Cancer incidence and mortality in adults with intellectual disabilities

Key Findings

- Adults with intellectual disabilities are three times more likely to die from metastatic cancer of unknown primary origin compared to the general population, indicating a delay to a diagnosis and lifesaving treatment.
- The population with intellectual disabilities are faced with excess cancer deaths, regardless of whether the number of diagnosed cancers were lower, higher, or comparable to the general population.
- Cancer deaths were particularly high for colorectal, kidney, female genital organs, and breast.
- Patterns of cancer incidence and mortality differ between adults with and without intellectual disabilities: Colorectal cancer incidence was lower in men with intellectual disabilities, but mortality rates were almost double, compared to the general population. Breast cancer incidence was lower in women with intellectual disabilities, but mortality rates were almost double, compared to the general population.

Why this study is important

People with intellectual disabilities continue to face significant health inequalities, including a 20-year mortality gap and a higher proportion of avoidable deaths compared with the general population. One of the most common avoidable mortalities is cancer, as many cancers are considered either preventable or treatable. However, there is a lack of robust evidence on cancer incidence and mortality between the population with and without intellectual disabilities.

This is the first study in more than 20 years which reports on the differences in cancer incidence and mortality between the population with intellectual disabilities and the general population. This research is crucial, as healthcare assumptions based on general population evidence are not necessarily applicable for the population with intellectual disabilities.

How we conducted the study

We looked at the entire Scottish population with intellectual disabilities with or without Autism and their experiences of cancer. To do this, we used population data from Scotland's 2011 Census linked to the National Records of Scotland death certificate data and Scottish Cancer Registry (Scottish Morbidity Records 06) held by National Services Scotland. We calculated cancer incidence and mortality rates between March 2011 and December 2019 (pre-COVID 19) from any newly diagnosed cancers (incidence) and cancer-related deaths (mortality) during that period.

Summary of key findings

This study found that adults with intellectual disabilities are more likely to die from cancer compared to the general population. Both the patterns of cancer incidence and mortality differ between adults with and without intellectual disabilities. Adults with intellectual disabilities were 24% less likely to be diagnosed with cancer but were 20% more likely to die from cancer compared to the general population. Adults with intellectual disabilities were most likely diagnosed with cancers of the digestive system, specifically colorectal (bowel), lung and breast. For women with intellectual disabilities, the leading cause of cancer was breast, followed by colorectal and genital organ cancers. For men with intellectual disabilities, the leading cause of cancer was colorectal, followed by genital organs and respiratory cancers.

Adults with intellectual disabilities were more likely to die regardless of whether the number of diagnosed cancers were lower, higher, or comparable to the general population. Cancer deaths were particularly high for colorectal, breast, kidney and female genital organs. Particularly striking was our finding that cancer incidence for metastatic cancer of unknown primary origin (cancer that had spread to other parts of the body) was twice as high in adults with intellectual disabilities, and cancer mortality 3 times higher, compared to the general population, indicating a delay to diagnosis and potentially lifesaving treatment.

Implications for policy and practice

- Our findings regarding metastatic cancers of unknown primary origin could be evidence of a later presentation or delay to diagnosis (therefore poorer outcomes), poorer treatment or both.
- This is the first robust study in Scotland and the UK, reporting on the differences in cancer incidence and mortality between the population with intellectual disabilities and the general population.

- This study is the first known study to report higher rates of cancer incidence and mortality in women with intellectual disabilities regarding female genital cancers, including ovarian and uterine.

Recommendations

- The evidence suggests an urgent need to promote awareness of cancer symptoms among people with intellectual disabilities, carers and clinicians, especially for early detection. These strategies also need to provide clear information and support for people with intellectual disabilities, their families and carers around symptoms to improve early detection.
- There is an urgent need to increase bowel and breast screening participation for people with intellectual disabilities given the increased mortality rates reported in this study.
- Public health strategies must consider the unique needs of people with intellectual disabilities, emphasising accessibility and innovation where existing screening options are not fit for purpose.

Next steps

- The Scottish Learning Disabilities Observatory is collaborating with leading cancer and intellectual disabilities specialists in Scotland (via the University of Glasgow Cancer Research Behaviour Group), Australia, The Netherlands and Ireland to develop further research in this area. In August 2024 the cancer programme lead (DC) hosted a symposium and roundtable discussion on cancer incidence, mortality and screening at the International Association for the Scientific Study of Intellectual and Developmental Disabilities World Conference.
- Further research has been funded by Cancer Research UK to better understand the barriers and facilitators for people with intellectual disabilities in relation to uptake of cancer screening programmes throughout the UK.
- The Observatory has recently received funding to develop and evaluate communication tools for people with intellectual disabilities to talk about cancer screening. This project is co-produced with people with intellectual disabilities and Talking Mats.
- We have identified that further research is required to understand and support the mental health of people with intellectual disabilities in relation to cancer and living with diagnoses and we are seeking funding to investigate this.

Additional Information

Most likely diagnosis in adults with intellectual disabilities:

Type of cancer	Percentage of population of intellectual disabilities with cancer
Digestive, specifically colorectal	Females: 10.0% Males: 18.6%
Lung	Females: 8.1% Males: 10.6%
Breast	Female: 22.9%
Body of the uterus	Female: 9.3%
Genital organs	Female: 17.2% Male: 17.6%

Higher incident cancers:

Type of cancer	Statistically Significant Standardised Incidence Ratio (SIR)
Metastatic cancer of unknown primary origin	Female SIR=1.70 Male SIR=2.08
Body of uterus	Female SIR=1.63
Ovarian	Female SIR = 1.59
Kidney	Female SIR = 1.85
Testicular	Male SIR = 2.49

Excess mortality risk was found for:

Type of cancer	Statistically Significant Standardised Mortality Ratio (SMR)
Metastatic cancer of unknown primary origin	Female SMR = 2.50 Male SMR = 2.84
Colorectal	Male SMR = 1.59
Kidney	Female SMR = 2.85
Breast	Female SMR =1.58
Body of the uterus	Female SMR=2,11
Ovarian	Female SMR=2.86

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