (n = 150) ICD code: J18.0, J18.1, J18.2, J18.8, **J18.9**	Other chronic obstructive pulmonary disease (n = 3,720) ICD code: **J44.0, J44.1, J44.8, J44.9**
5	Epilepsy (n = 137) ICD code: G40.0, G40.1, G40.2, G40.3, G40.4, G40.5, **G40.6,** G40.7, G40.8, **G40.9,** G41.0, G41.1, G41.2, G41.8, **G41.9**	Chronic Ischaemic heart disease (n = 3,672) ICD code: **I25.0, I25.1,** I25.2, **I25.3, I25.4, I25.5**, I25.6, I25.7, **I25.8, I25.9**
6	Pneumonitis due to solids and liquids (n = 128) ICD code: **J69.0**, J69.1, J69.8	Intracerebral haemorrhage, cerebral infarction, and stroke, not specified as haemorrhage or infarction (n = 2,614) ICD code: **I61.0, I61.2, I61.3, I61.4, I61.5, I61.6, I61.8, I61.9, I63.0,** I63.1**, I63.2, I63.3, I63.4, I63.5,** I63.8**, I63.9, I64**
7	Cerebral palsy (n = 123) ICD codes: **G80.0, G80.1,** G80.2, G80.3, G80.4, **G80.8**, **G80.9**	Pneumonia, organism unspecified (n = 2,194) ICD code: **J18.0, J18.1, J18.2,** J18.8, J18.9
8	Intracerebral haemorrhage, cerebral infarction, and stroke, not specified as haemorrhage or infarction (n = 111) ICD code: **I61.0,** I61.2, I61.3, **I61.4**, I61.5, **I61.6,** I61.8, **I61.9,** I63.0, I63.1, I63.2, **I63.3,** I63.4, **I63.5, I63.6,** I63.8, **I63.9, I64**	Vascular Dementia (n = 2,136) ICD code: F01.0, **F01.1, F01.2, F01.3**, F01.8, **F01.9**
9	Chronic Ischaemic heart disease (n = 110) ICD code: **I25.0, I25.1,** I25.2, I25.3, I25.4, I25.5, I25.6, I25.7, **I25.8, I25.9**	Malignant neoplasm of breast unspecified (n = 1,303) ICD code: C50.0, C50.1, C50.2, C50.3, C50.5, C50.6, C50.8, **C50.9**
10	Other chronic obstructive pulmonary disease (n = 78) ICD code: **J44.0, J44.1, J44.8, J44.9**	Malignant neoplasm of prostate (n = 1,237) ICD code: **C61**
11	Malignant neoplasm of bronchus and lung (n = 67) ICD code: **C34.0, C34.1,** C34.2, **C34.3,** C34.8, **C34.9**	Accidents: Other external causes of accidental injury: Falls (n = 1,005) ICD code: **W19**
12	Vascular Dementia (n = 61) ICD code: F01.0, **F01.1,** F01.2, F01.3, F01.8, **F01.9**	Malignant neoplasm of oesophagus (n = 999) ICD code: **C15.9**
13	Urinary tract infection (n = 48) ICD code: **N39.0**	Sequelae of other and unspecified cerebrovascular diseases (n = 996) ICD code: **I69.8**
14	Other specified respiratory disorders (n = 41)	Malignant neoplasm: pancreas (n = 886)

	ICD code: **J98.8**	ICD code: **C25.9**
15	Other ill identified cause of mortality (n = 38) ICD code: **R99**	Malignant neoplasm: colon (n = 728) ICD code: **C18.9**
16	Sequelae of other and unspecified cerebrovascular diseases (n = 37) ICD code: **I69.8**	Urinary tract infection (n = 638) ICD code: **N39.0**
17	Malignant neoplasm of oesophagus (n = 33) ICD code: **C15.9**	Malignant neoplasm: bladder (n = 628) ICD code: **C67.9**
18	Malignant neoplasm of breast (n = 30) ICD code: C50.0, C50.1, C50.2, C50.3, C50.5, C50.6, C50.8, **C50.9** Malignant neoplasm, site unspecified (n = 30) ICD code: **C80**	Malignant neoplasm, site unspecified (n = 594) ICD code: **C80**
19	Developmental disorder of scholastic skills, unspecified (n = 28) ICD code: **F81.9**	Other interstitial pulmonary diseases with fibrosis (n = 576) ICD code: **J84.1**
20	Sepsis, unspecified (n = 26) ICD code: **A41.9**	Parkinson disease (n = 554) ICD code: **G20**
	All contributing factors in deaths	
	Intellectual disabilities	Controls
1	Pneumonia, organism unspecified (n = 731) ICD codes: **J18.0, J18.1, J18.2,** J18.8, **J18.9**	Chronic Ischaemic heart disease (n = 12,607) ICD codes: **I25.0, I25.1,** I25.2, **I25.3, I25.4, I25.5,** I25.6, I25.7, **I25.8, I25.9**
2	Down syndrome (n = 593) ICD code: Q90.0, Q90.1, Q90.2, **Q90.9**	Pneumonia, organism unspecified (n = 9,833) ICD codes: **J18.0, J18.1, J18.2, J18.8, J18.9**
3	Pneumonitis due to solids and liquids (n = 487) ICD codes: **J69.0,** J69.1, J69.8	Other chronic obstructive pulmonary disease (n = 9,012) ICD codes: **J44.0, J44.1, J44.8, J44.9**
4	Epilepsy (n = 412) ICD codes: G40.0, G40.1, **G40.2, G40.3, G40.4,** G40.5, **G40.6,** G40.7, G40.8, **G40.9,** G41.0, G41.1, G41.2, G41.8, **G41.9**	Dementia (n = 8,474) ICD codes: F00.0, F00.1, F00.2, F00.9, **F03, G30.0, G30.1, G30.8, G30.9**
5	Developmental disorder of scholastic skills, unspecified (n = 380) ICD codes: F81.9	Acute myocardial infarction (n = 5,968) ICD codes: **I21.0,** I21.1, I21.2, I21.3, **I21.4, I21.9**
6	Dementia (n = 357) ICD codes: F00.0, F00.1, F00.2, F00.9, **F03, G30.0, G30.1,** G30.8, **G30.9**	Essential primary hypertension (n = 5,879) ICD codes: I10.0
7	Chronic ischemic heart disease (n = 295) ICD codes: **I25.0, I25.1,** I25.2, I25.3, I25.4, I25.5, I25.6, I25.7, **I25.8,** I25.9	Malignant neoplasm of bronchus and lung (n = 5,727) ICD codes: **C34.0, C34.1, C34.2, C34.3, C34.8, C34.**9
8	Cerebral Palsy (n = 215) ICD codes: **G80.0, G80.1,** G80.3, G80.4, **G80.8, G80.9**	Other general symptoms and signs (n = 5,058) ICD codes: R68.8
9	Acute myocardial infarction (n = 202) ICD codes: I21.0, I21.1, I21.2, I21.3, I21.4, **I21.9**	Intracerebral haemorrhage, cerebral infarction, and stroke, not specified as haemorrhage or infarction (n = 4,893) ICD codes: **I61.0, I61.1, I61.2, I61.3, I61.4, I61.5, I61.6, I61.8, I61.9, I63.0,** I63.1, **I63.2, I63.3, I63.4, I63.5, I63.6, I63.8, I63.9, I64**

10	Diabetes without complications (n = 196) ICD codes: E11.9	Diabetes without complications (n = 4,495) ICD codes: E11.9
11	Other general symptoms and signs (n = 185) ICD codes: R68.8	Vascular dementia (n = 3,948) ICD codes: F01.0, **F01.1, F01.2, F01.3,** F01.8, **F01.9**
12	Intracerebral haemorrhage, cerebral infarction, and stroke, not specified as haemorrhage or infarction (n = 178) ICD codes: **I61.0,** I61.1, I61.2, I61.3, **I61.4, I61.5, I61.6,** I61.8, **I61.9,** I63.0, I63.1, **I63.2, I63.3,** I63.4, **I63.5, I63.6, I63.9, I64**	Pneumonitis due to solids and liquids (n = 2,945) ICD codes: **J69.0,** J69.1, **J69.8**
13	Sepsis, unspecified (n = 173) ICD codes: **A41.9**	Atrial fibrillation and flutter (n = 2,734) ICD codes: **I48**
14	Other chronic obstructive pulmonary disease (n = 165) ICD codes: J44.0, **J44.1, J44.8, J44.9**	Sepsis, unspecified (n = 2,522) ICD codes: **A41.9**
15	Essential primary hypertension (n = 130) ICD codes: **I10**	Age related physical debility (n = 2,513) ICD codes: **R54**
16	Unspecified acute lower respiratory infection (n = 127) ICD codes: **J22**	Congestive Heart Failure (n = 2,409) ICD codes: **I50.0**
17	Urinary tract infection site not specified (n = 113) ICD codes: **N39.0**	Sequelae of other and unspecified cerebrovascular diseases (n = 2,346) ICD codes: **I69.8**
18	Acute renal failure unspecified (n = 86) ICD codes: **N17.9**	Unspecified acute lower respiratory infection (n = 2,229) ICD codes: **J22**
19	Congestive Heart Failure (n = 82) ICD codes: **I50.0**	Atrial fibrillation and atrial flutter, unspecified (n = 2,213) ICD codes: **I48.9**
20	Other respiratory disorders (n = 81) ICD code: **J98.8**	Acute renal failure, unspecified (n = 2,190) ICD codes: **N17.9**

NB: While all codes included in the ICD-10 groupings are listed above, the highlights in **bold** refer to those codes, which were present in the data.

Table 5. All-cause, avoidable, treatable, and preventable underlying cause of deaths for adults with and without intellectual disabilities

Variable	Deaths in group with intellectual disabilities (N)				Deaths in controls (N)				HR (95% CI)
	All	Avoidable*	Treatable*	Preventable*	All	Avoidable*	Treatable*	Preventable*	**†a** (All) **†b** (Avoidable) **†c** (Treatable) **†d** (Preventable)
Total	3,429	1,087	722	681	69,641	12,673	6,110	10,207	**†a** 3.304 (3.192-3.420) **2.978 (2.877-3.084) **†b** 3.350 (3.148-3.564) **2.701 (2.538-2.876) **†c** 4.672 (4.325-5.048) **3.903 (3.609-4.220) **†d** 2.611 (2.416-2.822) **2.042 (1.889-2.208)
Age									
25-34	163	76	44	44	734	522	146	456	**†a** 3.324 (3.211-3.440) **†b** 3.351 (3.149-3.565) **†c** 4.674 (4.326-5.050) **†d** 2.611 (2.416-2.822)
35-44	300	158	102	84	1,793	1,271	552	1,016	
45-54	740	342	221	215	4,410	3,164	1,558	2,551	
55-64	907	467	325	303	9,369	6,630	3,301	5,325	
65-74	717	44	30	35	17,169	1,086	553	879	
75+	602	0	0	0	36,166	0	0	0	

Sex									
Male	1784	619	395	417	33,222	7,413	3,418	6,445	†a 3.259 (3.148-3.373) †b 3.274 (3.077-3.483) †c 4.597 (4.255-4.967) †d 2.522 (2.333-2.726)
Female	1645	468	327	264	36,419	5,260	2,692	3,522	
SIMD									
1 (most deprived)	962	342	213	226	15,469	3,738	1,679	2,455	†a 3.019 (2.916-3.125) †b 2.768 (2.600-2.946) †c 3.970 (3.671-4.292) †d 2.119 (1.960-2.291)
2	908	304	203	189	15,467	2,938	1,366	2,155	
3	721	230	154	141	14,127	2,490	1,229	1,944	
4	512	127	94	78	13,159	2,020	1,023	1,555	
5 (least deprived)	326	84	58	47	11,419	1,487	813	1,128	

*Deaths at age 25-74 only as per the ONS definition of avoidable mortality

Abbreviations: SIMD=Scottish Index of Multiple Deprivation; HR=hazard ratio; CI=confidence interval

†a-d - Cox regression hazard ratio for risk of deaths (all, avoidable, treatable and preventable) by intellectual disabilities versus controls (total column = unadjusted and **adjusted for age, sex and SIMD)
Reference groups: no intellectual disabilities, male, most deprived, age (continuous)

Supplemental Table 1. Crude mortality rates (CMRs) for adults with intellectual disabilities per 100,000 by age, sex, and deprivation (SIMD)

Variable	All deaths CMR (95% CI)	Avoidable deaths CMR (95% CI)	Treatable deaths CMR (95% CI)	Preventable deaths CMR (95% CI)
All deaths	3033.342 (2933.494-3136.588)	1061.407 (1000.147-1126.418)	705.000 (655.407-757.947)	664.966 (616.852-716.832)
Age				
25-34	641.267 (550.006-747.670)	298.996 (238.795-374.373)	173.103 (128.819-232.609)	173.103 (128.819-232.609)
35-44	1082.162 (966.380-1211.815)	569.939 (487.652-666.11)	367.935 (303.033-446.738)	303.005 (244.668-375.253)
45-54	2508.555 (2334.172-2695.966)	1159.359 (1042.774-1288.979)	749.177 (656.638-855.756)	728.837 (637.645-833.071)
55-64	4980.093 (4666.312-5314.974)	2564.171 (2341.845-2807.605)	1784.488 (1600.654-1989.435)	1663.691 (1486.526-1861.971)
65-74	8168.600 (7592.048-8788.937)	2822.336 (2100.319-3792.557)	1924.320 (1345.457-2752.23)	2245.040 (1611.925-3126.823)
75+	17634.187 (16280.32-19100.64)	-	-	-
Sex				
Male	2858.277 (2728.673-2994.036)	1080.500 (998.648-1169.062)	689.495 (624.745-760.957)	727.898 (661.282-801.224)
Female	3249.165 (3095.885-3410.034)	1037.165 (947.329-1135.519)	724.686 (650.247-807.046)	585.067 (518.583-660.076)
SIMD				
1 (most deprived)	2889.038 (2712.123-3077.493)	1128.080 (1014.64-1254.202)	702.576 (614.285-803.557)	745.456 (654.336-849.265)
2	3075.061 (2881.414-3281.722)	1136.144 (1015.345-1271.315)	758.675 (661.17-870.589)	706.353 (612.500-814.587)
3	3148.364 (2926.743-3386.768)	1107.029 (972.820-1259.754)	741.228 (632.937-868.048)	678.657 (575.395-800.451)
4	2965.524 (2719.464-3233.848)	818.743 (688.044-974.271)	605.999 (495.082-741.966)	502.850 (402.772-627.796)

5 (least deprived)	3243.259 (2909.631-3615.142)	928.258 (749.540-1149.589)	640.940 (495.506-829.360)	519.383 (390.236-691.270)

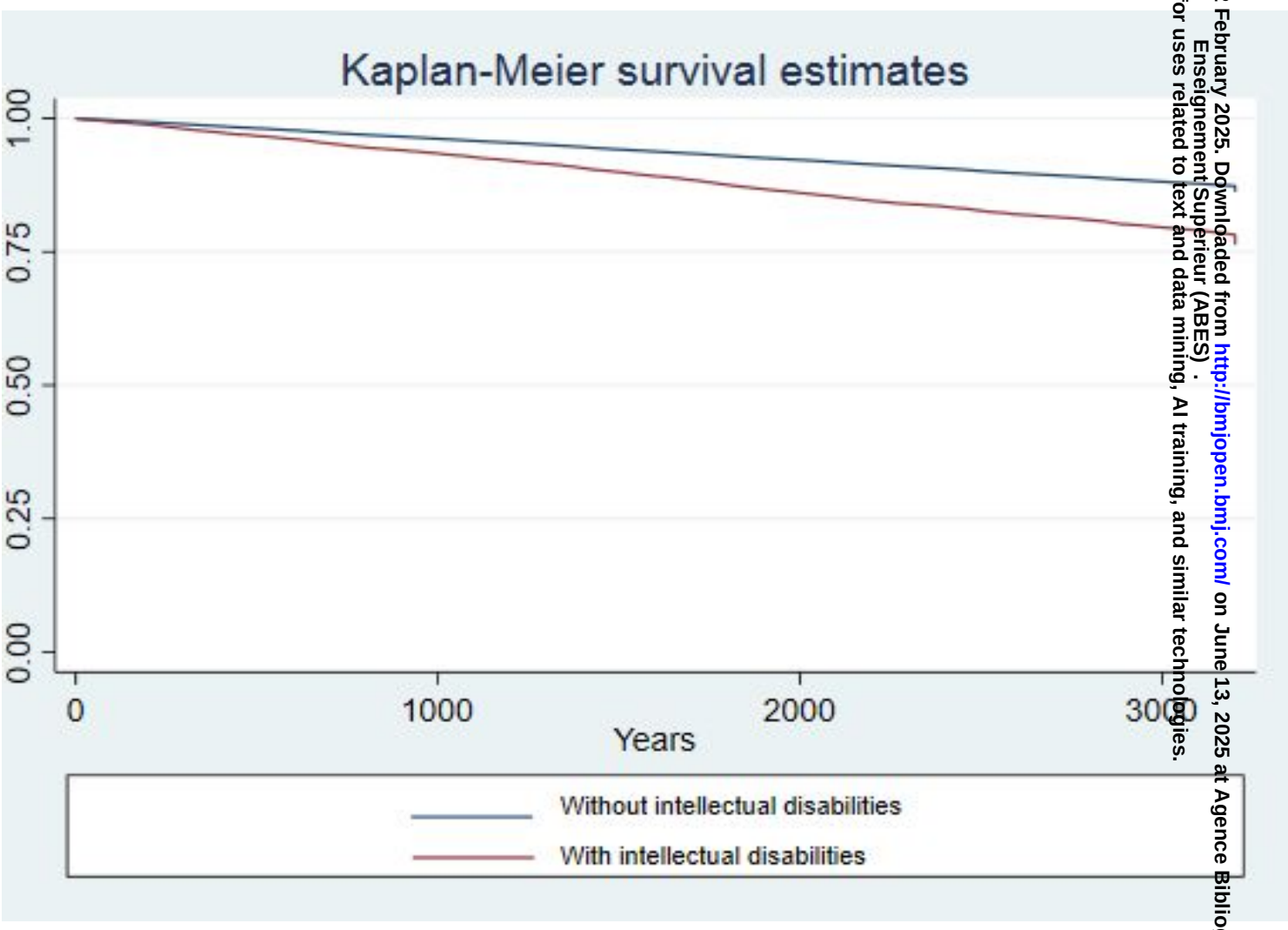
Abbreviations: CMR=Crude Mortality Rate; CI=confidence interval

Supplemental Table 2. Crude mortality rates (CMRs) for adults without intellectual disabilities per 100,000 by age sex, and deprivation (SIMD)

Variable	All deaths CMR (95% CI)	Avoidable deaths CMR (95% CI)	Treatable deaths CMR (95% CI)	Preventable deaths CMR (95% CI)
All deaths	1674.140 (1661.752-1686.62)	375.904 (369.416-382.506)	181.234 (176.746-185.883)	302.758 (296.941-308.689)
Age				
25-34	100.202 (93.209-107.719)	71.260 (65.402-77.643)	19.931 (16.947-23.44)	62.251 (56.791-68.235)
35-44	210.565 (201.041-220.540)	149.263 (141.278-157.698)	64.825 (59.637-70.465)	119.316 (112.201-126.883)
45-54	473.375 (459.608-487.554)	339.628 (327.998-351.670)	167.238 (159.136-175.7)	268.460 (258.143-279.191)
55-64	1201.950 (1177.857-1226.536)	850.563 (830.334-871.286)	423.486 (409.283-438)	686.994 (668.838-705.642)
65-74	3239.052 (3190.963-3287.866)	1425.095 (1342.809-1512.424)	725.670 (667.640-788.7)	1153.461 (1079.674-1232.291)
75+	10808.359 (10697.54-10920.33)	-	-	-
Sex				
Male	1699.664 (1681.485-1718.039)	457.480 (447.184-468.014)	210.936 (203.982-218.12)	399.593 (389.978-409.446)
Female	1651.515 (1634.641-1668.564)	300.410 (292.4-308.639)	153.746 (148.046-159.665)	213.142 (206.413-220.092)
SIMD				
1 (most deprived)	2092.940 (2060.217-2126.183)	609.863 (590.622-629.730)	273.933 (261.138-287.354)	509.851 (492.285-528.043)
2	1938.103 (1907.799-1968.889)	456.686 (440.468-473.502)	212.333 (201.366-223.893)	373.836 (359.190-389.079)
3	1650.828 (1623.829-1678.276)	359.964 (346.099-374.384)	177.669 (168.009-187.886)	288.260 (275.882-301.194)
4	1460.076 (1435.342-1485.237)	278.420 (266.540-290.831)	141.002 (132.621-149.91)	217.085 (206.625-228.075)
5 (least deprived)	1319.1242 (1295.15-1343.542)	213.08986 (202.5298-224.2005)	116.50441 (108.7651-124.7945)	158.778 (149.699-168.408)

Abbreviations: CMR=Crude Mortality Rate; CI=confidence interval

Supplemental Figure 1. Kaplan-Meier survival analysis for risk of death for intellectual disabilities population and controls from 2011-2019



BMJ Open

Rates, causes and predictors of all-cause and avoidable mortality in 514,878 adults with and without intellectual disabilities: a record linkage national cohort study

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2024-089962.R1
Article Type:	Original research
Date Submitted by the Author:	14-Nov-2024
Complete List of Authors:	Rydzewska, Ewelina; The University of Edinburgh Nijhof, Dewy; University of Glasgow Hughes-McCormack, Laura; University of Glasgow School of Health and Wellbeing, Mental Health and Wellbeing Melville, Craig; University of Glasgow Fleming, Michael ; University of Glasgow, Public Health Mackay, Daniel; University of Glasgow Sosenko, Filip; University of Glasgow College of Medical Veterinary and Life Sciences, Institute of Health and Wellbeing Ward, Laura; University of Dundee School of Medicine, Health Informatics Centre; University of Glasgow School of Health and Wellbeing, Mental Health and Wellbeing Dunn, Kirsty; University of Glasgow, Institute of Health and Wellbeing Truesdale, Maria; University of Glasgow College of Medical Veterinary and Life Sciences, Mental Health and Wellbeing Cairns, Deborah; University of Glasgow Pell, Jill; University of Glasgow Wyper, Grant; NHS Health Scotland Jani, Bhautesh; University of Glasgow Barlow, Fiona; University of Glasgow College of Medical Veterinary and Life Sciences, Mental Health and Wellbeing Henderson, Angela; University of Glasgow, Institute of Health and Wellbeing Callander, Ruth; Scottish Comission for People with Learning Disabilities Cooper, Sally-Ann; University of Glasgow, Institute of Health and Wellbeing
Primary Subject Heading:	Public health
Secondary Subject Heading:	Epidemiology
Keywords:	Mortality, PUBLIC HEALTH, Primary Care < Primary Health Care

I, the Submitting Author has the right to grant and does grant on behalf of all authors of the Work (as defined in the below author licence), an exclusive licence and/or a non-exclusive licence for contributions from authors who are: i) UK Crown employees; ii) where BMJ has agreed a CC-BY licence shall apply, and/or iii) in accordance with the terms applicable for US Federal Government officers or employees acting as part of their official duties; on a worldwide, perpetual, irrevocable, royalty-free basis to BMJ Publishing Group Ltd ("BMJ") its licensees and where the relevant Journal is co-owned by BMJ to the co-owners of the Journal, to publish the Work in this journal and any other BMJ products and to exploit all rights, as set out in our licence.

The Submitting Author accepts and understands that any supply made under these terms is made by BMJ to the Submitting Author unless you are acting as an employee on behalf of your employer or a postgraduate student of an affiliated institution which is paying any applicable article publishing charge ("APC") for Open Access articles. Where the Submitting Author wishes to make the Work available on an Open Access basis (and intends to pay the relevant APC), the terms of reuse of such Open Access shall be governed by a Creative Commons licence – details of these licences and which Creative Commons licence will apply to this Work are set out in our licence referred to above.

Other than as permitted in any relevant BMJ Author's Self Archiving Policies, I confirm this Work has not been accepted for publication elsewhere, is not being considered for publication elsewhere and does not duplicate material already published. I confirm all authors consent to publication of this Work and authorise the granting of this licence.

Title: Rates, causes and predictors of all-cause and avoidable mortality in 514,878 adults with and without intellectual disabilities: a record linkage national cohort study

Authors:

Ewelina Rydzewska,[1,2] Dewy Nijhof,[2] Laura Hughes,[2] Craig Melville,[2] Michael Fleming,[2] Daniel Mackay,[2] Filip Sosenko,[2] Laura Ward,[3] Kirsty Dunn,[2] Maria Truesdale,[2] Deborah Cairns,[2*] Jill P. Pell,[2] Grant M. A. Wyper,[2,4] Bhautesh D. Jani,[2] Fiona Barlow,[2] Angela Henderson,[2] Ruth Callander,[4] Sally-Ann Cooper[2]

1. School of Health in Social Science, University of Edinburgh, Edinburgh, Scotland, UK
2. School of Health and Wellbeing, University of Glasgow, Glasgow, Scotland, UK
3. School of Medicine, University of Dundee, Dundee, Scotland, UK
4. Population Health and Wellbeing, Public Health Scotland, Edinburgh, Scotland, UK
5. Scottish Commission for People with Learning Disabilities, Glasgow, Scotland, UK

*Corresponding author:

Professor Deborah Cairns
School of Health and Wellbeing
University of Glasgow
Glasgow
Scotland, UK
deborah.cairns@glasgow.ac.uk

Abstract

Background: Studies on avoidable mortality in adults with intellectual disabilities are limited, as are studies on causes of death.

Objectives: We aimed to quantify mortality rates, and causes, and identify factors (i.e., age, sex, Scottish Index of Multiple Deprivation [SIMD]) related to avoidable mortality in adults with intellectual disabilities.

Design: a record linkage national cohort study.

Setting: A cohort of adults with intellectual disabilities with or without co-occurring autism, aged 25+ years and a randomly selected comparison group aged 25+ years without intellectual disabilities or autism identified from Scotland's Census, 2011. Census records were linked to the National Records of Scotland Statutory Register of Deaths database to ascertain all deaths in 2011-2019.

Participants: We analysed data on 14,477 adults with intellectual disabilities aged 25+ years and a randomly selected comparison group of 506,207 adults aged 25+ without intellectual disabilities identified from Scotland's Census 2011.

Primary and secondary outcome measures: We ran χ^2 tests and t-tests to investigate individual characteristics and differences in age at death for adults with intellectual disabilities compared to peers in the general population. Cox proportional hazard models were fitted to calculate risk of mortality (all-cause, avoidable, treatable, preventable) unadjusted and adjusted for age, sex and SIMD. We then calculated mortality rates, using crude and indirect standardisation methods.

Results: During the 8.5-year-follow-up, 23.7% (crude death rate of 3033.3 per 100,000) of adults with intellectual disabilities died compared to 13.8% of controls. Median age at death among adults aged 25+ with intellectual disabilities was 65.0 years compared to 80.0 years for adults without intellectual disabilities. For all-cause mortality, the age-standardised mortality ratio (SMR) in the population with intellectual disabilities was 3.1 [95% CI 3.0-3.2]. The SMRs were higher for the youngest age groups, women and in the most affluent areas. This was also the case for SMRs for avoidable, treatable, and preventable deaths. For the population of adults with intellectual disabilities, 31.7% of recorded deaths were considered avoidable, 21.1% were treatable and 19.9% were preventable. In the controls, 18.2% of deaths were considered avoidable, 8.8% treatable and 14.7% preventable. Down syndrome and dementia were the two most commonly recorded underlying causes of death for people with intellectual disabilities while malignant neoplasm of bronchus and lung and acute myocardial infarction were most commonly recorded in the general population.

Conclusions: Risks of all-cause, avoidable, treatable, and preventable mortality were higher for adults with intellectual disabilities than their peers. The highest SMRs were observed for youngest adults, women, and individuals living in the most affluent areas.

Keywords: avoidable mortality, intellectual disabilities, adults, data linkage

Strengths and limitations of this study:

- Unique study of avoidable mortality in adults with intellectual disabilities in a whole country population
- High response rate of 94%, and systematic enquiry of everyone regarding intellectual disabilities
- Results of the study are generalisable to other adult populations in high-income countries
- The records of death were taken from death certificates, and not verified at post-mortem

Introduction

On average, people with intellectual disabilities have been reported to die 20 years younger than those without intellectual disabilities, including dying from causes considered to have been avoidable[1]. In recent years, there have been several studies of deaths in adults with intellectual disabilities, that have attempted to reduce the limitations of previous studies such as small sample sizes, or non-representative populations. These studies have typically used record-linkage methods and reported Standardised Mortality Ratios (SMRs) in the region of 2-4, higher in women than men, and at younger ages, though some report SMR to be only slightly above 1[1]. Direct comparisons between studies are difficult though due to differences in methods, reporting, and ages studied; a tabulated overview is provided in Cooper et al.[2]

There is much less information on the most common underlying causes of death in adults with intellectual disabilities, and less consistency in how these are reported (for example, grouping by ICD-10 categories, or by individual causes of death) which limits comparisons between studies. One study reported the most common causes of death to be pneumonia, other respiratory diseases, and diseases of the nervous system.[3] Another reported diseases of the circulatory and respiratory systems to be the most common cause of death.[4] A third reported that mortality rates due to influenza and pneumonia, septicaemia and aspiration pneumonia substantially exceeded the adult mortality rates in the general population.[5] A fourth reported diseases of the circulatory system, neoplasm, and the nervous system to be the most common cause of death.[6] A fifth noted that people with intellectual disabilities had increased odds of presentation, admission or death from conditions defined as ambulatory care sensitive, which are potentially preventable, specifically vaccine-preventable respiratory disease, asthma, cellulitis and convulsions and epilepsy.[7] Three studies reported cause-specific SMRs to be higher across most groups of disorders than in the general population.[2-4]

Avoidable mortality has also been little studied in adults with intellectual disabilities. Its definition includes preventable mortality (deaths which are preventable through public health interventions, for example, deaths from infectious diseases that can be prevented by vaccination, or alcohol or drug related deaths), and treatable (previously known as 'amenable') mortality (deaths amenable to timely and effective healthcare, for example, deaths due to epilepsy, diabetes, or respiratory infections) while some causes of death can be both preventable and treatable.[8,9] Recent studies that have reported on avoidable deaths suggest that up to 40% of deaths of adults with intellectual disabilities may be avoidable, compared to 28% of deaths in the general adult population.[2,4,10,11]

Specifically, one study in which 961 adults aged 16–83 years with intellectual disabilities had clinical examinations in 2001–2004 found that 102 (38.9%) of the 262 deaths were avoidable, 78 (29.8%) were treatable and 51 (19.5%) were preventable, while 27 (10.3%) were classed as both treatable and preventable.[2] In a study of 16,666 adults with intellectual disabilities from 343 general practices in the UK, 37.0% of all deaths among adults with intellectual disabilities were classified as being treatable, compared with 22.5% in the general population (Hazard Ratio (HR) 5.9; 95% CI 5.1, 6.8).[4] A study of 732 deaths in 19,362 adults aged 20+ years registered for intellectual disability services from 2005 to 2011 in New South Wales found that 31% of deaths were avoidable; higher than in the general population (17%).[6] Two further studies reported data on children, young people and adults combined.[10,11] Heslop et al.[10] undertook a population-based Confidential Inquiry of the deaths of 247 people with intellectual disabilities aged 4 years and older in southwest England who died between June 1 2010 and May 31 2012. Treatable deaths were more common in people with intellectual disabilities (37%) than in the general population (13%).[10] Glover et al.[11] used general practice data for people with and without intellectual disabilities of all ages, and reported that 44.7% of deaths were avoidable, with a higher proportion of deaths from causes classified as treatable, but a lower proportion from preventable causes compared with people without intellectual disabilities (actual figures not reported).[11] Two studies investigated patterns of mortality in adults with intellectual and developmental disabilities from Ontario, Canada. One of them reported a higher all-cause (6.1% vs. 1.6%) and amenable (21.4% vs. 14.1%) mortality levels compared with general population, but rates for all avoidable mortality were not provided.[12] The other study reported 1-year age-standardised mortality rates for years 2011-2014 to be between 30.3-37.4 for Manitoba adults with intellectual and developmental disabilities compared to the matched comparison group, meaning that 30.3-37.4 times more deaths occurred in this population than would be expected to occur in the Ontario population.[13] A further study on adults with intellectual and developmental disabilities from Manitoba, Canada reported crude avoidable premature mortality rates per 1,000 person-years to be between 2.3–3.3 for years 2013-2015, meaning that avoidable premature mortality was 2.3–3.3 times more prevalent among Manitoba adults with intellectual and developmental disabilities compared to the matched comparison group.[14] These studies demonstrated that rates of avoidable mortality are high in adults with intellectual disabilities, and higher than in the general population, suggesting that pervasive health inequalities may be contributing, and that further investigation is necessary.

The aim of this study was to investigate deaths in adults with intellectual disabilities, compared with controls, for an entire country's population from 2011-2019. For adults with intellectual disabilities compared with other adults, we investigated (a) age- sex- and neighbourhood

deprivation- standardised mortality ratios, (b) underlying cause of death, and all-contributory causes of death by ICD-10 chapters, and most common specific causes, and (c) the proportion of deaths considered avoidable, treatable, and preventable.

Methodology

Patient and public involvement

This study was undertaken by the XXXXXXXXXX due to the growing concern expressed by people with intellectual disabilities and their families about mortality. The XXXXXXXXXX's steering group includes people with intellectual disabilities and partners from third sector organisations. Results from this study will be disseminated to people with intellectual disabilities and their families in an easy-read version via the XXXXXXXXXX website and newsletters and in collaboration with the Scottish Commission for People with Learning Disabilities.

Approvals

Approval was gained from Scotland's Public Benefit and Privacy Panel for Health and Social Care (reference: 1819-0051), Scotland's Statistics Public Benefit and Privacy Panel (reference: 1819-0051), and the University of Glasgow's College of Medical, Veterinary, and Life Sciences Ethical Committee (reference: 200180081). Data sharing agreements were put in place with the data controllers of all the linked datasets.

Study sample, setting and process

Ninety four percent of the Scottish population completed Scotland's Census, 2011. We used these data to create a cohort of adults with intellectual disabilities with or without co-occurring autism, aged 25+ years at the Census date (27th March 2011), and a randomly selected comparison group aged 25+ years without intellectual disabilities or autism from a 15% unmatched sample of the Scottish population also identified from Scotland's Census, 2011. Their records were linked to the National Records of Scotland Statutory Register of Deaths database to ascertain all deaths up to 31st December 2019. Access to the anonymised linked data was given to the approved members of the research team via Scotland's National Safe Haven. Full details on Scotland's Census 2011 are available at: https://www.scotlandscensus.gov.uk/about/2011-census/. Further information on the record linkage and the cohorts have previously been reported in detail.[15]

Variables

Intellectual disabilities: Scotland's Census 2011 provides information on the number and characteristics of Scotland's population and households on the Census day, 27th March 2011.

The census is undertaken every 10 years. It includes people living in communal establishments (such as care homes and student halls of residence) as well as people living in private households. In 2011, the census in Scotland was estimated to have achieved a 94% response rate.[16] The Census team required the form to be completed by the head of household or joint head of household on behalf of all occupants in private households, and the manager was responsible on behalf of all occupants in communal dwellings. It was a legal requirement to complete the census, and non-compliance or supplying false information could result in a fine of £1,000. The Census team followed up non-responders and also provided help in responding when it was needed; hence, the high 94% completion rate.

Scotland's Census is probably one of few country censuses, which identifies people with intellectual disabilities and distinguishes these from specific learning disabilities such as dyslexia; indeed, it may be unique in this regard. Self-/proxy reporting was used to identify people with intellectual disabilities from the Census questionnaire, question 20: 'Do you have any of the following conditions which have lasted, or are expected to last, at least 12 months? Tick all that apply'. Respondents were given a choice of 10 response options, with option number (3) 'learning disability (e.g., Down's syndrome)' being synonymous in the UK with the international term 'intellectual disabilities'. The remaining response options were as follows: (1) deafness or partial hearing loss, (2) blindness or partial sight loss, (4) learning difficulty (e.g., dyslexia), (5) developmental disorder (e.g., autistic spectrum disorder or Asperger's syndrome), (6) physical disability, (7) mental health condition, (8) long-term illness, disease or condition, (9) other condition, (10) no condition. Importantly, the question distinguished between intellectual disability (for which the term 'learning disability' is used in the UK), learning difficulty (which in the UK is synonymous with the international term 'specific learning disability' such as dyslexia) and autism.

Age: Age was grouped into six categories of 1) 25-34 years, 2) 35-44 years, 3) 45-54 years, 4) 55-64 years, 5) 65-74 and 6) 75+ years, based on the Census data.

Sex: Sex was coded in two categories of male and female, based on the Census data.

Scottish Index of Multiple Deprivation (SIMD)*:* SIMD was grouped in population quintiles where SIMD 1 included the most deprived neighbourhoods and SIMD 5 corresponded with the most affluent neighbourhoods. SIMD was identified from postcodes, based on the Census data, and calculated at datazone level.

Deaths: We used data from death certificates registered at National Records of Scotland, to identify date of deaths, and underlying causes and all contributing factors in deaths for adults with intellectual disabilities and the general population comparison group. For cause of death analyses, we analysed the underlying cause of death; defined as the disease or injury which initiated the chain of morbid events leading directly to death, or the accident/act which produced the fatal injury.[17] We also analysed a broader composite outcome of all contributing factors in death, defined as a cause listed as either the underlying cause, secondary cause or a contributing factor. We used the Tenth Revision of the International Statistical Classification of Diseases and Related Health Problems (ICD-10)[18] to group causes of death into categories. The cancer codes included C00.0-D48.9 inclusive. The analyses were restricted to deaths recorded between the 28th March 2011 and the 31st December 2019.

We defined treatable and preventable deaths as per avoidable mortality outcomes outlined in the guidance of the Office for National Statistics,[8] noting that some causes of death are both treatable and preventable. As per the ONS guidance, avoidable mortality analyses excluded any deaths at the age of 75+, thus the following cases were excluded from the avoidable mortality analyses: 1) anyone who was 75+ years at the start of the study (i.e., Census day the 27th March 2011); 2) anyone who died at the age of 75+ years during the study duration; 3) anyone who turned 75+ years at any point during the study period.

Data processes

All follow-up/censoring*:* Adults aged 25+ years were followed up from the Census date (27th March 2011), and all models were censored on death or the study end date (31st December 2019), whichever came first, unless stated otherwise. Cases of individuals who died either before or on the day of Census (i.e., any deaths prior to the 28th of March 2011) were excluded from the analyses, as participants were expected to spend at least one day in the study to enable us to run survival analysis. Furthermore, in the comparison group, we also excluded individuals who subsequently died during the study period and had their cause of death recorded as a form of an intellectual disability/autism (ICD-10 codes: F70, F71, F72, F73, F78, F79, F84, Q90.0, Q90.1, Q90.2, Q90.9).

Missing data: Data linkage was conducted by the National Records of Scotland (NRS). All data provided to us for this study included complete cases only, i.e., no observations were included who had missing or imputed cells for any variable. We included all cases provided from NRS in the analysis apart from the exclusions mentioned above. Any errors in cause of death records such as omission, use of abbreviations, or ambiguous deaths were listed as an unknown cause.

Analyses

Information on age, sex, and SIMD was recorded on the Census day, i.e., the 27th March 2011. Explorative statistical analyses including t-tests and χ^2 tests were used to investigate characteristics of adults with intellectual disabilities compared to peers in the general population. Differences in mean age at death were explored using t-tests.

Crude mortality rates per 100,000 were calculated using the censor date/date of death. For indirect standardisation, observed deaths were assumed to be independent and vary with the Poisson distribution. The mortality rates were indirectly standardised for both men and women, using the expected age-specific mortality rates per 1-year age group, using Stata's 'strate' command, to calculate age-SMRs for adults with versus without intellectual disabilities. The 95% CIs were calculated based on the quadratic approximation of the log likelihood. Expected rates were calculated using fixed age and sex-specific rates from the large control population. The SMRs were subsequently calculated stratified by age category (25-34, 35-44, 45-54, 55-64, 65-74 and 75+ years), sex and SIMD.

For all-cause mortality, Kaplan-Meier survival curves were plotted for the study period for both groups and the proportional hazards assumption was tested.

For the underlying causes of death and all contributing factors in death, the total numbers of deaths in each ICD-10 chapter were collated. We then collated the number of deaths for the top 20 most commonly recorded underlying causes and all contributing factors in death. For cause-specific SMRs, indirect sex-standardisation was also performed (using 10-year age bands). The rates and age-standardised SMRs for avoidable, treatable, and preventable mortality were calculated using robust errors.

Cox proportional hazard models were fitted to the data to calculate risks of mortality (all-cause, avoidable, treatable, preventable) unadjusted and adjusted for age, sex, and SIMD. For categories which had fewer than 10 deaths, no calculation was attempted due to lack of reliability. Furthermore, in keeping with the Office of National Statistics mortality methodology, all mortality rates between 10 and 20 deaths were labelled as unreliable.[8] Two researchers (D.N. and E.R.) carried out the main analyses. All analyses were conducted in Stata version 17.

Results

The study cohort included 14,477 adults with intellectual disabilities aged 25+ and 506,207 adults without intellectual disabilities nor autism aged 25+, following exclusion of 71 individuals with a record of death before or on the date of the Census and exclusion of 51 cases without intellectual disabilities or autism who died during the study but had their cause of death recorded as a form of intellectual disability/autism.

Demographic information

Table 1 presents demographic information on the population of adults with and without intellectual disabilities, at the time of Scotland's Census, 2011. Compared with their peers, adults with intellectual disabilities had a higher proportion of men (n=7,927, 54.8% vs. n=238,036, 47.0%; p<0.001), were more likely to be living in more deprived neighbourhoods (p<0.001) and were overall younger (p<0.001).

All-cause mortality

Crude mortality: The study period (27th March 2011 – 31st December 2019) resulted in the equivalent of 4,272,853 person years of follow up. This included 113,044 person years contributed by the intellectual disabilities population and 4,159,809 person years for the population without intellectual disabilities. The median age at death for adults with intellectual disabilities was younger at 65 years (SD=14.1, IQR=56.0-76.0) compared with 80 years (SD=12.9, IQR=71.0-87.0) for adults without intellectual disabilities.

Of the 14,477 adults with intellectual disabilities 3,429 (23.7%) died during the 8.5 years of follow up. In the population without intellectual disabilities, 69,641/506,207 (13.8%) adults died during the same follow up period. Crude mortality over the study period was 3033.3 (95% CI 2933.5-3136.6) per 100,000 person years of follow up (Supplemental Table 1) among adults with intellectual disabilities, and 1674.1 (95% CI 1661.8-1686.6) per 100,000 for adults without intellectual disabilities (Supplemental Table 2). The proportional hazards assumption was visually assessed and met. Kaplan-Meier survival curves for the overall time period were run (Supplemental Figure 1).

Standardised mortality ratios (SMRs):

For all-cause mortality, compared with adults without intellectual disabilities, the age-standardised SMR in the population with intellectual disabilities was 3.1 (95% CI 3.0-3.2). The sex-standardised SMR was 1.8 (95% CI 1.7-1.9) and SIMD-standardised SMR was 1.7 (95% CI 1.6-1.7) (Table 2).

The age-stratified SMR was highest in the youngest age group (25-34 years old) at 6.4 (95% CI 5.5-7.5) and gradually decreased with age, with the lowest SMR recorded for the oldest age group of 75+ year old at 1.6 (95% CI 1.5-1.8). The sex-stratified SMR was higher for women (SMR 2.0, 95% CI 1.9-2.1) than men (SMR1.7, 95% CI 1.6-1.8). SMR was also highest in the most affluent areas (SMR=2.5, 95% CI 2.2-2.7) and gradually decreased with rising deprivation level, with SMR in the most deprived areas recorded at 1.4 (95% CI 1.3-1.5).

Cause-specific mortality

Table 3 reports the crude mortality rates for underlying causes of death and all contributing causes of death by ICD-10 chapters.

Underlying cause of death: The most common underlying causes of death in the adults with intellectual disabilities were: diseases of the circulatory system (n=692; Crude Mortality Rate (CMR)=612.2, 95% CI 568.2-659.5); neoplasms (n=489; CMR=432.6, 95% CI 395.9-472.7) diseases of the respiratory system (n=484, CMR=428.2, 95% CI 391.7-468.0), and diseases of the nervous system (n=442; CMR=391.0, 95% CI 356.2-429.2). In the control group without intellectual disabilities, the most common underlying causes of death were: neoplasms (n=20,667; CMR=496.8, 95% CI 490.1-503.6); diseases of the circulatory system (n=19,093; CMR=459.0, 95% CI 452.5-465.5), diseases of the respiratory system (n=8,716; CMR=209.5, 95% CI 205.2-214.0), then mental and behavioural disorders (n=5,084; CMR=122.2, 95% CI 118.9-125.6).

All contributing factors in death: In the group with intellectual disabilities, the most common all contributing factors in death were: diseases of the respiratory system (n=1,616; CMR=1,429.5, 95% CI 1,361.5-1,501.0); diseases of the circulatory system (n=1,271; CMR=1,124.3, 95% CI 1,064.2-1,187.9); mental and behavioural disorders (n=944; CMR=835.1, 95% CI 783.5-890.1) and diseases of the nervous system (n=943; CMR=834.2, 95% CI 782.6-889.2). In the control group without intellectual disabilities, the most common were diseases of the circulatory system (n=35,223; CMR=846.7, 95% CI 837.9-855.6), the respiratory system (N=24,834; CMR=597.0, 95% CI 589.6-604.5), and neoplasms (n=23,717; CMR=570.1, 95% CI 562.9-577.4).

Most common causes of death: Table 4 reports the most common individual underlying causes and all contributing factors. Based on pre-specified groupings of specific ICD-10 codes, among adults with intellectual disabilities the most commonly recorded underlying causes of death were Down syndrome, dementia and acute myocardial infarction. For all

contributing factors in death, pneumonia due to organism unspecified, Down syndrome and pneumonitis due to solids and liquids were the most commonly recorded. In the population of adults without intellectual disabilities, the most commonly recorded underlying causes of death were malignant neoplasm of bronchus or lung, acute myocardial infarction and dementia. For all contributing factors in death, chronic ischemic heart disease, pneumonia due to organism unspecified and other chronic obstructive pulmonary disease were most commonly recorded.

Avoidable mortality

Incidence: Of the 3,429 deaths recorded for the population of adults with intellectual disabilities 1,087 (31.7%) were considered avoidable. Of all deaths, 722 (21.1%) were treatable and 681 (19.9%) were preventable. In the population of adults without intellectual disabilities, 12,673 (18.2%) of the 69,641 deaths were considered avoidable; 6,110 (8.8%) treatable and 10,207 (14.7%) preventable (Table 5).

Crude avoidable mortality in adults with intellectual disabilities was 1,061.4 (95% CI 1,000.1-1126.4) per 100,000 person years of follow up and 375.9 (95% CI 369.4-382.5) for adults without intellectual disabilities. Treatable mortality in the intellectual disabilities group was 705.0 (95% CI 655.4-758.3) per 100,000 person years of follow up and 181.2 (95% CI 176.7-185.8) for adults without intellectual disabilities. Preventable mortality for the intellectual disabilities cohort was 665.0 (95% CI 616.9-716.8) per 100,000 person years of follow up and 302.8 (95% CI 296.9-308.7) for adults without intellectual disabilities. Further details are provided in Supplemental Tables 1 and 2.

Standardised mortality ratios: Table 2 shows that SMRs for individual age groups were highest in the youngest age groups, for all avoidable deaths as well as for treatable and preventable mortality. SMRs for avoidable, treatable and preventable deaths were higher for females (avoidable: 3.5, 95% CI 3.2-3.8; treatable: 4.7, 95% CI 4.2-5.3; preventable: 2.7, 95% CI 2.4-3.1) than males (avoidable: 2.4, 95% CI 2.2-2.6; treatable: 3.3, 95% CI 3.0-3.6; preventable: 1.8, 95% CI 1.7-2.0). There was a gradient of increasing SMRs for avoidable, treatable and preventable mortality as the extent of the neighbourhood deprivation decreased.

Table 5 reports underlying cause of death with the Cox proportional hazards, unadjusted (HR) and adjusted for age, sex and SIMD (aHR). For all deaths: HR=3.3 (95% CI 3.2-3.4) and aHR=3.0 (95% CI 2.9-3.1). For avoidable deaths: HR=3.3 (95% CI 3.1-3.6), treatable deaths: HR=4.7 (4.3-5.0) and preventable deaths: HR=2.6 (2.4-2.8), and aHRs were: avoidable deaths: aHR=2.7 (95% CI 2.5-2.9), treatable deaths: aHR=3.9 (95% CI 3.6-4.2) and preventable deaths: aHR=2.0 (95% CI 1.9-2.2) (Table 5).

Discussion

Summary of principal findings

For all-cause mortality, compared with adults without intellectual disabilities, the age-standardised SMR in the population with intellectual disabilities was 3.1. The SMRs were higher for the youngest age groups, women and in the most affluent areas. This gradient in increase in the SMRs in more affluent neighbourhoods is likely caused by the difference in the general population across extent of neighbourhood deprivation, rather than a difference across neighbourhoods in the population with intellectual disabilities, i.e., the general population experience higher rates of deaths in the more deprived areas whereas for adults with intellectual disabilities this trend is not as pronounced. Adults with intellectual disabilities also died younger than adults without intellectual disabilities (median age at death: 65.0 years vs. 80.0 years).

Avoidable deaths were substantially more common in people with intellectual disabilities than other people; particularly due to deaths from conditions that could have been treated by high quality care. Our paper is novel in investigating avoidable deaths in detail, including reporting SMRs for avoidable, treatable, and preventable deaths by the socio-demographic features of age, sex, and extent of neighbourhood deprivation. SMRs for avoidable deaths ranged from 4.2 to 2.0, being higher at younger age groups, in women, and the more affluent the neighbourhood.

For those with intellectual disabilities, the most common underlying causes of death were diseases of the circulatory system, neoplasms, diseases of the respiratory system and diseases of the nervous system, with fairly similar rates between each. This differs from the controls, where neoplasms were markedly more common, followed by diseases of the circulatory system, and then, though much less common, diseases of the respiratory system and mental and behavioural disorders. All contributing factors in death for adults with intellectual disabilities were most commonly diseases of the respiratory system, followed by diseases of the circulatory system, and equally mental and behavioural disorders and diseases of the nervous system. In the control group, the most common all contributing factors in death were diseases of the circulatory system by far. Sex-standardised SMRs for underlying causes of deaths ranged from 259.5 (congenital malformations, deformations and chromosomal abnormalities) to 1.4 (neoplasms). For all contributing factors in deaths, the range was 238.3 (congenital malformations, deformations and chromosomal abnormalities) to 1.4 (neoplasms).

Comparison with existing literature

We are aware of only three studies on avoidable mortality in adults with intellectual disabilities. These covered shorter periods of time and/or included smaller sample sizes, limiting opportunities for comparison.[2,4,6] We report that 31.7% of deaths of adults with intellectual disabilities were avoidable, compared to 46.3%,[4] 38.9%[2] and 31.0%[6]. Compared to the general population, we found much higher rates of avoidable (SMR=3.2), treatable (SMR=4.5), and preventable (SMR=2.5) deaths. The Incidence Rate Ratio (IRR) for avoidable deaths reported by Trollor et al.[6], whilst raised, showed a much lesser difference than in our study (IRR 1.47; 95% CI 1.54 to 1.99; p<0.001). Hosking et al.[4] reported hazard ratios that were more similar to our findings: avoidable (3.44), treatable (5.86), and preventable (1.69) deaths. Cooper et al.[2] did not calculate comparisons with the general population. We are not aware of any previous studies that have reported on avoidable, treatable, and preventable mortality in relation to socio-demographic factors such as age, sex, or neighbourhood deprivation with which we can compare our findings.

The high rate of SMR (3.1) we report for all-cause mortality is consistent with previous literature, as is the higher SMR in females, and at younger ages. However, we are not aware of previous studies of SMR in adults with intellectual disabilities in relation to the extent of neighbourhood deprivation. One Australian study reported contrary results to ours and other studies, with regards to the sex, and age findings.[6]

Few studies have reported causes of death by ICD-10 chapter, and reports are contradictory. By ICD-10 chapter, we found the most common underlying causes of death to be diseases of the circulatory system, neoplasms, diseases of the respiratory system and diseases of the nervous system, similarly to the report by Cooper et al.[2] whilst others reported the most common to be circulatory,[4] vascular,[19] heart disease,[20] and jointly circulatory and neoplasm[6]. With regard to findings from the analysis of pre-specified groupings of specific ICD-10 codes, we have found that Down syndrome was the most commonly recorded cause of death for adults with intellectual disabilities. This suggests that there may still exist prevailing uncertainty in relation to underlying causes of death in people with intellectual disabilities and there is continued conflation of disability and health among attending medical practitioners responsible for recording causes of death in Scotland.[21]

Implications for policy and practice

The higher risk of all-cause, avoidable, treatable, and preventable mortality, and earlier age at death for adults with intellectual disabilities than their peers without intellectual disabilities demonstrates a clear need for improvements in the early detection, prevention, care and

treatment of health problems experienced by people with intellectual disabilities. This is essential at all ages, and for people living in all areas; more so than for the general population, these are not issues related to older age nor neighbourhood deprivation. Recording of Down syndrome as a cause of death in adults with intellectual disabilities is still common among attending medical practitioners in Scotland. It is, therefore, crucial that we better understand how individual health conditions impact on the health and mortality of adults with intellectual disabilities. Research efforts should be directed particularly towards the management of epilepsy and pneumonia to reduce premature mortality due to the diseases of the nervous and respiratory systems, which are one of the leading causes of death in this population. Our findings on mortality caused by cardiovascular diseases and neoplasms in adults with intellectual disabilities also suggest that public health interventions aimed at circulatory diseases and cancer screening may need appropriate adaptation and tailoring for this population. Clinical and health training initiatives should be introduced across all age groups and all neighbourhoods, given that our findings suggest that mortality risk is highest in the most affluent areas for adults with intellectual disabilities.

Strengths and Limitations

A major strength of this study is that it includes a whole country population of adults with intellectual disabilities and a representative proportion of people in the general population, with a high response rate of 94% for Scotland's Census 2011,[16] thereby reducing the study bias. Whether each individual had intellectual disabilities was enquired about, and intellectual disabilities was specifically distinguished from specific learning disabilities, and from autism. Prior to the Census, these questions were field tested, to check their utility and acceptability, using cognitive question testing with 70 respondents on the whole questionnaire, and 102 respondents specifically on the health questions. Additionally, the prevalence of intellectual disabilities in the Census data (0.5%) is the same as that found in Scottish GP registers, and in other large data sources, which have been used to identify adults with intellectual disabilities.[22]

Limitations include the fact that the Census data do not specify whether a record of intellectual disabilities was reported by a person with intellectual disabilities or their proxy (e.g., a parent/carer, spouse etc.). Moreover, respondents reported whether or not each person was known to have intellectual disabilities rather than each person having an assessment for intellectual disabilities, so some reporting error is possible. Further, our death data was taken from death certificates, and not verified at post-mortem. The death certificates will have been completed by numerous clinicians, and there may be some error in reporting, including between underlying causes and all contributing factors in death, but such error in reporting

mostly poses limitations only when investigating more granular outcomes. Some data repression was necessary where very small numbers were identified to mitigate the risk of disclosure. In keeping with the ONS methodology for investigating avoidable mortality,[8] all crude mortality rates per 100,000 people based on fewer than 20 deaths were labelled as unreliable to warn users of their low reliability. It is also important to note that the ONS list of avoidable deaths is based on general population data and is, therefore, possibly an underestimate of avoidable deaths in the population with intellectual disabilities due to differing health and death profiles.

Given the strengths of the study, we believe the results will be generalisable to other high-income countries, as well as filling a significant gap in existing research on avoidable mortality in adults with intellectual disabilities, and contradictory reports on causes of death. However, this needs to be determined by replication of our findings.

Acknowledgements: We would like to acknowledge the support of the eDRIS Team (Public Health Scotland), particularly David Clark, for their involvement in obtaining approvals, provisioning and linking data, and for the use of the secure analytical platform within the National Safe Haven.

Contributors: DN and ER analysed the data and interpreted findings. ER wrote the first draft of the manuscript. S-AC developed the record linkage, conceived the study, analysed and interpreted the data and contributed to the manuscript. CM, AH, and DK conceived the study, analysed and interpreted the data and contributed to the manuscript. DN, LH, MF, DM, KD, LW, FS, FB, JM, J-DS, B-DJ, MT, GW and JP interpreted findings and contributed to the manuscript. All authors approved the final version of the manuscript. DK is the guarantor for the study.

Funding: This work was supported by the UK Medical Research Council, grant number: MC_PC_17217), Baily Thomas Charitable Fund and the Scottish Government via the XXXXXX.

Disclaimer: The funders had no role in the study design, collection, analyses or interpretation of data, writing the report nor the decision to submit the article for publication.

Competing interests: None declared.

Ethics approval: NHS Scotland Public Benefit and Privacy Panel for Health and Social Care (reference: 1819-0051), Scottish Government's Statistics Public Benefit and Privacy Panel (reference: 1819-0051), and the University of Glasgow's College of Medical, Veterinary, and Life Sciences Ethical Committee (reference: 200180081).

Data availability statement: No data are available. This study linked patient information held across several administrative health datasets within Information Services Division (ISD) of NHS National Services Scotland (NSS), with data externally held by the Scottish Government (Scotland's Census 2011) and National Records of Scotland (Statutory Register of Deaths). Linkage and de-identification of data was performed by ISD. A data processing agreement between NHS NSS and University of Glasgow and a data sharing agreement between the Scottish Government and University of Glasgow were drafted. University of Glasgow was authorised to receive record-linked data controlled and held by ISD within NSS, via access through the National Safe Haven. The ISD Statistical Disclosure Control Protocol was followed in all described processes.

References:

1. O'Leary L, Hughes-McCormack L, Dunn K, Cooper S-A. Early death and causes of death of people with Down syndrome: A systematic review. J Appl Res Intellect Disabil [Internet]. 2018;31(5):687–708. Available from: http://dx.doi.org/10.1111/jar.12446
2. Cooper S-A, 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 [Internet]. 2020;10(5):e036465. Available from: http://dx.doi.org/10.1136/bmjopen-2019-036465
3. Tyrer F, McGrother C. Cause-specific mortality and death certificate reporting in adults with moderate to profound intellectual disability. J Intellect Disabil Res [Internet]. 2009;53(11):898–904. Available from: http://dx.doi.org/10.1111/j.1365-2788.2009.01201.x
4. 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 [Internet]. 2016;106(8):1483–90. Available from: http://dx.doi.org/10.2105/AJPH.2016.303240
5. Lauer E, Grossman G, Oxx S, Trafton W, Russell K, 2012 & 2013 Mortality Report. Commonwealth of Massachusetts Executive Office of health & Human Services. Department of Developmental Services. Centre for Developmental Disabilities Evaluation and Research (CDDER). 2014. Available from: https://www.mass.gov/doc/2012-2013-mortality-report/download.
6. Trollor J, Srasuebkul P, Xu H, Howlett S. Cause of death and potentially avoidable deaths in Australian adults with intellectual disability using retrospective linked data. BMJ Open [Internet]. 2017;7(2):e013489. Available from: http://dx.doi.org/10.1136/bmjopen-2016-013489
7. Brameld K, Spilsbury K, Rosenwax L, Leonard H, Semmens J. Use of health services in the last year of life and cause of death in people with intellectual disability: a retrospective matched cohort study. BMJ Open [Internet]. 2018;8(2):e020268. Available from: http://dx.doi.org/10.1136/bmjopen-2017-020268
8. Office for National Statistics (ONS). Avoidable mortality in the UK. Quality and methodology information. 2022. Available from: https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/causesofdeath/methodologies/avoidablemortalityinenglandandwalesqmi
9. Office for National Statistics (ONS). Consultation response: review of avoidable mortality definition. 2016. Available from: https://www.ons.gov.uk/aboutus/whatwedo/statistics/consultationsandsurveys/allconsultationsandsurveys/reviewofavoidablemortalitydefinition
10. 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 [Internet]. 2014;383(9920):889–95. Available from: http://dx.doi.org/10.1016/S0140-6736(13)62026-7
11. Glover G, Williams R, Heslop P, Oyinlola J, Grey J. Mortality in people with intellectual disabilities in England. J Intellect Disabil Res [Internet]. 2017;61(1):62–74. Available from: http://dx.doi.org/10.1111/jir.12314
12. Lin E, Lunsky Y, Chung H, Durbin A, Volpe T, Dobranowski K, Benadict M B, Balogh R. Amenable deaths among adults with intellectual and developmental disabilities including Down syndrome: An Ontario population-based cohort study. J Appl Res Intellect Disabil [Internet]. 2023;36(1):165–175. Available from: https://doi.org/10.1111/jar.13047

13. Stankiewicz E, Ouellette-Kuntz H, McIsaac M, Shooshtari S, Balogh R. Patterns of mortality among adults with intellectual and developmental disabilities in Ontario. Can J Public Health [Internet]. 2018;109(5/6):866–872. Available from: https://doi.org/10.17269/s41997-018-0124-8
14. Shooshtari S, Ouellette-Kuntz H, Balogh R, McIsaac M, Stankiewicz E, Dik N, Burchill C. Patterns of mortality among adults with intellectual and developmental disabilities in the Canadian province of Manitoba. J Policy Pract Intellect Disabil [Internet]. 2020;17(3), 270–278. Available from: https://doi.org/10.1111/jppi.12346
15. Cooper S-A, Henderson A, Kinnear D, Mackay D, Fleming M, Smith GS, et al. Cohort profile: Scotland's record-linkage e-cohorts of people with intellectual disabilities, and autistic people (SCIDA). BMJ Open [Internet]. 2022;12(5):e057230. Available from: http://dx.doi.org/10.1136/bmjopen-2021-057230
16. National Records of Scotland (NRS). 2011 Census Release 1C - How the 2011 Census population estimates were obtained. Edinburgh: National Records of Scotland. 2013.
17. World Health Organization (WHO). International Statistical Classification of Diseases and Related Health Problems, 10th revision. Geneva: World Health Organization. 1992.
18. World Health Organization (WHO). International Statistical Classification of Diseases and Related Health Problems, 10th revision. 2010; Volume 2. Instruction manual. Available from: https://icd.who.int/browse10/Content/statichtml/ICD10Volume2_en_2010.pdf
19. Patja K, Mölsä P, Livanainen M. Cause-specific mortality of people with intellectual disability in a population-based, 35-year follow-up study: Cause-specific mortality. J Intellect Disabil Res [Internet]. 2001;45(1):30–40. Available from: http://dx.doi.org/10.1111/j.1365-2788.2001.00290.x
20. Arvio M, Salokivi T, Tiitinen A, Haataja L. Mortality in individuals with intellectual disabilities in Finland. Brain Behav [Internet]. 2016;6(2):e00431. Available from: http://dx.doi.org/10.1002/brb3.431
21. Landes SD, Turk MA, Finan JM. Factors associated with the reporting of Down syndrome as the underlying cause of death on US death certificates. J Intellect Disabil Res [Internet]. 2022;66(5):454–70. Available from: http://dx.doi.org/10.1111/jir.12926
22. Cooper S-A, Henderson A, Jacobs M, Smiley E. What Are Learning Disabilities? How Common Are Learning Disabilities? Scottish Learning Disabilities Observatory. 2016. Available from: https://www.sldo.ac.uk/media/1610/what-are-learning-disabilities-how-common-are-learning-disabilities.pdf

Table 1. Demographic information in 2011* for adults with and without intellectual disabilities

Demographic information*	Intellectual disabilities	Controls	P value †
Total, n (person-years)	14,477 (113,043.63)	506,207 (415,9808.6)	
Male sex, n (%)	7,927 (54.8%)	238,036 (47.0%)	<0.001
Co-occurring Autism			
Total n (%)	1,631 (11.3%)	-	
Male sex n (%)	1,017 (7.0%)	-	
Age, n (%) at time of Census			
25-34	2,974 (20.5%)	83,868 (16.6%)	<0.001
35-44	3,276 (22.6%)	97,881 (19.3%)	
45-54	3,663 (25.3%)	108,048 (21.3%)	
55-64	2,493 (17.2%)	92,693 (18.3%)	
65-74	1,330 (9.2%)	67,519 (13.3%)	
75+	741 (5.1%)	56,198 (11.1%)	
SIMD quintile, n (%) at time of Census			
1 (most deprived)	4,226 (29.2%)	91,378 (18.1%)	<0.001
2	3,781 (26.1%)	98,114 (19.4%)	
3	2,950 (20.4%)	104,062 (20.6%)	
4	2,209 (15.3%)	108,765 (21.5%)	
5 (least deprived)	1,311 (9.1%)	103,888 (20.5%)	
Deaths, crude rate per 100,000 (CI)**	3033.342 (2933.494-3136.588)	1674.140 (1661.752-1686.62)	

*Data taken from time of Census
**58 individuals aged 25+ had a record of death which occurred before the date of the Census and 13 individuals died on the day of the Census; both groups were removed
51 cases without intellectual disabilities or autism died during the study but had their cause of death recorded as a form of intellectual disability/autism and were subsequently removed from the study
† X^2 test for intellectual disabilities compared with control group (For age and SIMD, X^2 test was performed across all categories, overall *p* value)
Abbreviations: CI=Confidence interval; SIMD=Scottish Index of Multiple Deprivation

Table 2. Standardised Mortality Ratios (SMRs) for adults with intellectual disabilities compared to controls for age, sex, and deprivation (SIMD)

Demographic variables	All deaths SMR (95% CI)	Avoidable deaths SMR (95% CI)	Treatable deaths SMR (95% CI)	Preventable deaths SMR (95% CI)
Age				
Overall Age-SMR	3.130 (3.027-3.236)	3.227 (3.041-3.425)	4.490 (4.174-4.829)	2.511 (2.329-2.707)
25-34	6.400 (5.489-7.462)	4.196 (3.351-5.254)	8.685 (6.463-11.67)	2.781 (2.069-3.737)
35-44	5.139 (4.589-5.755)	3.818 (3.267-4.463)	5.676 (4.675-6.890)	2.540 (2.051-3.145)
45-54	5.299 (4.931-5.695)	3.414 (3.070-3.795)	4.480 (3.926-5.111)	2.715 (2.375-3.103)
55-64	4.143 (3.882-4.422)	3.015 (2.753-3.301)	4.214 (3.780-4.698)	2.422 (2.164-2.710)
65-74	2.522 (2.344-2.713)	1.980 (1.474-2.661)	2.652 (1.854-3.793)	1.946 (1.397-2.711)
75+	1.632 (1.506-1.767)	-	-	-
Sex				
Overall Sex-SMR	1.808 (1.748-1.869)	2.734 (2.576-2.901)	3.796 (3.529-4.083)	2.095 (1.943-2.258)
Male	1.682 (1.605-1.762)	2.362 (2.183-2.555)	3.269 (2.962-3.608)	1.822 (1.655-2.005)
Female	1.967 (1.875-2.065)	3.453 (3.153-3.780)	4.714 (4.229-5.255)	2.745 (2.433-3.097)
SIMD				
Overall SIMD-SMR	1.688 (1.632-1.745)	2.446 (2.305-2.596)	3.451 (3.209-3.713)	1.878 (1.743-2.025)
1 (most deprived)	1.380 (1.296-1.470)	1.850 (1.664-2.057)	2.565 (2.242-2.933)	1.462 (1.283-1.666)
2	1.587 (1.487-1.693)	2.488 (2.223-2.784)	3.573 (3.114-4.100)	1.889 (1.638-2.179)
3	1.907 (1.773-2.052)	3.075 (2.703-3.500)	4.172 (3.562-4.886)	2.354 (1.996-2.777)
4	2.031 (1.863-2.215)	2.941 (2.471-3.499)	4.298 (3.511-5.261)	2.316 (1.855-2.892)
5 (least deprived)	2.459 (2.206-2.741)	4.356 (3.517-5.395)	5.501 (4.253-7.116)	3.271 (2.458-4.354)

Abbreviations:
SMR=Standardised Mortality Ratio; CI=confidence interval

Table 3. Crude mortality rates per 100,000 person-years and standardised mortality ratios for underlying causes of death and all contributing factors in death by ICD-10 chapters for adults aged 25+ with and without intellectual disabilities

ICD-10 Chapter	Underlying cause of death						
	Intellectual disabilities		Controls		SMR (95% CI)		
	N (%)	CMR (95% CI)	N (%)	CMR (95% CI)	All	Men	Women
Ch. 1. Certain infectious and parasite diseases	53 (1.5%)	46.885 (35.819-61.369)	838 (1.2%)	20.145 (18.826-21.556)	4.144 (3.166-5.425)	4.434 (3.100-6.341)	3.728 (2.477-5.610)
Ch. 2. Neoplasms	489 (14.3%)	432.576 (395.886-472.667)	20,667 (29.7%)	496.826 (490.098-503.616)	1.366 (1.250-1.492)	1.234 (1.090-1.396)	1.510 (1.330-1.714)
Ch. 3. Diseases of the blood, blood-forming organs and immune mechanism	<10	-	135 (0.2%)	3.245 (2.742-3.842)	-	-	-
Ch. 4. Endocrine, nutritional and metabolic diseases	90 (2.6%)	79.615 (64.755-97.886)	1,389 (2.0%)	33.391 (31.680-35.194)	3.149 (1.501-6.605)	3.573 (2.715-4.701)	3.919 (2.863-5.364)
Ch. 5. Mental and behavioural disorders	243 (7.1%)	214.961 (189.564-243.761)	5,084 (7.3%)	122.217 (118.903-125.623)	3.919 (3.456-4.444)	3.961 (3.283-4.778)	3.833 (3.236-4.540)
Ch. 6. Diseases of the nervous system	442 (12.9%)	390.999 (356.196-429.204)	3981 (5.7%)	95.702 (92.774-98.721)	7.771 (7.080-8.531)	7.580 (6.631-8.664)	7.842 (6.885-8.931)
Ch. 7. Diseases of the eye and adnexa	<5	-	<5	-	-	-	-
Ch. 8. Diseases of the ear and mastoid process	<5	-	<5	-	-	-	-
Ch. 9. Diseases of the circulatory system	692 (20.2%)	612.1530 (568.201-659.505)	19093 (27.4%)	458.987 (452.523-465.544)	2.455 (2.278-2.645)	2.220 (2.006-2.456)	2.634 (2.360-2.941)
Ch. 10. Diseases of the respiratory system	484 (14.1%)	428.153 (391.659-468.048)	8716 (12.5%)	209.529 (205.176-213.984)	3.930 (3.595-4.296)	4.095 (3.628-4.622)	3.696 (3.240-4.215)
Ch. 11. Diseases of the digestive system	166 (4.8%)	146.846 (126.124-170.973)	3616 (5.2%)	86.927 (84.139-89.807)	2.548 (2.188-2.967)	2.328 (1.889-2.869)	2.732 (2.189-3.411)
Ch. 12. Diseases of the skin and subcutaneous tissue	12 (0.3%)[u]	10.615 (6.029-18.692)[u]	226 (0.3%)	5.433 (4.769-6.190)	3.483 (1.978-6.133)[u]	-	-
Ch. 13. Diseases of the musculoskeletal system and connective tissue	22 (0.6%)	19.461 (12.814-29.557)	449 (0.6%)	10.794 (9.840-11.840)	3.152 (2.075-4.787)	4.086 (2.263-7.378)[u]	2.631 (1.457-4.751)[u]
Ch. 14. Diseases of the genitourinary system	98 (2.9%)	86.692 (71.121-105.673)	1364 (2.0%)	32.790 (31.095-34.577)	5.602 (4.595-6.828)	6.460 (4.896-8.523)	4.919 (3.707-6.527)
Ch. 15. Pregnancy, childbirth and puerperium	<5	-	<5	-	-	-	-
Ch. 16. Certain conditions originating in the perinatal period	<5	-	<5	-	-	-	
Ch. 17. Congenital malformations, deformations and chromosomal abnormalities	426 (12.4%)	376.846 (342.707-414.385)	65 (0.1%)	1.563 (1.225-1.993)	259.5 (236.0-285.4)	224.4 (196.9-255.8)	306.5 (267.0-351.8)
Ch. 18. Symptoms, signs and abnormal clinical and laboratory findings	56 (1.6%)	49.538 (38.124-64.371)	936 (1.3%)	22.501 (21.105-23.990)	3.110 (2.393-4.041)	2.240 (1.488-3.370)	4.002 (2.845-5.629)
Ch. 19. Injury, poisoning and certain other consequences of external causes	<5	-	<5	-	-	-	-
Ch. 20. External causes of morbidity and mortality	115 (3.4%)	101.731 (84.738-122.131)	2,571 (3.7%)	61.806 (59.462-64.242)	2.118 (1.764-2.543)	1.719 (1.353-2.185)	2.636 (1.986-3.498)
Unknown cause of death or error in underlying cause of death code	<5	-	<5	-	-	-	-

Total number of deaths	3,429 (100%)	3033.342 (2933.494-3136.588)	69,641 (100%)	1674.140 (1661.752-1686.62)	3.130 (3.027-3.236)	2.882 (2.751-3.019)	3.329 (3.172-3.494)
ICD-10 Chapter	All contributing factors in death						
	Intellectual disabilities		Controls		SMR (95% CI)		
	N	CMR (95% CI)	N	CMR (95% CI)	All	Men	Women
Ch. 1. Certain infectious and parasite diseases	241 (7.0%)	213.192 (187.906-241.881)	3,774 (5.4%)	90.725 (87.877-93.667)	3.929 (3.463-4.457)	3.848 (3.242-4.567)	3.915 (3.248-4.719)
Ch. 2. Neoplasms	572 (16.7%)	505.999 (466.186-549.213)	23,717 (34.1%)	570.146 (562.936-577.48)	1.422 (1.310-1.544)	1.298 (1.159-1.454)	1.554 (1.380-1.750)
Ch. 3. Diseases of the blood, blood-forming organs and immune mechanism	33 (1.0%)	29.192 (20.754-41.062)	1,001 (1.4%)	24.064 (22.618-25.601)	2.151 (1.529-3.025)	1.566 (0.909-2.696)[u]	2.783 (1.796-4.314)[u]
Ch. 4. Endocrine, nutritional and metabolic diseases	467 (13.6%)	413.115 (377.296-452.335)	8,672 (12.5%)	208.471 (204.129-212.95)	3.327 (3.039-3.643)	2.706 (2.381-3.076)	4.071 (3.581-4.629)
Ch. 5. Mental and behavioural disorders	944 (27.5%)	835.076 (783.469-890.082)	10,899 (15.7%)	262.007 (257.134-266.93)	6.330 (5.939-6.747)	6.151 (5.625-6.726)	6.281 (5.734-6.880)
Ch. 6. Diseases of the nervous system	943 (27.5%)	834.191 (782.612-889.170)	7,266 (10.4%)	174.672 (170.701-178.74)	8.890 (8.341-9.476)	8.473 (7.747-9.267)	9.112 (8.319-9.980)
Ch. 7. Diseases of the eye and adnexa	<5	-	41 (0.06%)	0.986 (0.726-1.33)	-	-	-
Ch. 8. Diseases of the ear and mastoid process	<5	-	11 (0.02%)	0.264 (0.146-0.47)	-	-	-
Ch. 9. Diseases of the circulatory system	1,271 (37.1%)	1124.345 (1064.201-1187.888)	35,223 (50.6%)	846.746 (837.948-855.635)	2.459 (2.328-2.598)	2.231 (2.069-2.406)	2.644 (2.440-2.865)
Ch. 10. Diseases of the respiratory system	1,616 (47,1%)	1429.537 (1361.51-1500.962)	24,834 (35.7%)	596.999 (589.620-604.41)	4.506 (4.291-4.731)	4.400 (4.118-4.702)	4.506 (4.193-4.842)
Ch. 11. Diseases of the digestive system	288 (8.4%)	254.769 (226.981-285.959)	6,824 (9.8%)	164.046 (160.200-167.95)	2.374 (2.115-2.664)	2.248 (1.926-2.624)	2.440 (2.051-2.904)
Ch. 12. Diseases of the skin and subcutaneous tissue	46 (1.3%)	40.692 (30.480-54.327)	727 (1.0%)	17.477 (16.251-18.795)	4.173 (3.126-5.572)	3.857 (2.515-5.916)	4.443 (3.002-6.575)
Ch. 13. Diseases of the musculoskeletal system and connective tissue	62 (1.8%)	54.846 (42.761-70.347)	1,791 (2.6%)	43.055 (41.106-45.096)	2.324 (1.812-2.981)	2.672 (1.845-3.870)	2.143 (1.531-3.000)
Ch. 14. Diseases of the genitourinary system	379 (11.1%)	335.269 (303.159-370.780)	8,911 (12.8%)	214.217 (209.815-218.71)	3.150 (2.848-3.484)	3.261 (2.840-3.744)	2.984 (2.576-3.456)
Ch. 15. Pregnancy, childbirth and puerperium	<5	-	<5	-	-	-	-
Ch. 16. Certain conditions originating in the perinatal period	<5	-	<5	-	-	-	-
Ch. 17. Congenital malformations, deformations and chromosomal abnormalities	742 (21.6%)	656.384 (610.814-705.353)	127 (0.2%)	3.053 (2.566-3.633)	238.3 (221.8-256.1)	207.5 (188.2-228.9)	275.2 (247.5-306.0)
Ch. 18. Symptoms, signs and abnormal clinical and laboratory findings	521 (15.2%)	460.884 (422.961-502.208)	9,745 (14.0%)	234.266 (229.660-238.93)	3.808 (3.494-4.149)	3.784 (3.342-4.284)	3.763 (3.341-4.237)
Ch. 19. Injury, poisoning and certain other consequences of external causes	194 (5.7%)	171.615 (149.088-197.546)	4,068 (5.8%)	97.793 (94.834-100.845)	2.506 (2.177-2.885)	2.309 (1.928-2.766)	2.585 (2.064-3.237)
Ch. 20. External causes of morbidity and mortality	234 (6.8%)	207.000 (182.106-235.296)	4,927 (7.1%)	118.443 (115.182-121.797)	2.565 (2.257-2.916)	2.313 (1.957-2.733)	2.749 (2.251-3.358)
Unknown cause of death or error in underlying cause of death code	<5	-	<5	-	-	-	-
Total number of deaths	3,429 (100%)	3033.342 (2933.494-3136.588)	69,641 (100%)	1674.140 (1661.752-1686.62)	3.130 (3.027-3.236)	2.882 (2.751-3.019)	3.329 (3.172-3.494)

*n<5 repressed due to statistical disclosure; CMR, crude mortality rate – reported for ≥ 10 deaths; ICD-10, International Classification of Diseases, Tenth Revision; CMR rates based on 10-20 deaths labelled “u” for unreliable

Table 4. Most common causes of death in adults with and without intellectual disabilities

	Underlying causes of deaths			
	Intellectual disabilities		Controls	
	Cause (n)	ICD codes	Cause (n)	ICD codes
1	Down Syndrome (n=341)	Q90.0, Q90.1, Q90.2, **Q90.9**	Malignant neoplasm of bronchus and lung (n=5,163)	**C34.0, C34.1, C34.2, C34.3, C34.8, C34.9**
2	Dementia (n=227)	F00.0, F00.1, F00.2, F00.9, **F03, G30.0, G30.1**, G30.8, **G30.9**	Acute myocardial infarction (n=4,907)	I21.0, I21.1, I21.2, I21.3, **I21.4, I21.9**
3	Acute myocardial infarction (n=158)	I21.0, I21.1, I21.2, I21.3, I21.4, **I21.9**	Dementia (n=4,857)	F00.0, F00.1, F00.2, F00.9, **F03, G30.0, G30.1**, G30.8, **G30.9**
4	Pneumonia, organism unspecified (n=150)	J18.0, J18.1, J18.2, J18.8, **J18.9**	Other chronic obstructive pulmonary disease (n=3,720)	**J44.0, J44.1, J44.8, J44.9**
5	Epilepsy (n=137)	G40.0, G40.1, G40.2, G40.3, G40.4, G40.5, **G40.6,** G40.7, G40.8, **G40.9,** G41.0, G41.1, G41.2, G41.8, **G41.9**	Chronic Ischaemic heart disease (n=3,[illegible])	**I25.0, I25.1,** I25.2, **I25.3, I25.4, I25.5**, I25.6, I25.7, **I25.8, I25.9**
6	Pneumonitis due to solids and liquids (n=128)	**J69.0**, J69.1, J69.8	Intracerebral haemorrhage, cerebral infarction, and stroke, not specified as haemorrhage or infarction (n=2,814)	**I61.0, I61.2, I61.3, I61.4, I61.5, I61.6, I61.8, I61.9, I63.0,** I63.1**, I63.2, I63.3, I63.4, I63.5,** I63.6**, I63.8, I63.9, I64**
7	Cerebral palsy (n=123)	**G80.0, G80.1,** G80.2, G80.3, G80.4, **G80.8, G80.9**	Pneumonia, organism unspecified (n=2,[illegible])	**J18.0, J18.1, J18.2,** J18.8, J18.9
8	Intracerebral haemorrhage, cerebral infarction, and stroke, not specified as haemorrhage or infarction (n=111)	**I61.0,** I61.2, I61.3, **I61.4,** I61.5, **I61.6,** I61.8, **I61.9,** I63.0, I63.1, I63.2, **I63.3,** I63.4, **I63.5, I63.6,** I63.8, **I63.9, I64**	Vascular dementia (n=2,136)	F01.0, **F01.1, F01.2, F01.3**, F01.8, **F01.9**
9	Chronic Ischaemic heart disease (n=110)	**I25.0, I25.1,** I25.2, I25.3, I25.4, I25.5, I25.6, I25.7, **I25.8, I25.9**	Malignant neoplasm of breast unspecified (n=1,303)	C50.0, C50.1, C50.2, C50.3, C50.5, C50.6, C50.8, **C50.9**
10	Other chronic obstructive pulmonary disease (n=78)	**J44.0, J44.1, J44.8, J44.9**	Malignant neoplasm of prostate (n=1,287)	**C61**
11	Malignant neoplasm of bronchus and lung (n=67)	**C34.0, C34.1,** C34.2, **C34.3,** C34.8, **C34.9**	Accidents: Other external causes of accidental injury: Falls (n=1,005)	**W19**
12	Vascular dementia (n=61)	F01.0, **F01.1,** F01.2, F01.3, F01.8, **F01.9**	Malignant neoplasm of oesophagus (n=999)	**C15.9**
13	Urinary tract infection (n=48)	**N39.0**	Sequelae of other and unspecified cerebrovascular diseases (n=996)	**I69.8**
14	Other specified respiratory disorders (n=41)	**J98.8**	Malignant neoplasm: pancreas (n=886)	**C25.9**
15	Other ill identified cause of mortality (n=38)	**R99**	Malignant neoplasm: colon (n=728)	**C18.9**
16	Sequelae of other and unspecified cerebrovascular diseases (n=37)	**I69.8**	Urinary tract infection (n=638)	**N39.0**
17	Malignant neoplasm of oesophagus (n=33)	**C15.9**	Malignant neoplasm: bladder (n=628)	**C67.9**
18	Malignant neoplasm of breast (n=30): C50.0, C50.1, C50.2, C50.3, C50.5, C50.6, C50.8, **C50.9** Malignant neoplasm, site unspecified (n=30): **C80**		Malignant neoplasm, site unspecified (n=594)	**C80**
19	Developmental disorder of scholastic skills, unspecified (n=28)	**F81.9**	Other interstitial pulmonary diseases with fibrosis (n=576)	**J84.1**
20	Sepsis, unspecified (n=26)	**A41.9**	Parkinson disease (n=554)	**G20**

	All contributing factors in deaths			
	Intellectual disabilities		Controls	
	Cause (n)	ICD codes	Cause (n)	ICD codes
1	Pneumonia, organism unspecified (n=731)	**J18.0, J18.1, J18.2,** J18.8, **J18.9**	Chronic Ischaemic heart disease (n=12,607)	**I25.0, I25.1,** I25.2, **I25.3, I25.4, I25.5,** I25.6, I25.7, **I25.8, I25.9**
2	Down syndrome (n=593)	Q90.0, Q90.1, Q90.2, **Q90.9**	Pneumonia, organism unspecified (n=8,833)	**J18.0, J18.1, J18.2, J18.8, J18.9**
3	Pneumonitis due to solids and liquids (n=487)	**J69.0,** J69.1, J69.8	Other chronic obstructive pulmonary disease (n=9,012)	**J44.0, J44.1, J44.8, J44.9**
4	Epilepsy (n=412)	G40.0, G40.1, **G40.2, G40.3, G40.4,** G40.5, **G40.6,** G40.7, G40.8, **G40.9,** G41.0, G41.1, G41.2, G41.8, **G41.9**	Dementia (n=8,474)	F00.0, F00.1, F00.2, F00.9, **F03, G30.0, G30.1, G30.8, G30.9**
5	Developmental disorder of scholastic skills, unspecified (n=380)	**F81.9**	Acute myocardial infarction (n=5,968)	**I21.0,** I21.1, I21.2, I21.3, **I21.4, I21.9**
6	Dementia (n=357)	F00.0, F00.1, F00.2, F00.9, **F03, G30.0, G30.1,** G30.8, **G30.9**	Essential primary hypertension (n=5,883)	**I10.0**
7	Chronic ischemic heart disease (n=295)	**I25.0, I25.1,** I25.2, I25.3, I25.4, I25.5, I25.6, I25.7, **I25.8,** I25.9	Malignant neoplasm of bronchus and lung (n=5,727)	**C34.0, C34.1, C34.2, C34.3, C34.8, C34.**9
8	Cerebral Palsy (n=215)	**G80.0, G80.1,** G80.3, G80.4, **G80.8, G80.9**	Other general symptoms and signs (n=5,058)	**R68.8**
9	Acute myocardial infarction (n=202)	I21.0, I21.1, I21.2, I21.3, I21.4, **I21.9**	Intracerebral haemorrhage, cerebral infarction, and stroke, not specified as haemorrhage or infarction (n=4,733)	**I61.0, I61.1, I61.2, I61.3, I61.4, I61.5, I61.6, I61.8, I61.9, I63.0,** I63.1, **I63.2, I63.3, I63.4, I63.5, I63.6, I63.8, I63.9, I64**
10	Diabetes without complications (n=196)	**E11.9**	Diabetes without complications (n=4,485)	**E11.9**
11	Other general symptoms and signs (n=185)	**R68.8**	Vascular dementia (n=3,948)	F01.0, **F01.1, F01.2, F01.3,** F01.8, **F01.9**
12	Intracerebral haemorrhage, cerebral infarction, and stroke, not specified as haemorrhage or infarction (n=178)	**I61.0,** I61.1, I61.2, I61.3, **I61.4, I61.5, I61.6,** I61.8, **I61.9,** I63.0, I63.1, **I63.2, I63.3,** I63.4, **I63.5, I63.6, I63.9, I64**	Pneumonitis due to solids and liquids (n=2,945)	**J69.0,** J69.1, **J69.8**
13	Sepsis, unspecified (n=173)	**A41.9**	Atrial fibrillation and flutter (n=2,734)	**I48**
14	Other chronic obstructive pulmonary disease (n=165)	J44.0, **J44.1, J44.8, J44.9**	Sepsis, unspecified (n=2,522)	**A41.9**
15	Essential primary hypertension (n=130)	**I10**	Age related physical debility (n=2,513)	**R54**
16	Unspecified acute lower respiratory infection (n=127)	**J22**	Congestive Heart Failure (n=2,439)	**I50.0**
17	Urinary tract infection site not specified (n=113)	**N39.0**	Sequelae of other and unspecified cerebrovascular diseases (n=2,346)	**I69.8**
18	Acute renal failure unspecified (n=86)	**N17.9**	Unspecified acute lower respiratory infection (n=2,229)	**J22**
19	Congestive Heart Failure (n=82)	**I50.0**	Atrial fibrillation and atrial flutter, unspecified (n=2,213)	**I48.9**
20	Other respiratory disorders (n=81)	**J98.8**	Acute renal failure, unspecified (n=2,190)	**N17.9**

NB: While all codes included in the ICD-10 groupings are listed above, the highlights in **bold** refer to those codes, which were present in the data.

Table 5. All-cause, avoidable, treatable, and preventable underlying cause of deaths for adults with and without intellectual disabilities

Variable	Deaths in group with intellectual disabilities (N)				Deaths in controls (N)				HR (95% CI)
	All	Avoidable*	Treatable*	Preventable*	All	Avoidable*	Treatable*	Preventable*	†a (All) †b (Avoidable) †c (Treatable) †d (Preventable)
Total	3,429	1,087	722	681	69,641	12,673	6,110	20,207	†a 3.304 (3.192-3.420) **2.978 (2.877-3.084) †b 3.350 (3.148-3.564) **2.701 (2.538-2.876) †c 4.672 (4.325-5.048) **3.903 (3.609-4.220) †d 2.611 (2.416-2.822) **2.042 (1.889-2.208)
Age									
25-34	163	76	44	44	734	522	146	456	†a 3.324 (3.211-3.440) †b 3.351 (3.149-3.565) †c 4.674 (4.326-5.050) †d 2.611 (2.416-2.822)
35-44	300	158	102	84	1,793	1,271	552	1,016	
45-54	740	342	221	215	4,410	3,164	1,558	2,501	
55-64	907	467	325	303	9,369	6,630	3,301	5,355	
65-74	717	44	30	35	17,169	1,086	553	3,879	
75+	602	0	0	0	36,166	0	0	0	
Sex									
Male	1784	619	395	417	33,222	7,413	3,418	9,475	†a 3.259 (3.148-3.373) †b 3.274 (3.077-3.483) †c 4.597 (4.255-4.967) †d 2.522 (2.333-2.726)
Female	1645	468	327	264	36,419	5,260	2,692	10,732	
SIMD									
1 (most deprived)	962	342	213	226	15,469	3,738	1,679	5,125	†a 3.019 (2.916-3.125) †b 2.768 (2.600-2.946) †c 3.970 (3.671-4.292) †d 2.119 (1.960-2.291)
2	908	304	203	189	15,467	2,938	1,366	4,405	
3	721	230	154	141	14,127	2,490	1,229	3,994	
4	512	127	94	78	13,159	2,020	1,023	3,575	
5 (least deprived)	326	84	58	47	11,419	1,487	813	3,108	

*Deaths at age 25-74 only as per the ONS definition of avoidable mortality
Abbreviations: SIMD=Scottish Index of Multiple Deprivation; HR=hazard ratio; CI=confidence interval
†a-d - Cox regression hazard ratio for risk of deaths (all, avoidable, treatable and preventable) by intellectual disabilities versus controls (total column = unadjusted and **adjusted for age, sex and SIMD)
Reference groups: no intellectual disabilities, male, most deprived, age (continuous)

Supplemental Table 1. Crude mortality rates (CMRs) for adults with intellectual disabilities per 100,000 by age, sex, and deprivation (SIMD)

Variable	All deaths CMR (95% CI)	Avoidable deaths CMR (95% CI)	Treatable deaths CMR (95% CI)	Preventable deaths CMR (95% CI)
All deaths	3033.342 (2933.494-3136.588)	1061.407 (1000.147-1126.418)	705.000 (655.407-758.347)	664.966 (616.852-716.832)
Age				
25-34	641.267 (550.006-747.670)	298.996 (238.795-374.373)	173.103 (128.819-232.609)	173.103 (128.819-232.609)
35-44	1082.162 (966.380-1211.815)	569.939 (487.652-666.11)	367.935 (303.033-446.738)	303.005 (244.668-375.253)
45-54	2508.555 (2334.172-2695.966)	1159.359 (1042.774-1288.979)	749.177 (656.638-851.756)	728.837 (637.645-833.071)
55-64	4980.093 (4666.312-5314.974)	2564.171 (2341.845-2807.605)	1784.488 (1600.654-1989.435)	1663.691 (1486.526-1861.971)
65-74	8168.600 (7592.048-8788.937)	2822.336 (2100.319-3792.557)	1924.320 (1345.457-2752.23)	2245.040 (1611.925-3126.823)
75+	17634.187 (16280.32-19100.64)	-	-	-
Sex				
Male	2858.277 (2728.673-2994.036)	1080.500 (998.648-1169.062)	689.495 (624.745-760.957)	727.898 (661.282-801.224)
Female	3249.165 (3095.885-3410.034)	1037.165 (947.329-1135.519)	724.686 (650.247-807.646)	585.067 (518.583-660.076)
SIMD				
1 (most deprived)	2889.038 (2712.123-3077.493)	1128.080 (1014.64-1254.202)	702.576 (614.285-803.557)	745.456 (654.336-849.265)
2	3075.061 (2881.414-3281.722)	1136.144 (1015.345-1271.315)	758.675 (661.17-870.589)	706.353 (612.500-814.587)
3	3148.364 (2926.743-3386.768)	1107.029 (972.820-1259.754)	741.228 (632.937-868.048)	678.657 (575.395-800.451)
4	2965.524 (2719.464-3233.848)	818.743 (688.044-974.271)	605.999 (495.082-741.766)	502.850 (402.772-627.796)

5 (least deprived)	3243.259 (2909.631-3615.142)	928.258 (749.540-1149.589)	640.940 (495.506-829.360)	519.383 (390.236-691.270)

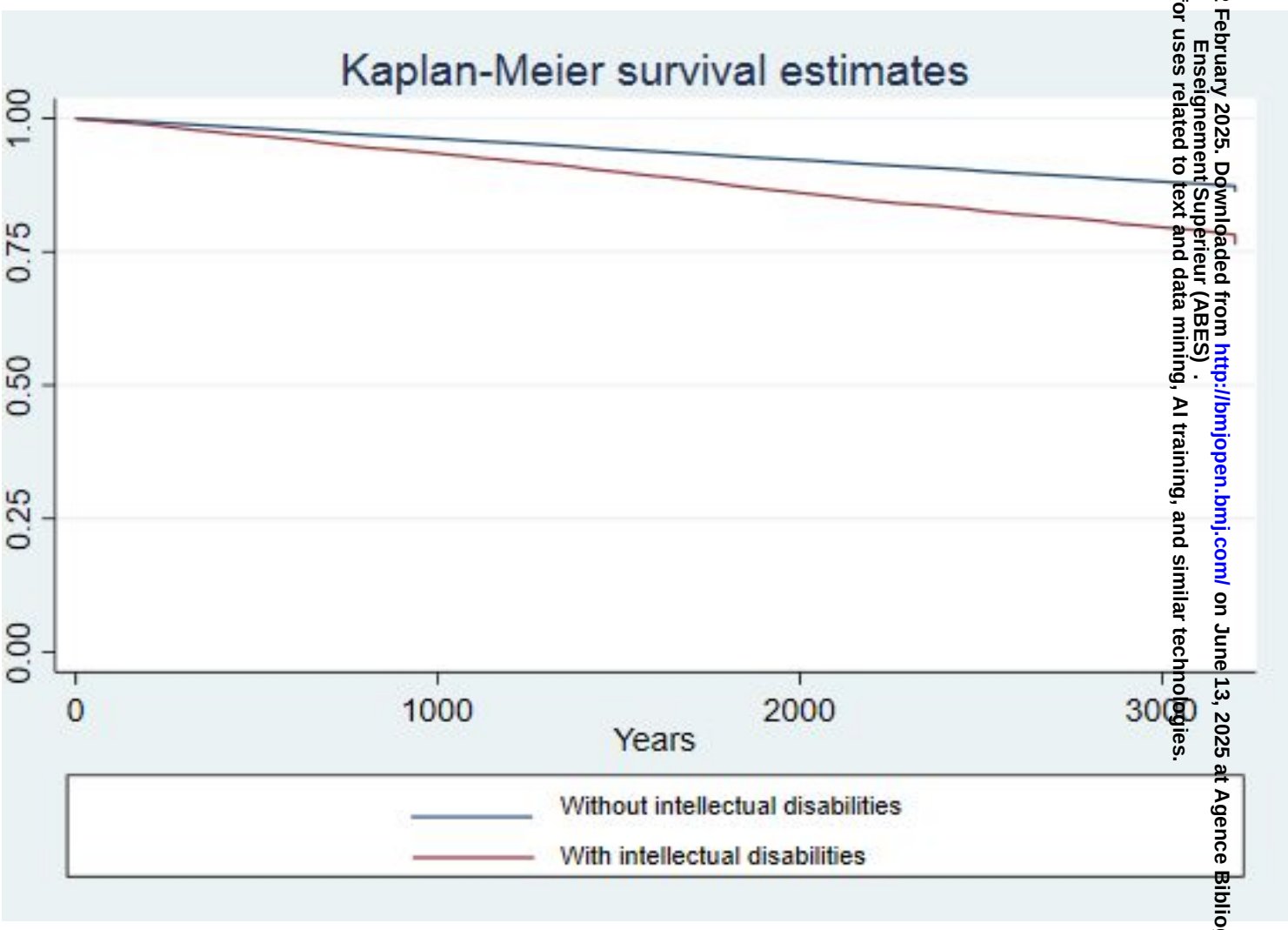
Abbreviations: CMR=Crude Mortality Rate; CI=confidence interval

Supplemental Table 2. Crude mortality rates (CMRs) for adults without intellectual disabilities per 100,000 by age sex, and deprivation (SIMD)

Variable	All deaths CMR (95% CI)	Avoidable deaths CMR (95% CI)	Treatable deaths CMR (95% CI)	Preventable deaths CMR (95% CI)
All deaths	1674.140 (1661.752-1686.62)	375.904 (369.416-382.506)	181.234 (176.746-185.883)	302.758 (296.941-308.689)
Age				
25-34	100.202 (93.209-107.719)	71.260 (65.402-77.643)	19.931 (16.947-23.44)	62.251 (56.791-68.235)
35-44	210.565 (201.041-220.540)	149.263 (141.278-157.698)	64.825 (59.637-70.465)	119.316 (112.201-126.883)
45-54	473.375 (459.608-487.554)	339.628 (327.998-351.670)	167.238 (159.136-175.7)	268.460 (258.143-279.191)
55-64	1201.950 (1177.857-1226.536)	850.563 (830.334-871.286)	423.486 (409.283-438)	686.994 (668.838-705.642)
65-74	3239.052 (3190.963-3287.866)	1425.095 (1342.809-1512.424)	725.670 (667.640-788.7)	1153.461 (1079.674-1232.291)
75+	10808.359 (10697.54-10920.33)	-	-	-
Sex				
Male	1699.664 (1681.485-1718.039)	457.480 (447.184-468.014)	210.936 (203.982-218.12)	399.593 (389.978-409.446)
Female	1651.515 (1634.641-1668.564)	300.410 (292.4-308.639)	153.746 (148.046-159.665)	213.142 (206.413-220.092)
SIMD				
1 (most deprived)	2092.940 (2060.217-2126.183)	609.863 (590.622-629.730)	273.933 (261.138-287.354)	509.851 (492.285-528.043)
2	1938.103 (1907.799-1968.889)	456.686 (440.468-473.502)	212.333 (201.366-223.893)	373.836 (359.190-389.079)
3	1650.828 (1623.829-1678.276)	359.964 (346.099-374.384)	177.669 (168.009-187.886)	288.260 (275.882-301.194)
4	1460.076 (1435.342-1485.237)	278.420 (266.540-290.831)	141.002 (132.621-149.91)	217.085 (206.625-228.075)
5 (least deprived)	1319.1242 (1295.15-1343.542)	213.08986 (202.5298-224.2005)	116.50441 (108.7651-124.7945)	158.778 (149.699-168.408)

Abbreviations: CMR=Crude Mortality Rate; CI=confidence interval

Supplemental Figure 1. Kaplan-Meier survival analysis for risk of death for intellectual disabilities population and controls from 2011-2019



BMJ Open

Rates, causes and predictors of all-cause and avoidable mortality in 514,878 adults with and without intellectual disabilities in Scotland: a record linkage national cohort study

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2024-089962.R2
Article Type:	Original research
Date Submitted by the Author:	28-Nov-2024
Complete List of Authors:	Rydzewska, Ewelina; The University of Edinburgh Nijhof, Dewy; University of Glasgow Hughes-McCormack, Laura; University of Glasgow School of Health and Wellbeing, Mental Health and Wellbeing Melville, Craig; University of Glasgow Fleming, Michael ; University of Glasgow, Public Health Mackay, Daniel; University of Glasgow Sosenko, Filip; University of Glasgow College of Medical Veterinary and Life Sciences, Institute of Health and Wellbeing Ward, Laura; University of Dundee School of Medicine, Health Informatics Centre; University of Glasgow School of Health and Wellbeing, Mental Health and Wellbeing Dunn, Kirsty; University of Glasgow, Institute of Health and Wellbeing Truesdale, Maria; University of Glasgow College of Medical Veterinary and Life Sciences, Mental Health and Wellbeing Cairns, Deborah; University of Glasgow Pell, Jill; University of Glasgow Wyper, Grant; NHS Health Scotland Jani, Bhautesh; University of Glasgow Barlow, Fiona; University of Glasgow College of Medical Veterinary and Life Sciences, Mental Health and Wellbeing Henderson, Angela; University of Glasgow, Institute of Health and Wellbeing Callander, Ruth; Scottish Comission for People with Learning Disabilities Cooper, Sally-Ann; University of Glasgow, Institute of Health and Wellbeing
Primary Subject Heading:	Public health
Secondary Subject Heading:	Epidemiology
Keywords:	Mortality, PUBLIC HEALTH, Primary Care < Primary Health Care

I, the Submitting Author has the right to grant and does grant on behalf of all authors of the Work (as defined in the below author licence), an exclusive licence and/or a non-exclusive licence for contributions from authors who are: i) UK Crown employees; ii) where BMJ has agreed a CC-BY licence shall apply, and/or iii) in accordance with the terms applicable for US Federal Government officers or employees acting as part of their official duties; on a worldwide, perpetual, irrevocable, royalty-free basis to BMJ Publishing Group Ltd ("BMJ") its licensees and where the relevant Journal is co-owned by BMJ to the co-owners of the Journal, to publish the Work in this journal and any other BMJ products and to exploit all rights, as set out in our licence.

The Submitting Author accepts and understands that any supply made under these terms is made by BMJ to the Submitting Author unless you are acting as an employee on behalf of your employer or a postgraduate student of an affiliated institution which is paying any applicable article publishing charge ("APC") for Open Access articles. Where the Submitting Author wishes to make the Work available on an Open Access basis (and intends to pay the relevant APC), the terms of reuse of such Open Access shall be governed by a Creative Commons licence – details of these licences and which Creative Commons licence will apply to this Work are set out in our licence referred to above.

Other than as permitted in any relevant BMJ Author's Self Archiving Policies, I confirm this Work has not been accepted for publication elsewhere, is not being considered for publication elsewhere and does not duplicate material already published. I confirm all authors consent to publication of this Work and authorise the granting of this licence.

Title: Rates, causes and predictors of all-cause and avoidable mortality in 514,878 adults with and without intellectual disabilities in Scotland: a record linkage national cohort study

Authors:

Ewelina Rydzewska,[1,2] Dewy Nijhof,[2] Laura Hughes,[2] Craig Melville,[2] Michael Fleming,[2] Daniel Mackay,[2] Filip Sosenko,[2] Laura Ward,[3] Kirsty Dunn,[2] Maria Truesdale,[2] Deborah Cairns,[2*] Jill P. Pell,[2] Grant M. A. Wyper,[2,4] Bhautesh D. Jani,[2] Fiona Barlow,[2] Angela Henderson,[2] Ruth Callander,[4] Sally-Ann Cooper[2]

1. School of Health in Social Science, University of Edinburgh, Edinburgh, Scotland, UK
2. School of Health and Wellbeing, University of Glasgow, Glasgow, Scotland, UK
3. School of Medicine, University of Dundee, Dundee, Scotland, UK
4. Population Health and Wellbeing, Public Health Scotland, Edinburgh, Scotland, UK
5. Scottish Commission for People with Learning Disabilities, Glasgow, Scotland, UK

*Corresponding author:

Professor Deborah Cairns
School of Health and Wellbeing
University of Glasgow
Glasgow
Scotland, UK
deborah.cairns@glasgow.ac.uk

Abstract

Background: Studies on avoidable mortality in adults with intellectual disabilities are limited, as are studies on causes of death.

Objectives: We aimed to quantify mortality rates, and causes, and identify factors (i.e., age, sex, Scottish Index of Multiple Deprivation [SIMD]) related to avoidable mortality in adults with intellectual disabilities.

Design: a record linkage national cohort study.

Setting: A cohort of adults with intellectual disabilities with or without co-occurring autism, aged 25+ years and a randomly selected comparison group aged 25+ years without intellectual disabilities or autism identified from Scotland's Census, 2011. Census records were linked to the National Records of Scotland Statutory Register of Deaths database to ascertain all deaths in 2011-2019.

Participants: We analysed data on 14,477 adults with intellectual disabilities aged 25+ years and a randomly selected comparison group of 506,207 adults aged 25+ without intellectual disabilities identified from Scotland's Census 2011.

Primary and secondary outcome measures: We ran χ^2 tests and t-tests to investigate individual characteristics and differences in age at death for adults with intellectual disabilities compared to peers in the general population. Cox proportional hazard models were fitted to calculate risk of mortality (all-cause, avoidable, treatable, preventable) unadjusted and adjusted for age, sex and SIMD. We then calculated mortality rates, using crude and indirect standardisation methods.

Results: During the 8.5-year-follow-up, 23.7% (crude death rate of 3033.3 per 100,000) of adults with intellectual disabilities died compared to 13.8% of controls. Median age at death among adults aged 25+ with intellectual disabilities was 65.0 years compared to 80.0 years for adults without intellectual disabilities. For all-cause mortality, the age-standardised mortality ratio (SMR) in the population with intellectual disabilities was 3.1 [95% CI 3.0-3.2]. The SMRs were higher for the youngest age groups, women and in the most affluent areas. This was also the case for SMRs for avoidable, treatable, and preventable deaths. For the population of adults with intellectual disabilities, 31.7% of recorded deaths were considered avoidable, 21.1% were treatable and 19.9% were preventable. In the controls, 18.2% of deaths were considered avoidable, 8.8% treatable and 14.7% preventable. Down syndrome and dementia were the two most commonly recorded underlying causes of death for people with intellectual disabilities while malignant neoplasm of bronchus and lung and acute myocardial infarction were most commonly recorded in the general population.

Conclusions: Risks of all-cause, avoidable, treatable, and preventable mortality were higher for adults with intellectual disabilities than their peers. The highest SMRs were observed for youngest adults, women, and individuals living in the most affluent areas.

Keywords: avoidable mortality, intellectual disabilities, adults, data linkage

Strengths and limitations of this study:

- Unique study of avoidable mortality in adults with intellectual disabilities in a whole country population
- High response rate of 94%, and systematic enquiry of everyone regarding intellectual disabilities
- Results of the study are generalisable to other adult populations in high-income countries
- The records of death were taken from death certificates, and not verified at post-mortem

Introduction

On average, people with intellectual disabilities have been reported to die 20 years younger than those without intellectual disabilities, including dying from causes considered to have been avoidable[1]. In recent years, there have been several studies of deaths in adults with intellectual disabilities, that have attempted to reduce the limitations of previous studies such as small sample sizes, or non-representative populations. These studies have typically used record-linkage methods and reported Standardised Mortality Ratios (SMRs) in the region of 2-4, higher in women than men, and at younger ages, though some report SMR to be only slightly above 1[1]. Direct comparisons between studies are difficult though due to differences in methods, reporting, and ages studied; a tabulated overview is provided in Cooper et al.[2]

There is much less information on the most common underlying causes of death in adults with intellectual disabilities, and less consistency in how these are reported (for example, grouping by ICD-10 categories, or by individual causes of death) which limits comparisons between studies. One study reported the most common causes of death to be pneumonia, other respiratory diseases, and diseases of the nervous system.[3] Another reported diseases of the circulatory and respiratory systems to be the most common cause of death.[4] A third reported that mortality rates due to influenza and pneumonia, septicaemia and aspiration pneumonia substantially exceeded the adult mortality rates in the general population.[5] A fourth reported diseases of the circulatory system, neoplasm, and the nervous system to be the most common cause of death.[6] A fifth noted that people with intellectual disabilities had increased odds of presentation, admission or death from conditions defined as ambulatory care sensitive, which are potentially preventable, specifically vaccine-preventable respiratory disease, asthma, cellulitis and convulsions and epilepsy.[7] Three studies reported cause-specific SMRs to be higher across most groups of disorders than in the general population.[2-4]

Avoidable mortality has also been little studied in adults with intellectual disabilities. Its definition includes preventable mortality (deaths which are preventable through public health interventions, for example, deaths from infectious diseases that can be prevented by vaccination, or alcohol or drug related deaths), and treatable (previously known as 'amenable') mortality (deaths amenable to timely and effective healthcare, for example, deaths due to epilepsy, diabetes, or respiratory infections) while some causes of death can be both preventable and treatable.[8,9] Recent studies that have reported on avoidable deaths suggest that up to 40% of deaths of adults with intellectual disabilities may be avoidable, compared to 28% of deaths in the general adult population.[2,4,10,11]

Specifically, one study in which 961 adults aged 16–83 years with intellectual disabilities had clinical examinations in 2001–2004 found that 102 (38.9%) of the 262 deaths were avoidable, 78 (29.8%) were treatable and 51 (19.5%) were preventable, while 27 (10.3%) were classed as both treatable and preventable.[2] In a study of 16,666 adults with intellectual disabilities from 343 general practices in the UK, 37.0% of all deaths among adults with intellectual disabilities were classified as being treatable, compared with 22.5% in the general population (Hazard Ratio (HR) 5.9; 95% CI 5.1, 6.8).[4] A study of 732 deaths in 19,362 adults aged 20+ years registered for intellectual disability services from 2005 to 2011 in New South Wales found that 31% of deaths were avoidable; higher than in the general population (17%).[6] Two further studies reported data on children, young people and adults combined.[10,11] Heslop et al.[10] undertook a population-based Confidential Inquiry of the deaths of 247 people with intellectual disabilities aged 4 years and older in southwest England who died between June 1 2010 and May 31 2012. Treatable deaths were more common in people with intellectual disabilities (37%) than in the general population (13%).[10] Glover et al.[11] used general practice data for people with and without intellectual disabilities of all ages, and reported that 44.7% of deaths were avoidable, with a higher proportion of deaths from causes classified as treatable, but a lower proportion from preventable causes compared with people without intellectual disabilities (actual figures not reported).[11] Two studies investigated patterns of mortality in adults with intellectual and developmental disabilities from Ontario, Canada. One of them reported a higher all-cause (6.1% vs. 1.6%) and amenable (21.4% vs. 14.1%) mortality levels compared with general population, but rates for all avoidable mortality were not provided.[12] The other study reported 1-year age-standardised mortality rates for years 2011-2014 to be between 30.3-37.4 for Manitoba adults with intellectual and developmental disabilities compared to the matched comparison group, meaning that 30.3-37.4 times more deaths occurred in this population than would be expected to occur in the Ontario population.[13] A further study on adults with intellectual and developmental disabilities from Manitoba, Canada reported crude avoidable premature mortality rates per 1,000 person-years to be between 2.3–3.3 for years 2013-2015, meaning that avoidable premature mortality was 2.3–3.3 times more prevalent among Manitoba adults with intellectual and developmental disabilities compared to the matched comparison group.[14] These studies demonstrated that rates of avoidable mortality are high in adults with intellectual disabilities, and higher than in the general population, suggesting that pervasive health inequalities may be contributing, and that further investigation is necessary.

The aim of this study was to investigate deaths in adults with intellectual disabilities, compared with controls, for an entire country's population from 2011-2019. For adults with intellectual disabilities compared with other adults, we investigated (a) age- sex- and neighbourhood

deprivation- standardised mortality ratios, (b) underlying cause of death, and all-contributory causes of death by ICD-10 chapters, and most common specific causes, and (c) the proportion of deaths considered avoidable, treatable, and preventable.

Methodology

Patient and public involvement

This study was undertaken by the Scottish Learning Disabilities Observatory at the University of Glasgow due to the growing concern expressed by people with intellectual disabilities and their families about mortality. The Scottish Learning Disabilities Observatory's steering group includes people with intellectual disabilities and partners from third sector organisations. Results from this study will be disseminated to people with intellectual disabilities and their families in an easy-read version via the Scottish Learning Disabilities Observatory website and newsletters and in collaboration with the Scottish Commission for People with Learning Disabilities.

Approvals

Approval was gained from Scotland's Public Benefit and Privacy Panel for Health and Social Care (reference: 1819-0051), Scotland's Statistics Public Benefit and Privacy Panel (reference: 1819-0051), and the University of Glasgow's College of Medical, Veterinary, and Life Sciences Ethical Committee (reference: 200180081). Data sharing agreements were put in place with the data controllers of all the linked datasets.

Study sample, setting and process

Ninety four percent of the Scottish population completed Scotland's Census, 2011. We used these data to create a cohort of adults with intellectual disabilities with or without co-occurring autism, aged 25+ years at the Census date (27th March 2011), and a randomly selected comparison group aged 25+ years without intellectual disabilities or autism from a 15% unmatched sample of the Scottish population also identified from Scotland's Census, 2011. Their records were linked to the National Records of Scotland Statutory Register of Deaths database to ascertain all deaths up to 31st December 2019. Access to the anonymised linked data was given to the approved members of the research team via Scotland's National Safe Haven. Full details on Scotland's Census 2011 are available at: https://www.scotlandscensus.gov.uk/about/2011-census/. Further information on the record linkage and the cohorts have previously been reported in detail.[15]

Variables

Intellectual disabilities: Scotland's Census 2011 provides information on the number and characteristics of Scotland's population and households on the Census day, 27th March 2011. The census is undertaken every 10 years. It includes people living in communal establishments (such as care homes and student halls of residence) as well as people living in private households. In 2011, the census in Scotland was estimated to have achieved a 94% response rate.[16] The Census team required the form to be completed by the head of household or joint head of household on behalf of all occupants in private households, and the manager was responsible on behalf of all occupants in communal dwellings. It was a legal requirement to complete the census, and non-compliance or supplying false information could result in a fine of £1,000. The Census team followed up non-responders and also provided help in responding when it was needed; hence, the high 94% completion rate.

Scotland's Census is probably one of few country censuses, which identifies people with intellectual disabilities and distinguishes these from specific learning disabilities such as dyslexia; indeed, it may be unique in this regard. Self-/proxy reporting was used to identify people with intellectual disabilities from the Census questionnaire, question 20: 'Do you have any of the following conditions which have lasted, or are expected to last, at least 12 months? Tick all that apply'. Respondents were given a choice of 10 response options, with option number (3) 'learning disability (e.g., Down's syndrome)' being synonymous in the UK with the international term 'intellectual disabilities'. The remaining response options were as follows: (1) deafness or partial hearing loss, (2) blindness or partial sight loss, (4) learning difficulty (e.g., dyslexia), (5) developmental disorder (e.g., autistic spectrum disorder or Asperger's syndrome), (6) physical disability, (7) mental health condition, (8) long-term illness, disease or condition, (9) other condition, (10) no condition. Importantly, the question distinguished between intellectual disability (for which the term 'learning disability' is used in the UK), learning difficulty (which in the UK is synonymous with the international term 'specific learning disability' such as dyslexia) and autism.

Age: Age was grouped into six categories of 1) 25-34 years, 2) 35-44 years, 3) 45-54 years, 4) 55-64 years, 5) 65-74 and 6) 75+ years, based on the Census data.

Sex: Sex was coded in two categories of male and female, based on the Census data.

Scottish Index of Multiple Deprivation (SIMD)*:* SIMD was grouped in population quintiles where SIMD 1 included the most deprived neighbourhoods and SIMD 5 corresponded with

the most affluent neighbourhoods. SIMD was identified from postcodes, based on the Census data, and calculated at datazone level.

Deaths: We used data from death certificates registered at National Records of Scotland, to identify date of deaths, and underlying causes and all contributing factors in deaths for adults with intellectual disabilities and the general population comparison group. For cause of death analyses, we analysed the underlying cause of death; defined as the disease or injury which initiated the chain of morbid events leading directly to death, or the accident/act which produced the fatal injury.[17] We also analysed a broader composite outcome of all contributing factors in death, defined as a cause listed as either the underlying cause, secondary cause or a contributing factor. We used the Tenth Revision of the International Statistical Classification of Diseases and Related Health Problems (ICD-10)[18] to group causes of death into categories. The cancer codes included C00.0-D48.9 inclusive. The analyses were restricted to deaths recorded between the 28th March 2011 and the 31st December 2019.

We defined treatable and preventable deaths as per avoidable mortality outcomes outlined in the guidance of the Office for National Statistics,[8] noting that some causes of death are both treatable and preventable. As per the ONS guidance, avoidable mortality analyses excluded any deaths at the age of 75+, thus the following cases were excluded from the avoidable mortality analyses: 1) anyone who was 75+ years at the start of the study (i.e., Census day the 27th March 2011); 2) anyone who died at the age of 75+ years during the study duration; 3) anyone who turned 75+ years at any point during the study period.

Data processes

All follow-up/censoring*:* Adults aged 25+ years were followed up from the Census date (27th March 2011), and all models were censored on death or the study end date (31st December 2019), whichever came first, unless stated otherwise. Cases of individuals who died either before or on the day of Census (i.e., any deaths prior to the 28th of March 2011) were excluded from the analyses, as participants were expected to spend at least one day in the study to enable us to run survival analysis. Furthermore, in the comparison group, we also excluded individuals who subsequently died during the study period and had their cause of death recorded as a form of an intellectual disability/autism (ICD-10 codes: F70, F71, F72, F73, F78, F79, F84, Q90.0, Q90.1, Q90.2, Q90.9).

Missing data: Data linkage was conducted by the National Records of Scotland (NRS). All data provided to us for this study included complete cases only, i.e., no observations were included who had missing or imputed cells for any variable. We included all cases provided

from NRS in the analysis apart from the exclusions mentioned above. Any errors in cause of death records such as omission, use of abbreviations, or ambiguous deaths were listed as an unknown cause.

Analyses

Information on age, sex, and SIMD was recorded on the Census day, i.e., the 27th March 2011. Explorative statistical analyses including t-tests and χ^2 tests were used to investigate characteristics of adults with intellectual disabilities compared to peers in the general population. Differences in mean age at death were explored using t-tests.

Crude mortality rates per 100,000 were calculated using the censor date/date of death. For indirect standardisation, observed deaths were assumed to be independent and vary with the Poisson distribution. The mortality rates were indirectly standardised for both men and women, using the expected age-specific mortality rates per 1-year age group, using Stata's 'strate' command, to calculate age-SMRs for adults with versus without intellectual disabilities. The 95% CIs were calculated based on the quadratic approximation of the log likelihood. Expected rates were calculated using fixed age and sex-specific rates from the large control population. The SMRs were subsequently calculated stratified by age category (25-34, 35-44, 45-54, 55-64, 65-74 and 75+ years), sex and SIMD.

For all-cause mortality, Kaplan-Meier survival curves were plotted for the study period for both groups and the proportional hazards assumption was tested.

For the underlying causes of death and all contributing factors in death, the total numbers of deaths in each ICD-10 chapter were collated. We then collated the number of deaths for the top 20 most commonly recorded underlying causes and all contributing factors in death. For cause-specific SMRs, indirect sex-standardisation was also performed (using 10-year age bands). The rates and age-standardised SMRs for avoidable, treatable, and preventable mortality were calculated using robust errors.

Cox proportional hazard models were fitted to the data to calculate risks of mortality (all-cause, avoidable, treatable, preventable) unadjusted and adjusted for age, sex, and SIMD. For categories which had fewer than 10 deaths, no calculation was attempted due to lack of reliability. Furthermore, in keeping with the Office of National Statistics mortality methodology, all mortality rates between 10 and 20 deaths were labelled as unreliable.[8] Two researchers (D.N. and E.R.) carried out the main analyses. All analyses were conducted in Stata version 17.

Results

The study cohort included 14,477 adults with intellectual disabilities aged 25+ and 506,207 adults without intellectual disabilities nor autism aged 25+, following exclusion of 71 individuals with a record of death before or on the date of the Census and exclusion of 51 cases without intellectual disabilities or autism who died during the study but had their cause of death recorded as a form of intellectual disability/autism.

Demographic information

Table 1 presents demographic information on the population of adults with and without intellectual disabilities, at the time of Scotland's Census, 2011. Compared with their peers, adults with intellectual disabilities had a higher proportion of men (n=7,927, 54.8% vs. n=238,036, 47.0%; p<0.001), were more likely to be living in more deprived neighbourhoods (p<0.001) and were overall younger (p<0.001).

All-cause mortality

Crude mortality: The study period (27th March 2011 – 31st December 2019) resulted in the equivalent of 4,272,853 person years of follow up. This included 113,044 person years contributed by the intellectual disabilities population and 4,159,809 person years for the population without intellectual disabilities. The median age at death for adults with intellectual disabilities was younger at 65 years (SD=14.1, IQR=56.0-76.0) compared with 80 years (SD=12.9, IQR=71.0-87.0) for adults without intellectual disabilities.

Of the 14,477 adults with intellectual disabilities 3,429 (23.7%) died during the 8.5 years of follow up. In the population without intellectual disabilities, 69,641/506,207 (13.8%) adults died during the same follow up period. Crude mortality over the study period was 3033.3 (95% CI 2933.5-3136.6) per 100,000 person years of follow up (Supplemental Table 1) among adults with intellectual disabilities, and 1674.1 (95% CI 1661.8-1686.6) per 100,000 for adults without intellectual disabilities (Supplemental Table 2). The proportional hazards assumption was visually assessed and met. Kaplan-Meier survival curves for the overall time period were run (Supplemental Figure 1).

Standardised mortality ratios (SMRs):

For all-cause mortality, compared with adults without intellectual disabilities, the age-standardised SMR in the population with intellectual disabilities was 3.1 (95% CI 3.0-3.2). The

sex-standardised SMR was 1.8 (95% CI 1.7-1.9) and SIMD-standardised SMR was 1.7 (95% CI 1.6-1.7) (Table 2).

The age-stratified SMR was highest in the youngest age group (25-34 years old) at 6.4 (95% CI 5.5-7.5) and gradually decreased with age, with the lowest SMR recorded for the oldest age group of 75+ year old at 1.6 (95% CI 1.5-1.8). The sex-stratified SMR was higher for women (SMR 2.0, 95% CI 1.9-2.1) than men (SMR1.7, 95% CI 1.6-1.8). SMR was also highest in the most affluent areas (SMR=2.5, 95% CI 2.2-2.7) and gradually decreased with rising deprivation level, with SMR in the most deprived areas recorded at 1.4 (95% CI 1.3-1.5).

Cause-specific mortality

Table 3 reports the crude mortality rates for underlying causes of death and all contributing causes of death by ICD-10 chapters.

Underlying cause of death: The most common underlying causes of death in the adults with intellectual disabilities were: diseases of the circulatory system (n=692; Crude Mortality Rate (CMR)=612.2, 95% CI 568.2-659.5); neoplasms (n=489; CMR=432.6, 95% CI 395.9-472.7) diseases of the respiratory system (n=484, CMR=428.2, 95% CI 391.7-468.0), and diseases of the nervous system (n=442; CMR=391.0, 95% CI 356.2-429.2). In the control group without intellectual disabilities, the most common underlying causes of death were: neoplasms (n=20,667; CMR=496.8, 95% CI 490.1-503.6); diseases of the circulatory system (n=19,093; CMR=459.0, 95% CI 452.5-465.5), diseases of the respiratory system (n=8,716; CMR=209.5, 95% CI 205.2-214.0), then mental and behavioural disorders (n=5,084; CMR=122.2, 95% CI 118.9-125.6).

All contributing factors in death: In the group with intellectual disabilities, the most common all contributing factors in death were: diseases of the respiratory system (n=1,616; CMR=1,429.5, 95% CI 1,361.5-1,501.0); diseases of the circulatory system (n=1,271; CMR=1,124.3, 95% CI 1,064.2-1,187.9); mental and behavioural disorders (n=944; CMR=835.1, 95% CI 783.5-890.1) and diseases of the nervous system (n=943; CMR=834.2, 95% CI 782.6-889.2). In the control group without intellectual disabilities, the most common were diseases of the circulatory system (n=35,223; CMR=846.7, 95% CI 837.9-855.6), the respiratory system (N=24,834; CMR=597.0, 95% CI 589.6-604.5), and neoplasms (n=23,717; CMR=570.1, 95% CI 562.9-577.4).

Most common causes of death: Table 4 reports the most common individual underlying causes and all contributing factors. Based on pre-specified groupings of specific ICD-10 codes, among adults with intellectual disabilities the most commonly recorded underlying causes of death were Down syndrome, dementia and acute myocardial infarction. For all contributing factors in death, pneumonia due to organism unspecified, Down syndrome and pneumonitis due to solids and liquids were the most commonly recorded. In the population of adults without intellectual disabilities, the most commonly recorded underlying causes of death were malignant neoplasm of bronchus or lung, acute myocardial infarction and dementia. For all contributing factors in death, chronic ischemic heart disease, pneumonia due to organism unspecified and other chronic obstructive pulmonary disease were most commonly recorded.

Avoidable mortality

Incidence: Of the 3,429 deaths recorded for the population of adults with intellectual disabilities 1,087 (31.7%) were considered avoidable. Of all deaths, 722 (21.1%) were treatable and 681 (19.9%) were preventable. In the population of adults without intellectual disabilities, 12,673 (18.2%) of the 69,641 deaths were considered avoidable; 6,110 (8.8%) treatable and 10,207 (14.7%) preventable (Table 5).

Crude avoidable mortality in adults with intellectual disabilities was 1,061.4 (95% CI 1,000.1-1126.4) per 100,000 person years of follow up and 375.9 (95% CI 369.4-382.5) for adults without intellectual disabilities. Treatable mortality in the intellectual disabilities group was 705.0 (95% CI 655.4-758.3) per 100,000 person years of follow up and 181.2 (95% CI 176.7-185.8) for adults without intellectual disabilities. Preventable mortality for the intellectual disabilities cohort was 665.0 (95% CI 616.9-716.8) per 100,000 person years of follow up and 302.8 (95% CI 296.9-308.7) for adults without intellectual disabilities. Further details are provided in Supplemental Tables 1 and 2.

Standardised mortality ratios: Table 2 shows that SMRs for individual age groups were highest in the youngest age groups, for all avoidable deaths as well as for treatable and preventable mortality. SMRs for avoidable, treatable and preventable deaths were higher for females (avoidable: 3.5, 95% CI 3.2-3.8; treatable: 4.7, 95% CI 4.2-5.3; preventable: 2.7, 95% CI 2.4-3.1) than males (avoidable: 2.4, 95% CI 2.2-2.6; treatable: 3.3, 95% CI 3.0-3.6; preventable: 1.8, 95% CI 1.7-2.0). There was a gradient of increasing SMRs for avoidable, treatable and preventable mortality as the extent of the neighbourhood deprivation decreased.

Table 5 reports underlying cause of death with the Cox proportional hazards, unadjusted (HR) and adjusted for age, sex and SIMD (aHR). For all deaths: HR=3.3 (95% CI 3.2-3.4) and

aHR=3.0 (95% CI 2.9-3.1). For avoidable deaths: HR=3.3 (95% CI 3.1-3.6), treatable deaths: HR=4.7 (4.3-5.0) and preventable deaths: HR=2.6 (2.4-2.8), and aHRs were: avoidable deaths: aHR=2.7 (95% CI 2.5-2.9), treatable deaths: aHR=3.9 (95% CI 3.6-4.2) and preventable deaths: aHR=2.0 (95% CI 1.9-2.2) (Table 5).

Discussion

Summary of principal findings

For all-cause mortality, compared with adults without intellectual disabilities, the age-standardised SMR in the population with intellectual disabilities was 3.1. The SMRs were higher for the youngest age groups, women and in the most affluent areas. This gradient in increase in the SMRs in more affluent neighbourhoods is likely caused by the difference in the general population across extent of neighbourhood deprivation, rather than a difference across neighbourhoods in the population with intellectual disabilities, i.e., the general population experience higher rates of deaths in the more deprived areas whereas for adults with intellectual disabilities this trend is not as pronounced. Adults with intellectual disabilities also died younger than adults without intellectual disabilities (median age at death: 65.0 years vs. 80.0 years).

Avoidable deaths were substantially more common in people with intellectual disabilities than other people; particularly due to deaths from conditions that could have been treated by high quality care. Our paper is novel in investigating avoidable deaths in detail, including reporting SMRs for avoidable, treatable, and preventable deaths by the socio-demographic features of age, sex, and extent of neighbourhood deprivation. SMRs for avoidable deaths ranged from 4.2 to 2.0, being higher at younger age groups, in women, and the more affluent the neighbourhood.

For those with intellectual disabilities, the most common underlying causes of death were diseases of the circulatory system, neoplasms, diseases of the respiratory system and diseases of the nervous system, with fairly similar rates between each. This differs from the controls, where neoplasms were markedly more common, followed by diseases of the circulatory system, and then, though much less common, diseases of the respiratory system and mental and behavioural disorders. All contributing factors in death for adults with intellectual disabilities were most commonly diseases of the respiratory system, followed by diseases of the circulatory system, and equally mental and behavioural disorders and diseases of the nervous system. In the control group, the most common all contributing factors in death were diseases of the circulatory system by far. Sex-standardised SMRs for underlying causes of deaths ranged from 259.5 (congenital malformations, deformations and

chromosomal abnormalities) to 1.4 (neoplasms). For all contributing factors in deaths, the range was 238.3 (congenital malformations, deformations and chromosomal abnormalities) to 1.4 (neoplasms).

Comparison with existing literature

We are aware of only three studies on avoidable mortality in adults with intellectual disabilities. These covered shorter periods of time and/or included smaller sample sizes, limiting opportunities for comparison.[2,4,6] We report that 31.7% of deaths of adults with intellectual disabilities were avoidable, compared to 46.3%,[4] 38.9%[2] and 31.0%[6]. Compared to the general population, we found much higher rates of avoidable (SMR=3.2), treatable (SMR=4.5), and preventable (SMR=2.5) deaths. The Incidence Rate Ratio (IRR) for avoidable deaths reported by Trollor et al.[6], whilst raised, showed a much lesser difference than in our study (IRR 1.47; 95% CI 1.54 to 1.99; p<0.001). Hosking et al.[4] reported hazard ratios that were more similar to our findings: avoidable (3.44), treatable (5.86), and preventable (1.69) deaths. Cooper et al.[2] did not calculate comparisons with the general population. We are not aware of any previous studies that have reported on avoidable, treatable, and preventable mortality in relation to socio-demographic factors such as age, sex, or neighbourhood deprivation with which we can compare our findings.

The high rate of SMR (3.1) we report for all-cause mortality is consistent with previous literature, as is the higher SMR in females, and at younger ages. However, we are not aware of previous studies of SMR in adults with intellectual disabilities in relation to the extent of neighbourhood deprivation. One Australian study reported contrary results to ours and other studies, with regards to the sex, and age findings.[6]

Few studies have reported causes of death by ICD-10 chapter, and reports are contradictory. By ICD-10 chapter, we found the most common underlying causes of death to be diseases of the circulatory system, neoplasms, diseases of the respiratory system and diseases of the nervous system, similarly to the report by Cooper et al.[2] whilst others reported the most common to be circulatory,[4] vascular,[19] heart disease,[20] and jointly circulatory and neoplasm[6]. With regard to findings from the analysis of pre-specified groupings of specific ICD-10 codes, we have found that Down syndrome was the most commonly recorded cause of death for adults with intellectual disabilities. This suggests that there may still exist prevailing uncertainty in relation to underlying causes of death in people with intellectual disabilities and there is continued conflation of disability and health among attending medical practitioners responsible for recording causes of death in Scotland.[21]

Implications for policy and practice

The higher risk of all-cause, avoidable, treatable, and preventable mortality, and earlier age at death for adults with intellectual disabilities than their peers without intellectual disabilities demonstrates a clear need for improvements in the early detection, prevention, care and treatment of health problems experienced by people with intellectual disabilities. This is essential at all ages, and for people living in all areas; more so than for the general population, these are not issues related to older age nor neighbourhood deprivation. Recording of Down syndrome as a cause of death in adults with intellectual disabilities is still common among attending medical practitioners in Scotland. It is, therefore, crucial that we better understand how individual health conditions impact on the health and mortality of adults with intellectual disabilities. Research efforts should be directed particularly towards the management of epilepsy and pneumonia to reduce premature mortality due to the diseases of the nervous and respiratory systems, which are one of the leading causes of death in this population. Our findings on mortality caused by cardiovascular diseases and neoplasms in adults with intellectual disabilities also suggest that public health interventions aimed at circulatory diseases and cancer screening may need appropriate adaptation and tailoring for this population. Clinical and health training initiatives should be introduced across all age groups and all neighbourhoods, given that our findings suggest that mortality risk is highest in the most affluent areas for adults with intellectual disabilities.

Strengths and Limitations

A major strength of this study is that it includes a whole country population of adults with intellectual disabilities and a representative proportion of people in the general population, with a high response rate of 94% for Scotland's Census 2011,[16] thereby reducing the study bias. Whether each individual had intellectual disabilities was enquired about, and intellectual disabilities was specifically distinguished from specific learning disabilities, and from autism. Prior to the Census, these questions were field tested, to check their utility and acceptability, using cognitive question testing with 70 respondents on the whole questionnaire, and 102 respondents specifically on the health questions. Additionally, the prevalence of intellectual disabilities in the Census data (0.5%) is the same as that found in Scottish GP registers, and in other large data sources, which have been used to identify adults with intellectual disabilities.[22]

Limitations include the fact that the Census data do not specify whether a record of intellectual disabilities was reported by a person with intellectual disabilities or their proxy (e.g., a parent/carer, spouse etc.). Moreover, respondents reported whether or not each person was known to have intellectual disabilities rather than each person having an assessment for

intellectual disabilities, so some reporting error is possible. Further, our death data was taken from death certificates, and not verified at post-mortem. The death certificates will have been completed by numerous clinicians, and there may be some error in reporting, including between underlying causes and all contributing factors in death, but such error in reporting mostly poses limitations only when investigating more granular outcomes. Some data repression was necessary where very small numbers were identified to mitigate the risk of disclosure. In keeping with the ONS methodology for investigating avoidable mortality,[8] all crude mortality rates per 100,000 people based on fewer than 20 deaths were labelled as unreliable to warn users of their low reliability. It is also important to note that the ONS list of avoidable deaths is based on general population data and is, therefore, possibly an underestimate of avoidable deaths in the population with intellectual disabilities due to differing health and death profiles.

Given the strengths of the study, we believe the results will be generalisable to other high-income countries, as well as filling a significant gap in existing research on avoidable mortality in adults with intellectual disabilities, and contradictory reports on causes of death. However, this needs to be determined by replication of our findings.

Acknowledgements: We would like to acknowledge the support of the eDRIS Team (Public Health Scotland), particularly David Clark, for their involvement in obtaining approvals, provisioning and linking data, and for the use of the secure analytical platform within the National Safe Haven.

Contributors: DN and ER analysed the data and interpreted findings. ER wrote the first draft of the manuscript. S-AC developed the record linkage, conceived the study, analysed and interpreted the data and contributed to the manuscript. CM, AH, and DK conceived the study, analysed and interpreted the data and contributed to the manuscript. DN, LH, MF, DM, KD, LW, FS, FB, JM, J-DS, B-DJ, MT, GW and JP interpreted findings and contributed to the manuscript. All authors approved the final version of the manuscript. DK is the guarantor for the study.

Funding: This work was supported by the UK Medical Research Council, grant number: MC_PC_17217), Baily Thomas Charitable Fund and the Scottish Government via the Scottish Learning Disabilities Observatory.

Disclaimer: The funders had no role in the study design, collection, analyses or interpretation of data, writing the report nor the decision to submit the article for publication.

Competing interests: None declared.

Ethics approval: NHS Scotland Public Benefit and Privacy Panel for Health and Social Care (reference: 1819-0051), Scottish Government's Statistics Public Benefit and Privacy Panel (reference: 1819-0051), and the University of Glasgow's College of Medical, Veterinary, and Life Sciences Ethical Committee (reference: 200180081).

Data availability statement: No data are available. This study linked patient information held across several administrative health datasets within Information Services Division (ISD) of NHS National Services Scotland (NSS), with data externally held by the Scottish Government (Scotland's Census 2011) and National Records of Scotland (Statutory Register of Deaths). Linkage and de-identification of data was performed by ISD. A data processing agreement between NHS NSS and University of Glasgow and a data sharing agreement between the Scottish Government and University of Glasgow were drafted. University of Glasgow was authorised to receive record-linked data controlled and held by ISD within NSS, via access through the National Safe Haven. The ISD Statistical Disclosure Control Protocol was followed in all described processes.

References:

1. O'Leary L, Hughes-McCormack L, Dunn K, Cooper S-A. Early death and causes of death of people with Down syndrome: A systematic review. J Appl Res Intellect Disabil [Internet]. 2018;31(5):687–708. Available from: http://dx.doi.org/10.1111/jar.12446
2. Cooper S-A, 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 [Internet]. 2020;10(5):e036465. Available from: http://dx.doi.org/10.1136/bmjopen-2019-036465
3. Tyrer F, McGrother C. Cause-specific mortality and death certificate reporting in adults with moderate to profound intellectual disability. J Intellect Disabil Res [Internet]. 2009;53(11):898–904. Available from: http://dx.doi.org/10.1111/j.1365-2788.2009.01201.x
4. 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 [Internet]. 2016;106(8):1483–90. Available from: http://dx.doi.org/10.2105/AJPH.2016.303240
5. Lauer E, Grossman G, Oxx S, Trafton W, Russell K, 2012 & 2013 Mortality Report. Commonwealth of Massachusetts Executive Office of health & Human Services. Department of Developmental Services. Centre for Developmental Disabilities Evaluation and Research (CDDER). 2014. Available from: https://www.mass.gov/doc/2012-2013-mortality-report/download.
6. Trollor J, Srasuebkul P, Xu H, Howlett S. Cause of death and potentially avoidable deaths in Australian adults with intellectual disability using retrospective linked data. BMJ Open [Internet]. 2017;7(2):e013489. Available from: http://dx.doi.org/10.1136/bmjopen-2016-013489
7. Brameld K, Spilsbury K, Rosenwax L, Leonard H, Semmens J. Use of health services in the last year of life and cause of death in people with intellectual disability: a retrospective matched cohort study. BMJ Open [Internet]. 2018;8(2):e020268. Available from: http://dx.doi.org/10.1136/bmjopen-2017-020268
8. Office for National Statistics (ONS). Avoidable mortality in the UK. Quality and methodology information. 2022. Available from: https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/causesofdeath/methodologies/avoidablemortalityinenglandandwalesqmi
9. Office for National Statistics (ONS). Consultation response: review of avoidable mortality definition. 2016. Available from: https://www.ons.gov.uk/aboutus/whatwedo/statistics/consultationsandsurveys/allconsultationsandsurveys/reviewofavoidablemortalitydefinition
10. 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 [Internet]. 2014;383(9920):889–95. Available from: http://dx.doi.org/10.1016/S0140-6736(13)62026-7
11. Glover G, Williams R, Heslop P, Oyinlola J, Grey J. Mortality in people with intellectual disabilities in England. J Intellect Disabil Res [Internet]. 2017;61(1):62–74. Available from: http://dx.doi.org/10.1111/jir.12314
12. Lin E, Lunsky Y, Chung H, Durbin A, Volpe T, Dobranowski K, Benadict M B, Balogh R. Amenable deaths among adults with intellectual and developmental disabilities including Down syndrome: An Ontario population-based cohort study. J Appl Res Intellect Disabil [Internet]. 2023;36(1):165–175. Available from: https://doi.org/10.1111/jar.13047

13. Stankiewicz E, Ouellette-Kuntz H, McIsaac M, Shooshtari S, Balogh R. Patterns of mortality among adults with intellectual and developmental disabilities in Ontario. Can J Public Health [Internet]. 2018;109(5/6):866–872. Available from: https://doi.org/10.17269/s41997-018-0124-8
14. Shooshtari S, Ouellette-Kuntz H, Balogh R, McIsaac M, Stankiewicz E, Dik N, Burchill C. Patterns of mortality among adults with intellectual and developmental disabilities in the Canadian province of Manitoba. J Policy Pract Intellect Disabil [Internet]. 2020;17(3), 270–278. Available from: https://doi.org/10.1111/jppi.12346
15. Cooper S-A, Henderson A, Kinnear D, Mackay D, Fleming M, Smith GS, et al. Cohort profile: Scotland's record-linkage e-cohorts of people with intellectual disabilities, and autistic people (SCIDA). BMJ Open [Internet]. 2022;12(5):e057230. Available from: http://dx.doi.org/10.1136/bmjopen-2021-057230
16. National Records of Scotland (NRS). 2011 Census Release 1C - How the 2011 Census population estimates were obtained. Edinburgh: National Records of Scotland. 2013.
17. World Health Organization (WHO). International Statistical Classification of Diseases and Related Health Problems, 10th revision. Geneva: World Health Organization. 1992.
18. World Health Organization (WHO). International Statistical Classification of Diseases and Related Health Problems, 10th revision. 2010; Volume 2. Instruction manual. Available from: https://icd.who.int/browse10/Content/statichtml/ICD10Volume2_en_2010.pdf
19. Patja K, Mölsä P, Livanainen M. Cause-specific mortality of people with intellectual disability in a population-based, 35-year follow-up study: Cause-specific mortality. J Intellect Disabil Res [Internet]. 2001;45(1):30–40. Available from: http://dx.doi.org/10.1111/j.1365-2788.2001.00290.x
20. Arvio M, Salokivi T, Tiitinen A, Haataja L. Mortality in individuals with intellectual disabilities in Finland. Brain Behav [Internet]. 2016;6(2):e00431. Available from: http://dx.doi.org/10.1002/brb3.431
21. Landes SD, Turk MA, Finan JM. Factors associated with the reporting of Down syndrome as the underlying cause of death on US death certificates. J Intellect Disabil Res [Internet]. 2022;66(5):454–70. Available from: http://dx.doi.org/10.1111/jir.12926
22. Cooper S-A, Henderson A, Jacobs M, Smiley E. What Are Learning Disabilities? How Common Are Learning Disabilities? Scottish Learning Disabilities Observatory. 2016. Available from: https://www.sldo.ac.uk/media/1610/what-are-learning-disabilities-how-common-are-learning-disabilities.pdf

Table 1. Demographic information in 2011* for adults with and without intellectual disabilities

Demographic information*	Intellectual disabilities	Controls	P value †
Total, n (person-years)	14,477 (113,043.63)	506,207 (415,9808.6)	
Male sex, n (%)	7,927 (54.8%)	238,036 (47.0%)	<0.001
Co-occurring Autism			
Total n (%)	1,631 (11.3%)	-	
Male sex n (%)	1,017 (7.0%)	-	
Age, n (%) at time of Census			
25-34	2,974 (20.5%)	83,868 (16.6%)	<0.001
35-44	3,276 (22.6%)	97,881 (19.3%)	
45-54	3,663 (25.3%)	108,048 (21.3%)	
55-64	2,493 (17.2%)	92,693 (18.3%)	
65-74	1,330 (9.2%)	67,519 (13.3%)	
75+	741 (5.1%)	56,198 (11.1%)	
SIMD quintile, n (%) at time of Census			
1 (most deprived)	4,226 (29.2%)	91,378 (18.1%)	<0.001
2	3,781 (26.1%)	98,114 (19.4%)	
3	2,950 (20.4%)	104,062 (20.6%)	
4	2,209 (15.3%)	108,765 (21.5%)	
5 (least deprived)	1,311 (9.1%)	103,888 (20.5%)	
Deaths, crude rate per 100,000 (CI)**	3033.342 (2933.494-3136.588)	1674.140 (1661.752-1686.62)	

*Data taken from time of Census
**58 individuals aged 25+ had a record of death which occurred before the date of the Census and 13 individuals died on the day of the Census; both groups were removed
51 cases without intellectual disabilities or autism died during the study but had their cause of death recorded as a form of intellectual disability/autism and were subsequently removed from the study
† X^2 test for intellectual disabilities compared with control group (For age and SIMD, X^2 test was performed across all categories, overall *p* value)
Abbreviations: CI=Confidence interval; SIMD=Scottish Index of Multiple Deprivation

Table 2. Standardised Mortality Ratios (SMRs) for adults with intellectual disabilities compared to controls for age, sex, and deprivation (SIMD)

Demographic variables	All deaths SMR (95% CI)	Avoidable deaths SMR (95% CI)	Treatable deaths SMR (95% CI)	Preventable deaths SMR (95% CI)
Age				
Overall Age-SMR	3.130 (3.027-3.236)	3.227 (3.041-3.425)	4.490 (4.174-4.829)	2.511 (2.329-2.707)
25-34	6.400 (5.489-7.462)	4.196 (3.351-5.254)	8.685 (6.463-11.67)	2.781 (2.069-3.737)
35-44	5.139 (4.589-5.755)	3.818 (3.267-4.463)	5.676 (4.675-6.890)	2.540 (2.051-3.145)
45-54	5.299 (4.931-5.695)	3.414 (3.070-3.795)	4.480 (3.926-5.111)	2.715 (2.375-3.103)
55-64	4.143 (3.882-4.422)	3.015 (2.753-3.301)	4.214 (3.780-4.698)	2.422 (2.164-2.710)
65-74	2.522 (2.344-2.713)	1.980 (1.474-2.661)	2.652 (1.854-3.793)	1.946 (1.397-2.711)
75+	1.632 (1.506-1.767)	-	-	-
Sex				
Overall Sex-SMR	1.808 (1.748-1.869)	2.734 (2.576-2.901)	3.796 (3.529-4.083)	2.095 (1.943-2.258)
Male	1.682 (1.605-1.762)	2.362 (2.183-2.555)	3.269 (2.962-3.608)	1.822 (1.655-2.005)
Female	1.967 (1.875-2.065)	3.453 (3.153-3.780)	4.714 (4.229-5.255)	2.745 (2.433-3.097)
SIMD				
Overall SIMD-SMR	1.688 (1.632-1.745)	2.446 (2.305-2.596)	3.451 (3.209-3.713)	1.878 (1.743-2.025)
1 (most deprived)	1.380 (1.296-1.470)	1.850 (1.664-2.057)	2.565 (2.242-2.933)	1.462 (1.283-1.666)
2	1.587 (1.487-1.693)	2.488 (2.223-2.784)	3.573 (3.114-4.100)	1.889 (1.638-2.179)
3	1.907 (1.773-2.052)	3.075 (2.703-3.500)	4.172 (3.562-4.886)	2.354 (1.996-2.777)
4	2.031 (1.863-2.215)	2.941 (2.471-3.499)	4.298 (3.511-5.261)	2.316 (1.855-2.892)
5 (least deprived)	2.459 (2.206-2.741)	4.356 (3.517-5.395)	5.501 (4.253-7.116)	3.271 (2.458-4.354)

Abbreviations:
SMR=Standardised Mortality Ratio; CI=confidence interval

Table 3. Crude mortality rates per 100,000 person-years and standardised mortality ratios for underlying causes of death and all contributing factors in death by ICD-10 chapters for adults aged 25+ with and without intellectual disabilities

ICD-10 Chapter	Underlying cause of death						
	Intellectual disabilities		Controls		SMR (95% CI)		
	N (%)	CMR (95% CI)	N (%)	CMR (95% CI)	All	Men	Women
Ch. 1. Certain infectious and parasite diseases	53 (1.5%)	46.885 (35.819-61.369)	838 (1.2%)	20.145 (18.826-21.556)	4.144 (3.166-5.425)	4.434 (3.100-6.341)	3.728 (2.477-5.610)
Ch. 2. Neoplasms	489 (14.3%)	432.576 (395.886-472.667)	20,667 (29.7%)	496.826 (490.098-503.616)	1.366 (1.250-1.492)	1.234 (1.090-1.396)	1.510 (1.330-1.714)
Ch. 3. Diseases of the blood, blood-forming organs and immune mechanism	<10	-	135 (0.2%)	3.245 (2.742-3.842)	-	-	-
Ch. 4. Endocrine, nutritional and metabolic diseases	90 (2.6%)	79.615 (64.755-97.886)	1,389 (2.0%)	33.391 (31.680-35.194)	3.149 (1.501-6.605)	3.573 (2.715-4.701)	3.919 (2.863-5.364)
Ch. 5. Mental and behavioural disorders	243 (7.1%)	214.961 (189.564-243.761)	5,084 (7.3%)	122.217 (118.903-125.623)	3.919 (3.456-4.444)	3.961 (3.283-4.778)	3.833 (3.236-4.540)
Ch. 6. Diseases of the nervous system	442 (12.9%)	390.999 (356.196-429.204)	3981 (5.7%)	95.702 (92.774-98.721)	7.771 (7.080-8.531)	7.580 (6.631-8.664)	7.842 (6.885-8.931)
Ch. 7. Diseases of the eye and adnexa	<5	-	<5	-	-	-	-
Ch. 8. Diseases of the ear and mastoid process	<5	-	<5	-	-	-	-
Ch. 9. Diseases of the circulatory system	692 (20.2%)	612.1530 (568.201-659.505)	19093 (27.4%)	458.987 (452.523-465.544)	2.455 (2.278-2.645)	2.220 (2.006-2.456)	2.634 (2.360-2.941)
Ch. 10. Diseases of the respiratory system	484 (14.1%)	428.153 (391.659-468.048)	8716 (12.5%)	209.529 (205.176-213.984)	3.930 (3.595-4.296)	4.095 (3.628-4.622)	3.696 (3.240-4.215)
Ch. 11. Diseases of the digestive system	166 (4.8%)	146.846 (126.124-170.973)	3616 (5.2%)	86.927 (84.139-89.807)	2.548 (2.188-2.967)	2.328 (1.889-2.869)	2.732 (2.189-3.411)
Ch. 12. Diseases of the skin and subcutaneous tissue	12 (0.3%)[u]	10.615 (6.029-18.692)[u]	226 (0.3%)	5.433 (4.769-6.190)	3.483 (1.978-6.133)[u]	-	-
Ch. 13. Diseases of the musculoskeletal system and connective tissue	22 (0.6%)	19.461 (12.814-29.557)	449 (0.6%)	10.794 (9.840-11.840)	3.152 (2.075-4.787)	4.086 (2.263-7.378)[u]	2.631 (1.457-4.751)[u]
Ch. 14. Diseases of the genitourinary system	98 (2.9%)	86.692 (71.121-105.673)	1364 (2.0%)	32.790 (31.095-34.577)	5.602 (4.595-6.828)	6.460 (4.896-8.523)	4.919 (3.707-6.527)
Ch. 15. Pregnancy, childbirth and puerperium	<5	-	<5	-	-	-	-
Ch. 16. Certain conditions originating in the perinatal period	<5	-	<5	-	-	-	
Ch. 17. Congenital malformations, deformations and chromosomal abnormalities	426 (12.4%)	376.846 (342.707-414.385)	65 (0.1%)	1.563 (1.225-1.993)	259.5 (236.0-285.4)	224.4 (196.9-255.8)	306.5 (267.0-351.8)
Ch. 18. Symptoms, signs and abnormal clinical and laboratory findings	56 (1.6%)	49.538 (38.124-64.371)	936 (1.3%)	22.501 (21.105-23.990)	3.110 (2.393-4.041)	2.240 (1.488-3.370)	4.002 (2.845-5.629)
Ch. 19. Injury, poisoning and certain other consequences of external causes	<5	-	<5	-	-	-	-
Ch. 20. External causes of morbidity and mortality	115 (3.4%)	101.731 (84.738-122.131)	2,571 (3.7%)	61.806 (59.462-64.242)	2.118 (1.764-2.543)	1.719 (1.353-2.185)	2.636 (1.986-3.498)
Unknown cause of death or error in underlying cause of death code	<5	-	<5	-	-	-	-

Total number of deaths	3,429 (100%)	3033.342 (2933.494-3136.588)	69,641 (100%)	1674.140 (1661.752-1686.62)	3.130 (3.027-3.236)	2.882 (2.751-3.019)	3.329 (3.172-3.494)
ICD-10 Chapter	All contributing factors in death						
	Intellectual disabilities		Controls		SMR (95% CI)		
	N	CMR (95% CI)	N	CMR (95% CI)	All	Men	Women
Ch. 1. Certain infectious and parasite diseases	241 (7.0%)	213.192 (187.906-241.881)	3,774 (5.4%)	90.725 (87.877-93.667)	3.929 (3.463-4.457)	3.848 (3.242-4.567)	3.915 (3.248-4.719)
Ch. 2. Neoplasms	572 (16.7%)	505.999 (466.186-549.213)	23,717 (34.1%)	570.146 (562.936-577.48)	1.422 (1.310-1.544)	1.298 (1.159-1.454)	1.554 (1.380-1.750)
Ch. 3. Diseases of the blood, blood-forming organs and immune mechanism	33 (1.0%)	29.192 (20.754-41.062)	1,001 (1.4%)	24.064 (22.618-25.601)	2.151 (1.529-3.025)	1.566 (0.909-2.696)[u]	2.783 (1.796-4.314)[u]
Ch. 4. Endocrine, nutritional and metabolic diseases	467 (13.6%)	413.115 (377.296-452.335)	8,672 (12.5%)	208.471 (204.129-212.95)	3.327 (3.039-3.643)	2.706 (2.381-3.076)	4.071 (3.581-4.629)
Ch. 5. Mental and behavioural disorders	944 (27.5%)	835.076 (783.469-890.082)	10,899 (15.7%)	262.007 (257.134-266.93)	6.330 (5.939-6.747)	6.151 (5.625-6.726)	6.281 (5.734-6.880)
Ch. 6. Diseases of the nervous system	943 (27.5%)	834.191 (782.612-889.170)	7,266 (10.4%)	174.672 (170.701-178.74)	8.890 (8.341-9.476)	8.473 (7.747-9.267)	9.112 (8.319-9.980)
Ch. 7. Diseases of the eye and adnexa	<5	-	41 (0.06%)	0.986 (0.726-1.33)	-	-	-
Ch. 8. Diseases of the ear and mastoid process	<5	-	11 (0.02%)	0.264 (0.146-0.47)	-	-	-
Ch. 9. Diseases of the circulatory system	1,271 (37.1%)	1124.345 (1064.201-1187.888)	35,223 (50.6%)	846.746 (837.948-855.635)	2.459 (2.328-2.598)	2.231 (2.069-2.406)	2.644 (2.440-2.865)
Ch. 10. Diseases of the respiratory system	1,616 (47,1%)	1429.537 (1361.51-1500.962)	24,834 (35.7%)	596.999 (589.620-604.41)	4.506 (4.291-4.731)	4.400 (4.118-4.702)	4.506 (4.193-4.842)
Ch. 11. Diseases of the digestive system	288 (8.4%)	254.769 (226.981-285.959)	6,824 (9.8%)	164.046 (160.200-167.95)	2.374 (2.115-2.664)	2.248 (1.926-2.624)	2.440 (2.051-2.904)
Ch. 12. Diseases of the skin and subcutaneous tissue	46 (1.3%)	40.692 (30.480-54.327)	727 (1.0%)	17.477 (16.251-18.795)	4.173 (3.126-5.572)	3.857 (2.515-5.916)	4.443 (3.002-6.575)
Ch. 13. Diseases of the musculoskeletal system and connective tissue	62 (1.8%)	54.846 (42.761-70.347)	1,791 (2.6%)	43.055 (41.106-45.096)	2.324 (1.812-2.981)	2.672 (1.845-3.870)	2.143 (1.531-3.000)
Ch. 14. Diseases of the genitourinary system	379 (11.1%)	335.269 (303.159-370.780)	8,911 (12.8%)	214.217 (209.815-218.71)	3.150 (2.848-3.484)	3.261 (2.840-3.744)	2.984 (2.576-3.456)
Ch. 15. Pregnancy, childbirth and puerperium	<5	-	<5	-	-	-	-
Ch. 16. Certain conditions originating in the perinatal period	<5	-	<5	-	-	-	-
Ch. 17. Congenital malformations, deformations and chromosomal abnormalities	742 (21.6%)	656.384 (610.814-705.353)	127 (0.2%)	3.053 (2.566-3.633)	238.3 (221.8-256.1)	207.5 (188.2-228.9)	275.2 (247.5-306.0)
Ch. 18. Symptoms, signs and abnormal clinical and laboratory findings	521 (15.2%)	460.884 (422.961-502.208)	9,745 (14.0%)	234.266 (229.660-238.93)	3.808 (3.494-4.149)	3.784 (3.342-4.284)	3.763 (3.341-4.237)
Ch. 19. Injury, poisoning and certain other consequences of external causes	194 (5.7%)	171.615 (149.088-197.546)	4,068 (5.8%)	97.793 (94.834-100.845)	2.506 (2.177-2.885)	2.309 (1.928-2.766)	2.585 (2.064-3.237)
Ch. 20. External causes of morbidity and mortality	234 (6.8%)	207.000 (182.106-235.296)	4,927 (7.1%)	118.443 (115.182-121.797)	2.565 (2.257-2.916)	2.313 (1.957-2.733)	2.749 (2.251-3.358)
Unknown cause of death or error in underlying cause of death code	<5	-	<5	-	-	-	-
Total number of deaths	3,429 (100%)	3033.342 (2933.494-3136.588)	69,641 (100%)	1674.140 (1661.752-1686.62)	3.130 (3.027-3.236)	2.882 (2.751-3.019)	3.329 (3.172-3.494)

*n<5 repressed due to statistical disclosure; CMR, crude mortality rate – reported for ≥ 10 deaths; ICD-10, International Classification of Diseases, Tenth Revision; CMR rates based on 10-20 deaths labelled “u” for unreliable

Table 4. Most common causes of death in adults with and without intellectual disabilities

	Underlying causes of deaths			
	Intellectual disabilities		Controls	
	Cause (n)	ICD codes	Cause (n)	ICD codes
1	Down Syndrome (n=341)	Q90.0, Q90.1, Q90.2, **Q90.9**	Malignant neoplasm of bronchus and lung (n=5,163)	**C34.0, C34.1, C34.2, C34.3, C34.8, C34.9**
2	Dementia (n=227)	F00.0, F00.1, F00.2, F00.9, **F03, G30.0, G30.1**, G30.8, **G30.9**	Acute myocardial infarction (n=4,907)	I21.0, I21.1, I21.2, I21.3, **I21.4, I21.9**
3	Acute myocardial infarction (n=158)	I21.0, I21.1, I21.2, I21.3, I21.4, **I21.9**	Dementia (n=4,857)	F00.0, F00.1, F00.2, F00.9, **F03, G30.0, G30.1**, G30.8, **G30.9**
4	Pneumonia, organism unspecified (n=150)	J18.0, J18.1, J18.2, J18.8, **J18.9**	Other chronic obstructive pulmonary disease (n=3,720)	**J44.0, J44.1, J44.8, J44.9**
5	Epilepsy (n=137)	G40.0, G40.1, G40.2, G40.3, G40.4, G40.5, **G40.6,** G40.7, G40.8, **G40.9,** G41.0, G41.1, G41.2, G41.8, **G41.9**	Chronic Ischaemic heart disease (n=3,[illegible])	**I25.0, I25.1,** I25.2, **I25.3, I25.4, I25.5**, I25.6, I25.7, **I25.8, I25.9**
6	Pneumonitis due to solids and liquids (n=128)	**J69.0**, J69.1, J69.8	Intracerebral haemorrhage, cerebral infarction, and stroke, not specified as haemorrhage or infarction (n=2,814)	**I61.0, I61.2, I61.3, I61.4, I61.5, I61.6, I61.8, I61.9, I63.0,** I63.1**, I63.2, I63.3, I63.4, I63.5,** I63.6**, I63.8, I63.9, I64**
7	Cerebral palsy (n=123)	**G80.0, G80.1,** G80.2, G80.3, G80.4, **G80.8, G80.9**	Pneumonia, organism unspecified (n=2,[illegible])	**J18.0, J18.1, J18.2,** J18.8, J18.9
8	Intracerebral haemorrhage, cerebral infarction, and stroke, not specified as haemorrhage or infarction (n=111)	**I61.0,** I61.2, I61.3, **I61.4,** I61.5, **I61.6,** I61.8, **I61.9,** I63.0, I63.1, I63.2, **I63.3,** I63.4, **I63.5, I63.6,** I63.8, **I63.9, I64**	Vascular dementia (n=2,136)	F01.0, **F01.1, F01.2, F01.3**, F01.8, **F01.9**
9	Chronic Ischaemic heart disease (n=110)	**I25.0, I25.1,** I25.2, I25.3, I25.4, I25.5, I25.6, I25.7, **I25.8, I25.9**	Malignant neoplasm of breast unspecified (n=1,303)	C50.0, C50.1, C50.2, C50.3, C50.5, C50.6, C50.8, **C50.9**
10	Other chronic obstructive pulmonary disease (n=78)	**J44.0, J44.1, J44.8, J44.9**	Malignant neoplasm of prostate (n=1,287)	**C61**
11	Malignant neoplasm of bronchus and lung (n=67)	**C34.0, C34.1,** C34.2, **C34.3,** C34.8, **C34.9**	Accidents: Other external causes of accidental injury: Falls (n=1,005)	**W19**
12	Vascular dementia (n=61)	F01.0, **F01.1,** F01.2, F01.3, F01.8, **F01.9**	Malignant neoplasm of oesophagus (n=999)	**C15.9**
13	Urinary tract infection (n=48)	**N39.0**	Sequelae of other and unspecified cerebrovascular diseases (n=996)	**I69.8**
14	Other specified respiratory disorders (n=41)	**J98.8**	Malignant neoplasm: pancreas (n=886)	**C25.9**
15	Other ill identified cause of mortality (n=38)	**R99**	Malignant neoplasm: colon (n=728)	**C18.9**
16	Sequelae of other and unspecified cerebrovascular diseases (n=37)	**I69.8**	Urinary tract infection (n=638)	**N39.0**
17	Malignant neoplasm of oesophagus (n=33)	**C15.9**	Malignant neoplasm: bladder (n=628)	**C67.9**
18	Malignant neoplasm of breast (n=30): C50.0, C50.1, C50.2, C50.3, C50.5, C50.6, C50.8, **C50.9** Malignant neoplasm, site unspecified (n=30): **C80**		Malignant neoplasm, site unspecified (n=594)	**C80**
19	Developmental disorder of scholastic skills, unspecified (n=28)	**F81.9**	Other interstitial pulmonary diseases with fibrosis (n=576)	**J84.1**
20	Sepsis, unspecified (n=26)	**A41.9**	Parkinson disease (n=554)	**G20**

	All contributing factors in deaths			
	Intellectual disabilities		Controls	
	Cause (n)	ICD codes	Cause (n)	ICD codes
1	Pneumonia, organism unspecified (n=731)	**J18.0, J18.1, J18.2,** J18.8, **J18.9**	Chronic Ischaemic heart disease (n=12,607)	**I25.0, I25.1,** I25.2, **I25.3, I25.4, I25.5,** I25.6, I25.7, **I25.8, I25.9**
2	Down syndrome (n=593)	Q90.0, Q90.1, Q90.2, **Q90.9**	Pneumonia, organism unspecified (n=8,833)	**J18.0, J18.1, J18.2, J18.8, J18.9**
3	Pneumonitis due to solids and liquids (n=487)	**J69.0,** J69.1, J69.8	Other chronic obstructive pulmonary disease (n=9,012)	**J44.0, J44.1, J44.8, J44.9**
4	Epilepsy (n=412)	G40.0, G40.1, **G40.2, G40.3, G40.4,** G40.5, **G40.6,** G40.7, G40.8, **G40.9,** G41.0, G41.1, G41.2, G41.8, **G41.9**	Dementia (n=8,474)	F00.0, F00.1, F00.2, F00.9, **F03, G30.0, G30.1, G30.8, G30.9**
5	Developmental disorder of scholastic skills, unspecified (n=380)	**F81.9**	Acute myocardial infarction (n=5,968)	**I21.0,** I21.1, I21.2, I21.3, **I21.4, I21.9**
6	Dementia (n=357)	F00.0, F00.1, F00.2, F00.9, **F03, G30.0, G30.1,** G30.8, **G30.9**	Essential primary hypertension (n=5,883)	**I10.0**
7	Chronic ischemic heart disease (n=295)	**I25.0, I25.1,** I25.2, I25.3, I25.4, I25.5, I25.6, I25.7, **I25.8,** I25.9	Malignant neoplasm of bronchus and lung (n=5,727)	**C34.0, C34.1, C34.2, C34.3, C34.8, C34.**9
8	Cerebral Palsy (n=215)	**G80.0, G80.1,** G80.3, G80.4, **G80.8, G80.9**	Other general symptoms and signs (n=5,058)	**R68.8**
9	Acute myocardial infarction (n=202)	I21.0, I21.1, I21.2, I21.3, I21.4, **I21.9**	Intracerebral haemorrhage, cerebral infarction, and stroke, not specified as haemorrhage or infarction (n=4,733)	**I61.0, I61.1, I61.2, I61.3, I61.4, I61.5, I61.6, I61.8, I61.9, I63.0,** I63.1, **I63.2, I63.3, I63.4, I63.5, I63.6, I63.8, I63.9, I64**
10	Diabetes without complications (n=196)	**E11.9**	Diabetes without complications (n=4,485)	**E11.9**
11	Other general symptoms and signs (n=185)	**R68.8**	Vascular dementia (n=3,948)	F01.0, **F01.1, F01.2, F01.3,** F01.8, **F01.9**
12	Intracerebral haemorrhage, cerebral infarction, and stroke, not specified as haemorrhage or infarction (n=178)	**I61.0,** I61.1, I61.2, I61.3, **I61.4, I61.5, I61.6,** I61.8, **I61.9,** I63.0, I63.1, **I63.2, I63.3,** I63.4, **I63.5, I63.6, I63.9, I64**	Pneumonitis due to solids and liquids (n=2,945)	**J69.0,** J69.1, **J69.8**
13	Sepsis, unspecified (n=173)	**A41.9**	Atrial fibrillation and flutter (n=2,734)	**I48**
14	Other chronic obstructive pulmonary disease (n=165)	J44.0, **J44.1, J44.8, J44.9**	Sepsis, unspecified (n=2,522)	**A41.9**
15	Essential primary hypertension (n=130)	**I10**	Age related physical debility (n=2,513)	**R54**
16	Unspecified acute lower respiratory infection (n=127)	**J22**	Congestive Heart Failure (n=2,439)	**I50.0**
17	Urinary tract infection site not specified (n=113)	**N39.0**	Sequelae of other and unspecified cerebrovascular diseases (n=2,346)	**I69.8**
18	Acute renal failure unspecified (n=86)	**N17.9**	Unspecified acute lower respiratory infection (n=2,229)	**J22**
19	Congestive Heart Failure (n=82)	**I50.0**	Atrial fibrillation and atrial flutter, unspecified (n=2,213)	**I48.9**
20	Other respiratory disorders (n=81)	**J98.8**	Acute renal failure, unspecified (n=2,190)	**N17.9**

NB: While all codes included in the ICD-10 groupings are listed above, the highlights in **bold** refer to those codes, which were present in the data.

Table 5. All-cause, avoidable, treatable, and preventable underlying cause of deaths for adults with and without intellectual disabilities

Variable	Deaths in group with intellectual disabilities (N)				Deaths in controls (N)				HR (95% CI)
	All	Avoidable*	Treatable*	Preventable*	All	Avoidable*	Treatable*	Preventable*	†a (All) †b (Avoidable) †c (Treatable) †d (Preventable)
Total	3,429	1,087	722	681	69,641	12,673	6,110	20,207	†a 3.304 (3.192-3.420) **2.978 (2.877-3.084) †b 3.350 (3.148-3.564) **2.701 (2.538-2.876) †c 4.672 (4.325-5.048) **3.903 (3.609-4.220) †d 2.611 (2.416-2.822) **2.042 (1.889-2.208)
Age									
25-34	163	76	44	44	734	522	146	456	†a 3.324 (3.211-3.440) †b 3.351 (3.149-3.565) †c 4.674 (4.326-5.050) †d 2.611 (2.416-2.822)
35-44	300	158	102	84	1,793	1,271	552	1,016	
45-54	740	342	221	215	4,410	3,164	1,558	2,501	
55-64	907	467	325	303	9,369	6,630	3,301	5,355	
65-74	717	44	30	35	17,169	1,086	553	3,879	
75+	602	0	0	0	36,166	0	0	0	
Sex									
Male	1784	619	395	417	33,222	7,413	3,418	9,475	†a 3.259 (3.148-3.373) †b 3.274 (3.077-3.483) †c 4.597 (4.255-4.967) †d 2.522 (2.333-2.726)
Female	1645	468	327	264	36,419	5,260	2,692	10,732	
SIMD									
1 (most deprived)	962	342	213	226	15,469	3,738	1,679	5,125	†a 3.019 (2.916-3.125) †b 2.768 (2.600-2.946) †c 3.970 (3.671-4.292) †d 2.119 (1.960-2.291)
2	908	304	203	189	15,467	2,938	1,366	4,405	
3	721	230	154	141	14,127	2,490	1,229	3,994	
4	512	127	94	78	13,159	2,020	1,023	3,575	
5 (least deprived)	326	84	58	47	11,419	1,487	813	3,108	

*Deaths at age 25-74 only as per the ONS definition of avoidable mortality
Abbreviations: SIMD=Scottish Index of Multiple Deprivation; HR=hazard ratio; CI=confidence interval
†a-d - Cox regression hazard ratio for risk of deaths (all, avoidable, treatable and preventable) by intellectual disabilities versus controls (total column = unadjusted and **adjusted for age, sex and SIMD)
Reference groups: no intellectual disabilities, male, most deprived, age (continuous)

Supplemental Table 1. Crude mortality rates (CMRs) for adults with intellectual disabilities per 100,000 by age, sex, and deprivation (SIMD)

Variable	All deaths CMR (95% CI)	Avoidable deaths CMR (95% CI)	Treatable deaths CMR (95% CI)	Preventable deaths CMR (95% CI)
All deaths	3033.342 (2933.494-3136.588)	1061.407 (1000.147-1126.418)	705.000 (655.407-758.347)	664.966 (616.852-716.832)
Age				
25-34	641.267 (550.006-747.670)	298.996 (238.795-374.373)	173.103 (128.819-232.609)	173.103 (128.819-232.609)
35-44	1082.162 (966.380-1211.815)	569.939 (487.652-666.11)	367.935 (303.033-446.738)	303.005 (244.668-375.253)
45-54	2508.555 (2334.172-2695.966)	1159.359 (1042.774-1288.979)	749.177 (656.638-851.756)	728.837 (637.645-833.071)
55-64	4980.093 (4666.312-5314.974)	2564.171 (2341.845-2807.605)	1784.488 (1600.654-1989.435)	1663.691 (1486.526-1861.971)
65-74	8168.600 (7592.048-8788.937)	2822.336 (2100.319-3792.557)	1924.320 (1345.457-2752.23)	2245.040 (1611.925-3126.823)
75+	17634.187 (16280.32-19100.64)	-	-	-
Sex				
Male	2858.277 (2728.673-2994.036)	1080.500 (998.648-1169.062)	689.495 (624.745-760.957)	727.898 (661.282-801.224)
Female	3249.165 (3095.885-3410.034)	1037.165 (947.329-1135.519)	724.686 (650.247-807.646)	585.067 (518.583-660.076)
SIMD				
1 (most deprived)	2889.038 (2712.123-3077.493)	1128.080 (1014.64-1254.202)	702.576 (614.285-803.557)	745.456 (654.336-849.265)
2	3075.061 (2881.414-3281.722)	1136.144 (1015.345-1271.315)	758.675 (661.17-870.539)	706.353 (612.500-814.587)
3	3148.364 (2926.743-3386.768)	1107.029 (972.820-1259.754)	741.228 (632.937-868.048)	678.657 (575.395-800.451)
4	2965.524 (2719.464-3233.848)	818.743 (688.044-974.271)	605.999 (495.082-741.766)	502.850 (402.772-627.796)

5 (least deprived)	3243.259 (2909.631-3615.142)	928.258 (749.540-1149.589)	640.940 (495.506-829.360)	519.383 (390.236-691.270)

Abbreviations: CMR=Crude Mortality Rate; CI=confidence interval

Supplemental Table 2. Crude mortality rates (CMRs) for adults without intellectual disabilities per 100,000 by age sex, and deprivation (SIMD)

Variable	All deaths CMR (95% CI)	Avoidable deaths CMR (95% CI)	Treatable deaths CMR (95% CI)	Preventable deaths CMR (95% CI)
All deaths	1674.140 (1661.752-1686.62)	375.904 (369.416-382.506)	181.234 (176.746-185.883)	302.758 (296.941-308.689)
Age				
25-34	100.202 (93.209-107.719)	71.260 (65.402-77.643)	19.931 (16.947-23.44)	62.251 (56.791-68.235)
35-44	210.565 (201.041-220.540)	149.263 (141.278-157.698)	64.825 (59.637-70.465)	119.316 (112.201-126.883)
45-54	473.375 (459.608-487.554)	339.628 (327.998-351.670)	167.238 (159.136-175.7)	268.460 (258.143-279.191)
55-64	1201.950 (1177.857-1226.536)	850.563 (830.334-871.286)	423.486 (409.283-438)	686.994 (668.838-705.642)
65-74	3239.052 (3190.963-3287.866)	1425.095 (1342.809-1512.424)	725.670 (667.640-788.7)	1153.461 (1079.674-1232.291)
75+	10808.359 (10697.54-10920.33)	-	-	-
Sex				
Male	1699.664 (1681.485-1718.039)	457.480 (447.184-468.014)	210.936 (203.982-218.12)	399.593 (389.978-409.446)
Female	1651.515 (1634.641-1668.564)	300.410 (292.4-308.639)	153.746 (148.046-159.665)	213.142 (206.413-220.092)
SIMD				
1 (most deprived)	2092.940 (2060.217-2126.183)	609.863 (590.622-629.730)	273.933 (261.138-287.354)	509.851 (492.285-528.043)
2	1938.103 (1907.799-1968.889)	456.686 (440.468-473.502)	212.333 (201.366-223.893)	373.836 (359.190-389.079)
3	1650.828 (1623.829-1678.276)	359.964 (346.099-374.384)	177.669 (168.009-187.886)	288.260 (275.882-301.194)
4	1460.076 (1435.342-1485.237)	278.420 (266.540-290.831)	141.002 (132.621-149.91)	217.085 (206.625-228.075)
5 (least deprived)	1319.1242 (1295.15-1343.542)	213.08986 (202.5298-224.2005)	116.50441 (108.7651-124.7945)	158.778 (149.699-168.408)

Abbreviations: CMR=Crude Mortality Rate; CI=confidence interval

Supplemental Figure 1. Kaplan-Meier survival analysis for risk of death for intellectual disabilities population and controls from 2011-2019