

Cancer Care Inequities in People with Intellectual Disabilities



Evidence from three UK population-based cohort studies covering Bowel, Prostate, and all cancers using linked national health records

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What is cancer?



Cancer is an illness (stops parts of your body working properly).

Cancer can happen to anyone.

If doctors find cancer early, it is easier to treat.

BACKGROUND

A hidden driver of cancer mortality

Intellectual disability (ID), also referred to as learning disability (LD), is a lifelong neurodevelopmental condition affecting intellectual functioning and adaptive behaviour, with onset in childhood.

~200 million

People living with an intellectual disability worldwide (1–3% of the global population)

19–23 years

Shorter average life expectancy for adults with an ID vs the general population

42%

Of deaths in people with an ID are considered preventable



Cancer is increasingly recognised as a hidden driver of this mortality gap — yet, until now, evidence on cancer care and outcomes for this population has remained limited and inconsistent.

NHS Long Term Plan, NICE guidance, and the LeDeR programme all identify this as a UK health priority

METHODS

Three studies, one national dataset

All three studies used the same population-based matched-cohort design, drawing on linked English primary care, hospital, mortality, and cancer registry data.

CPRD Aurum
Primary care records, ~25% of UK population

NCRAS
National Cancer Registration & Analysis Service

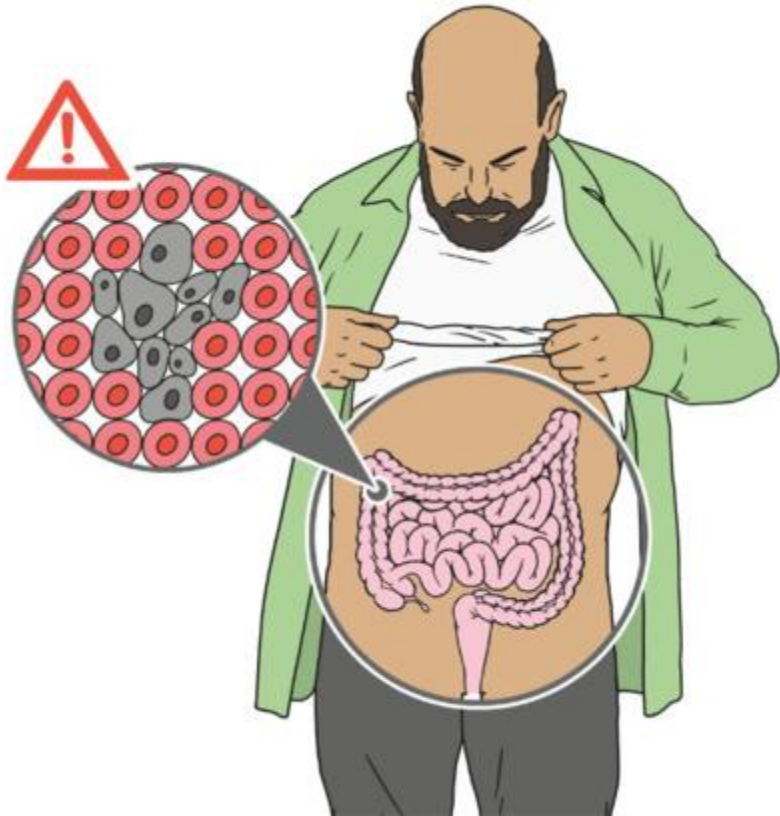
ONS
Office for National Statistics mortality data

HES
Hospital Episode Statistics

Study	Journal	ID / LD group	Comparators
1. Bowel cancer care	BMC Medicine (2026)	111,034 people	1,964,420 people
2. Prostate cancer care	Eur Urol Oncology (2026)	29,554 men	518,739 men
3. All-cancer diagnoses, referrals & survival	Lancet Regional Health – Europe (2025)	180,911 people	3,405,467 people

All studies adjusted for age, ethnicity, and deprivation; outcomes covered symptoms, referral, diagnosis, treatment, and survival

Bowel cancer: getting checked



People with an Intellectual disability can get bowel cancer more often than other people.

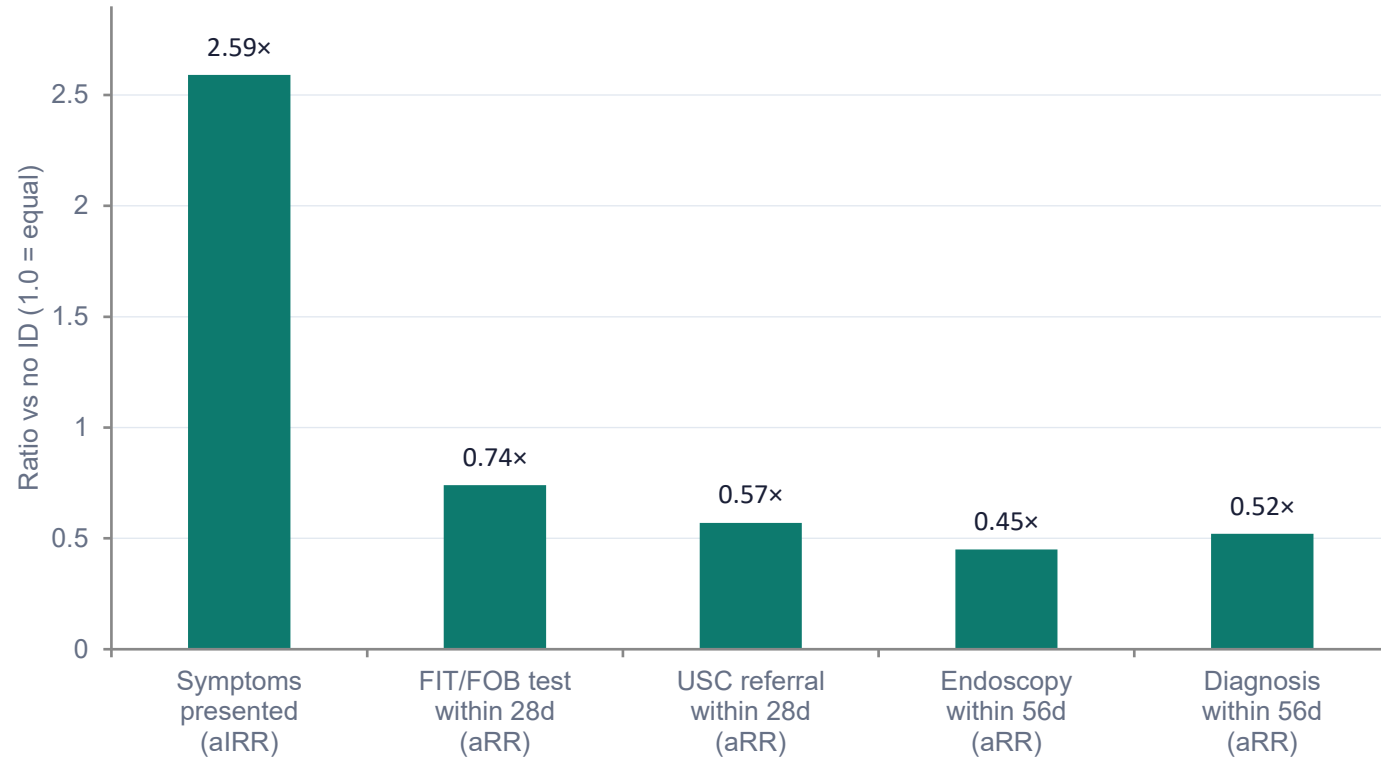
This is especially true for younger people.

They tell their doctor about symptoms often.

But they are less likely to get a poo test or a camera

Bowel cancer: a narrowing pathway to diagnosis

111,034 people with an ID vs 1,964,420 comparators — far more symptoms, but less investigation at every step that follows.

**2.59x**

Higher incidence of symptoms suggestive of bowel cancer (aIRR, 95% CI 2.53–2.65)

0.45x

As likely to have an endoscopy within 56 days of a first symptom (aRR, 95% CI 0.42–0.49)

0.27x

As likely to be diagnosed via a screening programme (aRR, 95% CI 0.14–0.50)

Bowel cancer: People with an Intellectual disability



Less likely to be found through cancer screening.



More likely to be found late, or in an emergency.



If cancer has spread, they are less likely to get strong medicine.



More likely to die from bowel cancer.

Later diagnosis, worse survival

1.76×

More likely to be diagnosed via emergency presentation

5.08×

Higher risk of the diagnosis being first recorded on the date of death

1.25×

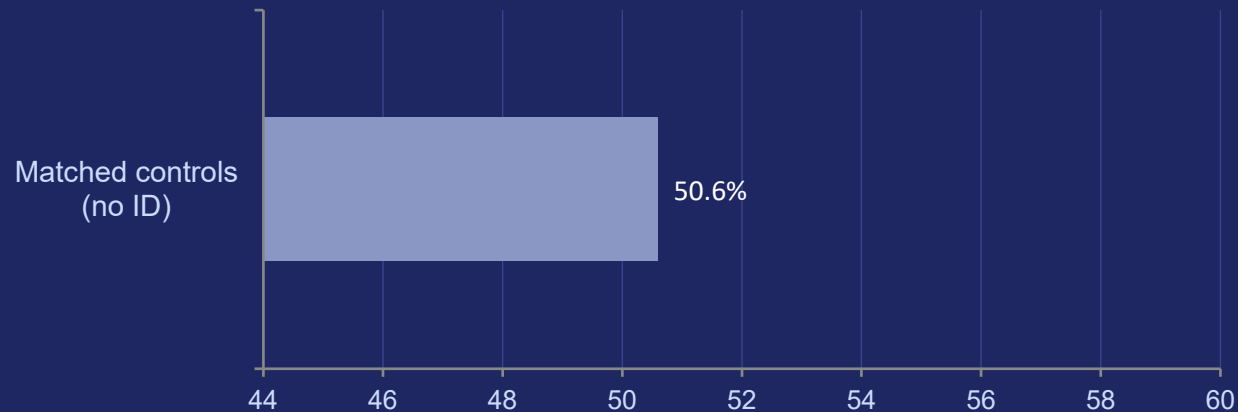
More likely to be diagnosed with stage IV disease

2.00×

Higher risk of death from bowel cancer after diagnosis

Treatment access narrows sharply for stage IV disease

Receipt of systemic anticancer therapy (SACT) within 6 months, stage IV disease



Fewer than 5 of 34 people with an ID and metastatic disease received SACT within 6 months (RR 0.15, 95% CI 0.05–0.46) — versus 241 of 476 (50.6%) without an ID. Curative surgery rates for stage I–III disease, by contrast, were similar between groups (RR 0.98, 0.79–1.19).

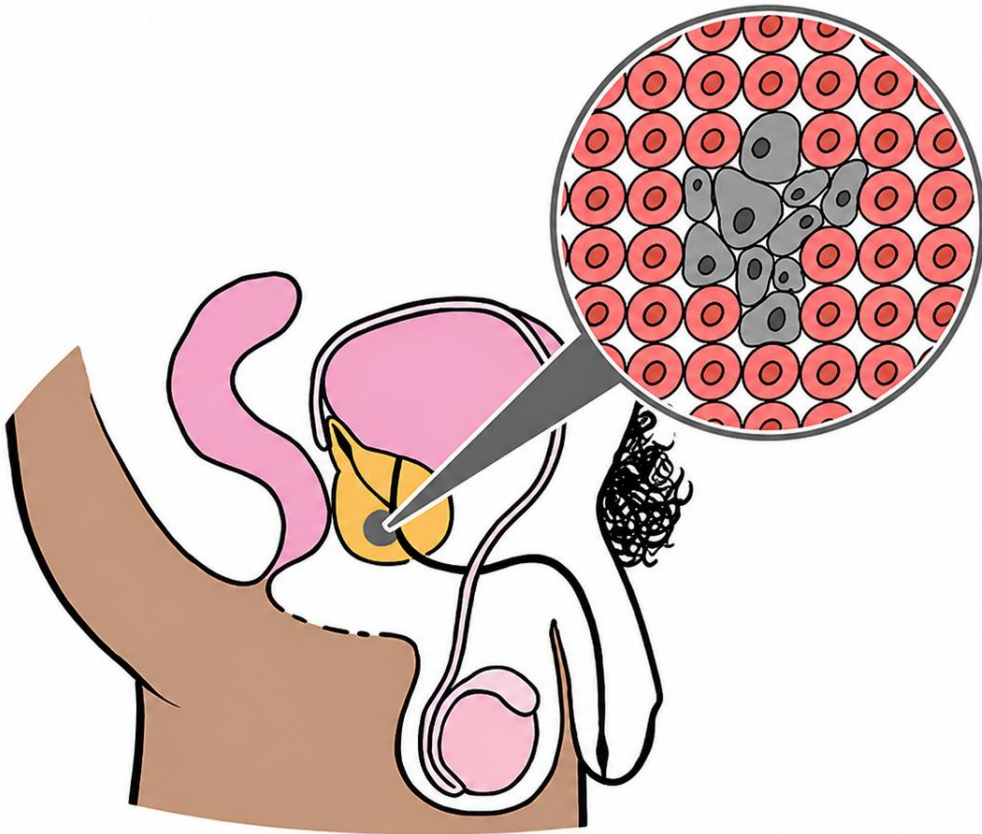
Prostate cancer: getting checked

Prostate cancer only affects men.

Men with an Intellectual disability tell their doctor about symptoms more often than other men.

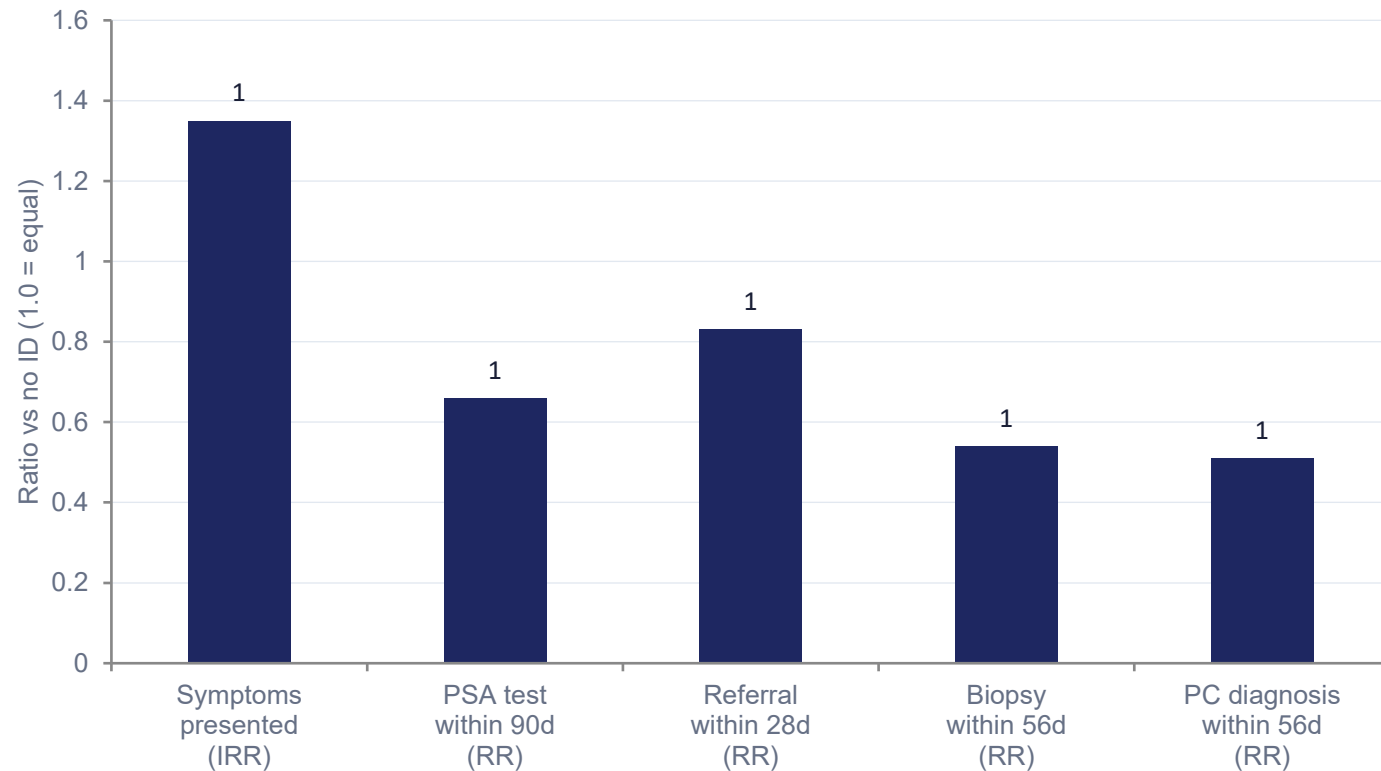
But they are less likely to get a simple blood test that checks for prostate cancer.

If the blood test shows a problem, they are less likely to be sent to a specialist quickly.



Prostate cancer: a narrowing pathway to diagnosis

29,554 men with an ID vs 518,739 comparators — more symptoms, but progressively less investigation at every step following an elevated PSA.

**1.35×**

More likely to present with symptoms suggestive of prostate cancer (IRR, 95% CI 1.28–1.43)

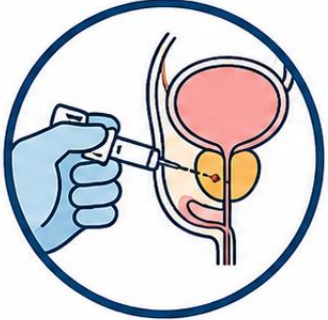
0.51×

As likely to be diagnosed within 56 days of an elevated PSA (RR, 95% CI 0.41–0.65)

5.96×

Higher risk of prostate cancer being diagnosed on the date of death (RR, 95% CI 2.70–11.77)

Prostate cancer: findings



Men with an intellectual disability are less likely to get a small test called a biopsy.



Sometimes, prostate cancer is only found when a man dies.



Men with an intellectual disability are more likely to die from prostate cancer.

Later diagnosis, worse survival

1.79×

Higher risk of
de novo metastatic
disease at diagnosis

1.61×

More likely to have
a missing Gleason
score

0.73×

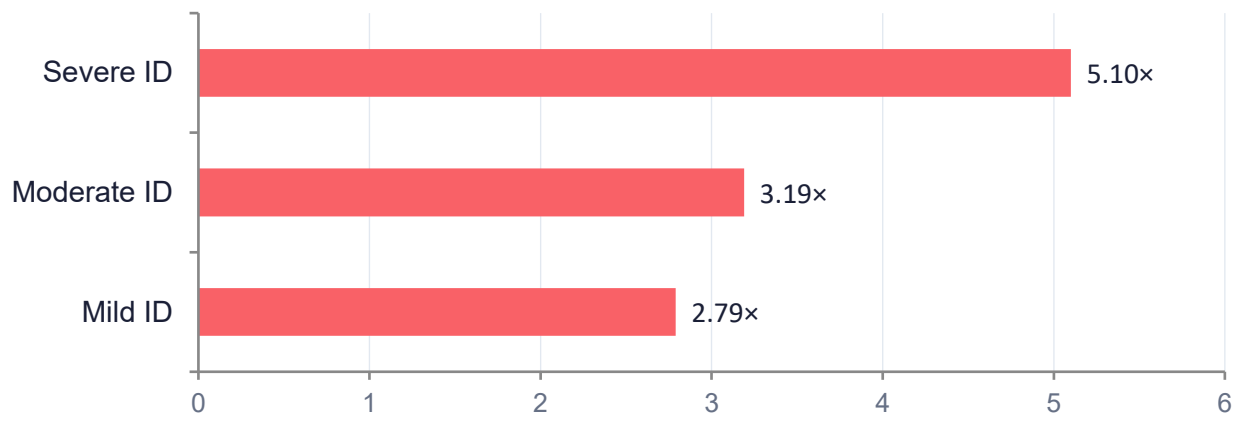
Less likely to receive
radical treatment for
non-metastatic disease

2.11×

Higher risk of death
from prostate cancer
after diagnosis

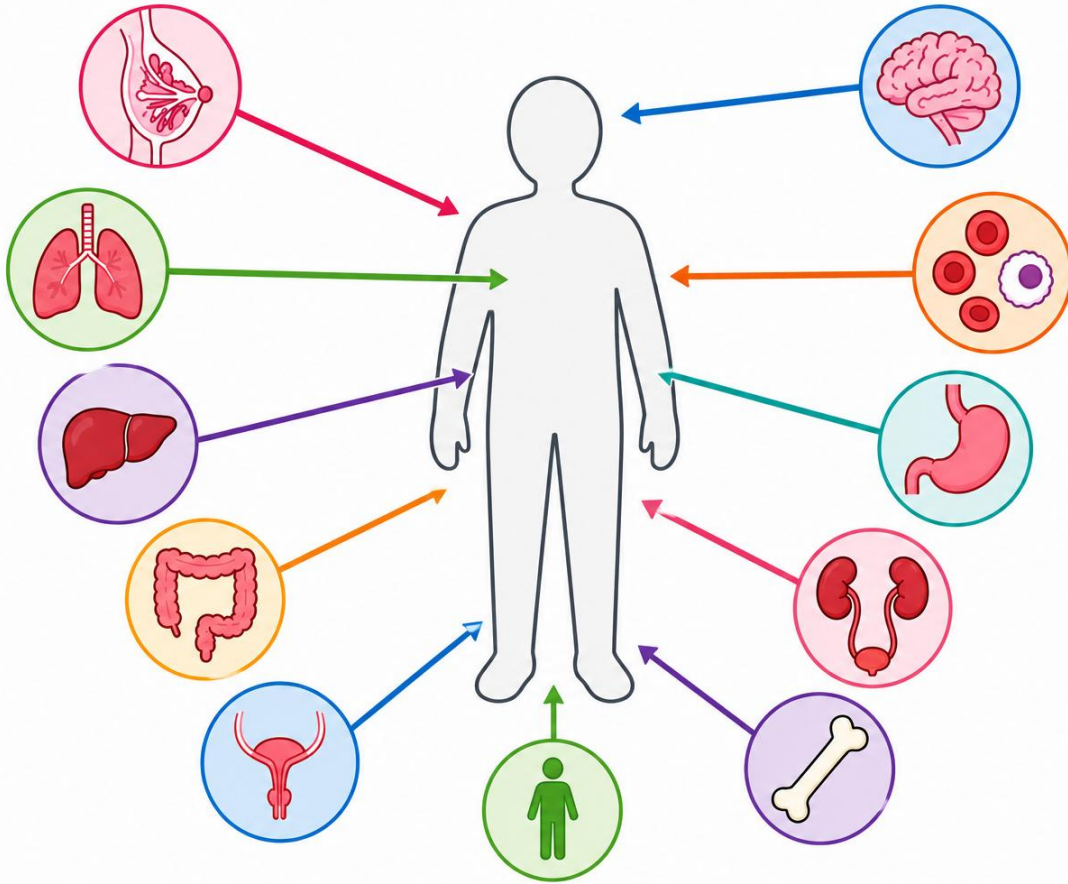
Risk of death rises with ID severity

Hazard ratio for prostate-cancer-specific mortality, by ID severity



Compared with a RR of 0.96 for clinically significant disease (Gleason ≥ 7) among those with a recorded score — disparities emerge from the care pathway, not from more aggressive underlying disease.

All cancers: getting checked



This study looked at all types of cancer, not just one.

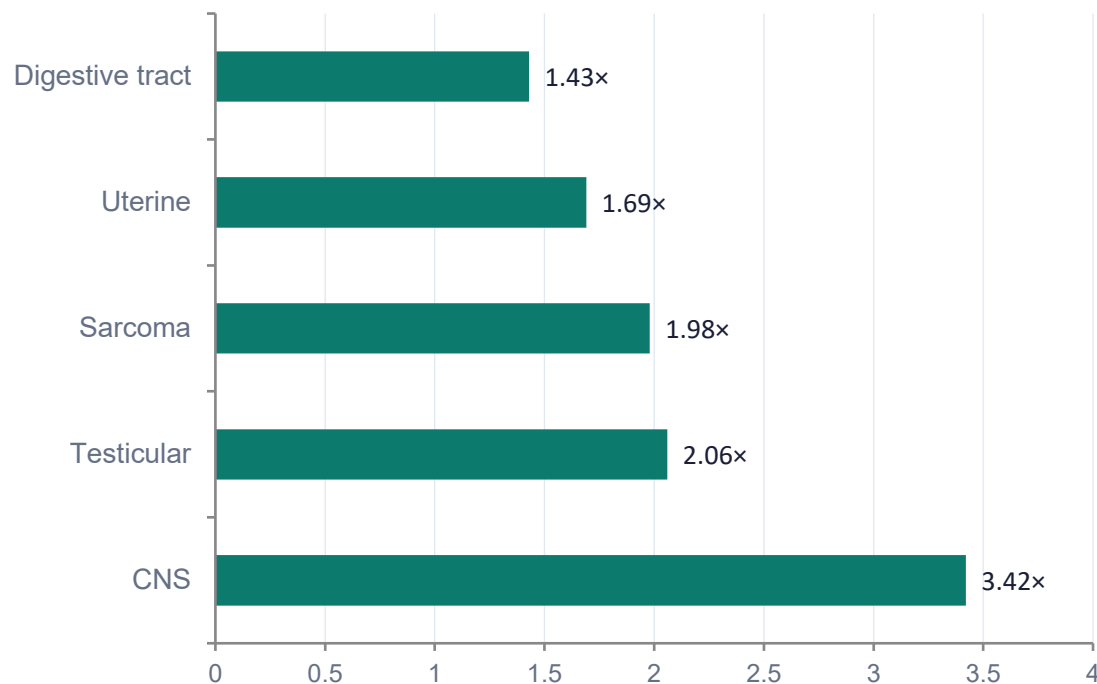
Some types of cancer happen more often in people with a learning disability.

People with a learning disability are less likely to be sent quickly to a specialist after symptoms.

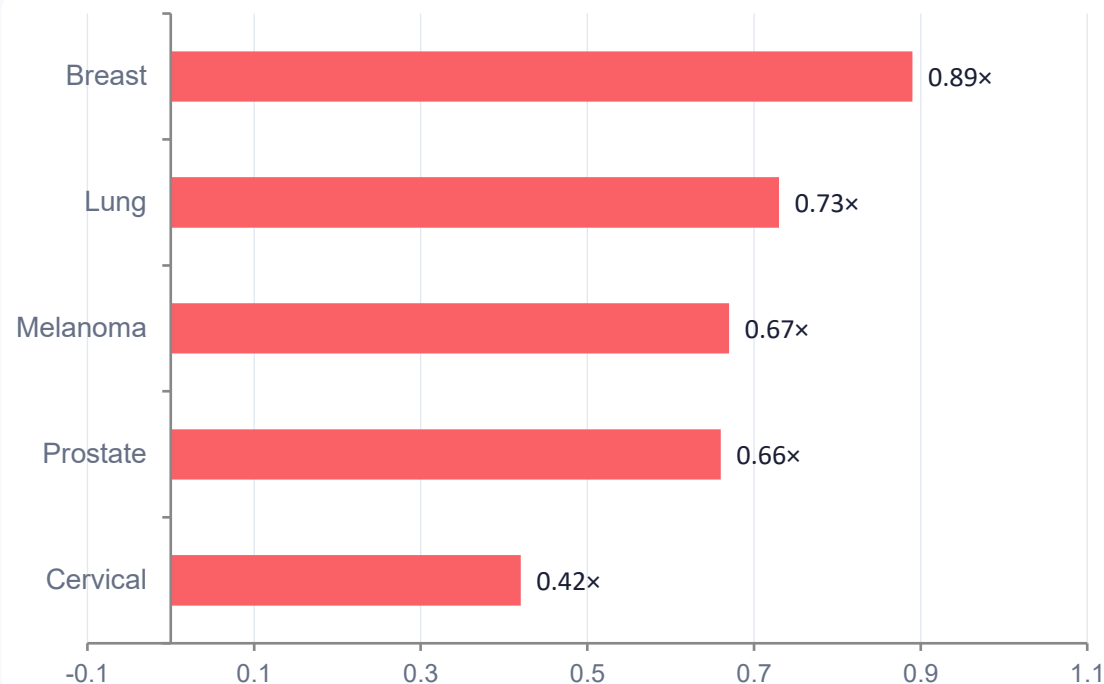
All cancers: a mixed risk picture

180,911 people with a learning disability vs 3,405,467 matched controls — elevated risk for some cancers, reduced diagnosis rates for others.

HIGHER RISK (aHR vs no LD)



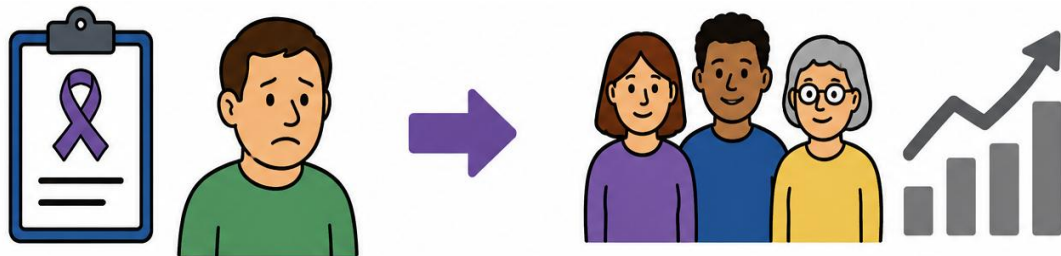
LOWER DIAGNOSIS RATE (aHR vs no LD)



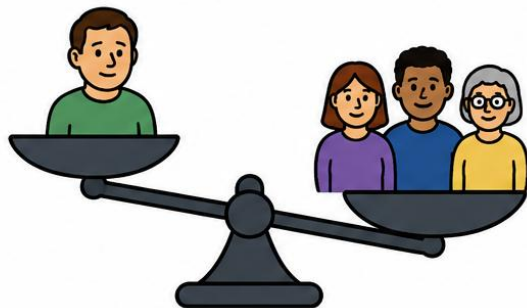
All cancers: findings



People with a learning disability are less likely to get treatment, like surgery or strong medicine.



They do not live as long after a cancer diagnosis, compared to other people.



This shows that cancer care is not equal for everyone.

A masked burden, a narrower path to diagnosis



3.19× higher all-cause mortality

Premature death from all causes masks the true cancer burden — crude cancer incidence looked similar, but age-standardised risk was higher.



Half as many urgent referrals

Adjusted risk ratio 0.52 for referral within 28 days of a possible cancer symptom, compared with matched controls.



Fewer diagnoses via referral pathway

Adjusted risk ratio 0.81 for a cancer diagnosis preceded by an urgent suspected cancer referral.

STAGE AT DIAGNOSIS

1.12×

More likely to be diagnosed with stage 4 cancer (vs stages 1–3)

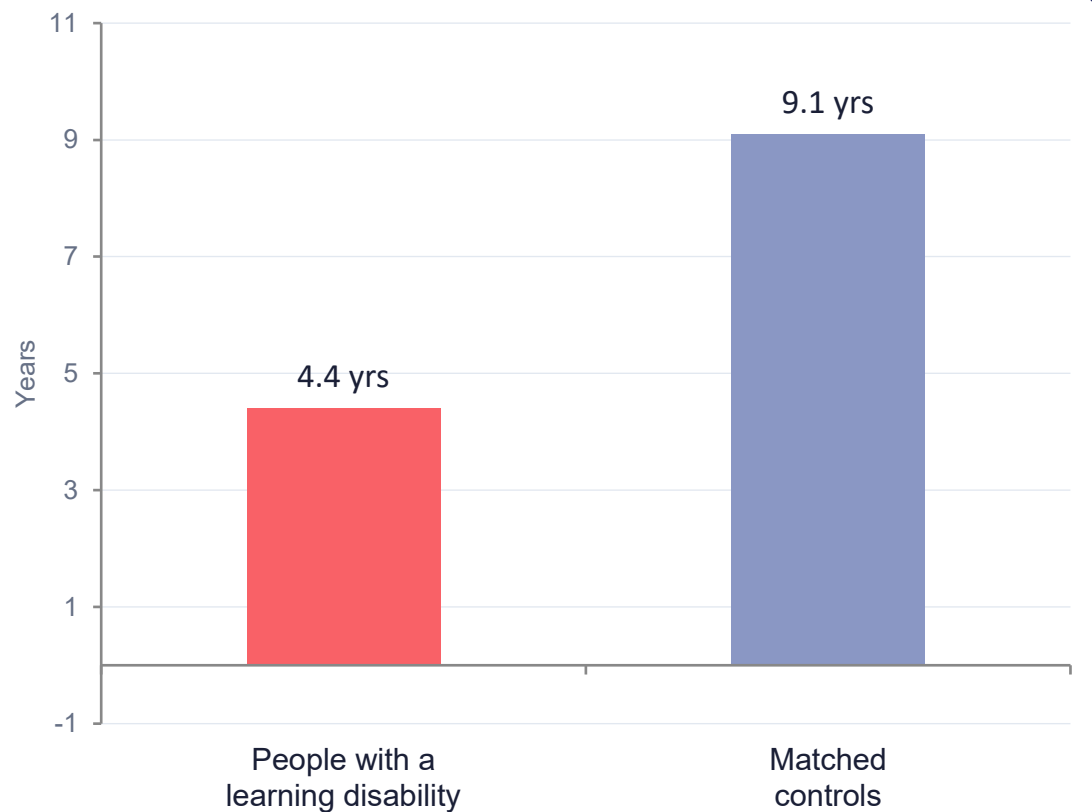
1.30×

More likely to be diagnosed with unstaged cancer

Associations with stage 4 or unstaged disease were seen across digestive tract, breast, and gynaecological cancers — and were strongest in those with severe ID or Down syndrome.

Less treatment, half the survival time

Median overall survival following cancer diagnosis



aRR 0.83

Less likely to receive treatment (surgery, radiotherapy, or systemic therapy) within six months of diagnosis

aHR 1.73

Overall risk of death following a cancer diagnosis, adjusted for age, sex, ethnicity, and deprivation

Up to 4×

Melanoma, breast, and prostate cancers were diagnosed less often in people with a ID — but carried up to a fourfold increased risk of death after diagnosis

Same story, all cancers, one dataset

Across bowel, prostate, and all-cancer analyses, the same four-stage pattern of disparity recurs — independent of cancer type.



Where targeted action is needed



Equitable access to investigations

Ensure PSA testing, stool testing, biopsy, and endoscopy are offered on the same clinical basis, regardless of ID status.



Referral pathway training

Support primary care clinicians to recognise and act on red-flag symptoms in patients with an ID, and to reassess persistent symptoms.



Reasonable adjustments

Address barriers around consent, communication, and appointment systems that limit access to biopsy and treatment.



Monitoring via registers

Use LD register data to track cancer pathway metrics and flag disparities in real time.



Research into mechanisms

Investigate why testing and referral rates are lower — including clinician decision-making and patient-level barriers.



Policy alignment

Embed cancer-pathway equity within NHS Long Term Plan, NICE guidance, and LeDeR priorities.

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