

Cancer diagnoses, referrals, and survival in people with intellectual disability in the UK



Evidence from UK population-based cohort studies

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Conference

Competing Interests

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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

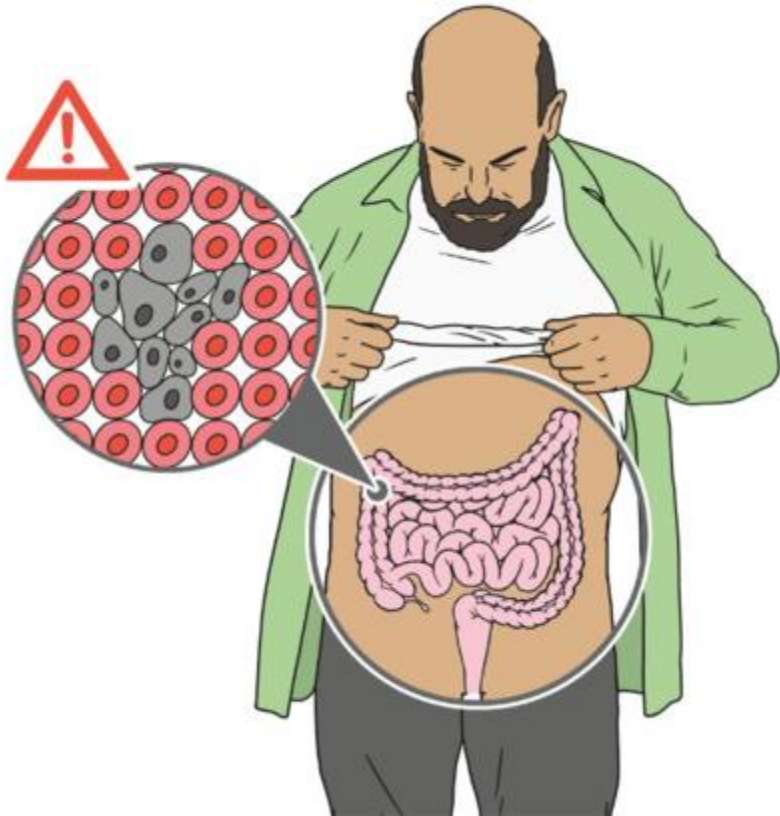
ONS
Office for National Statistics mortality data

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.

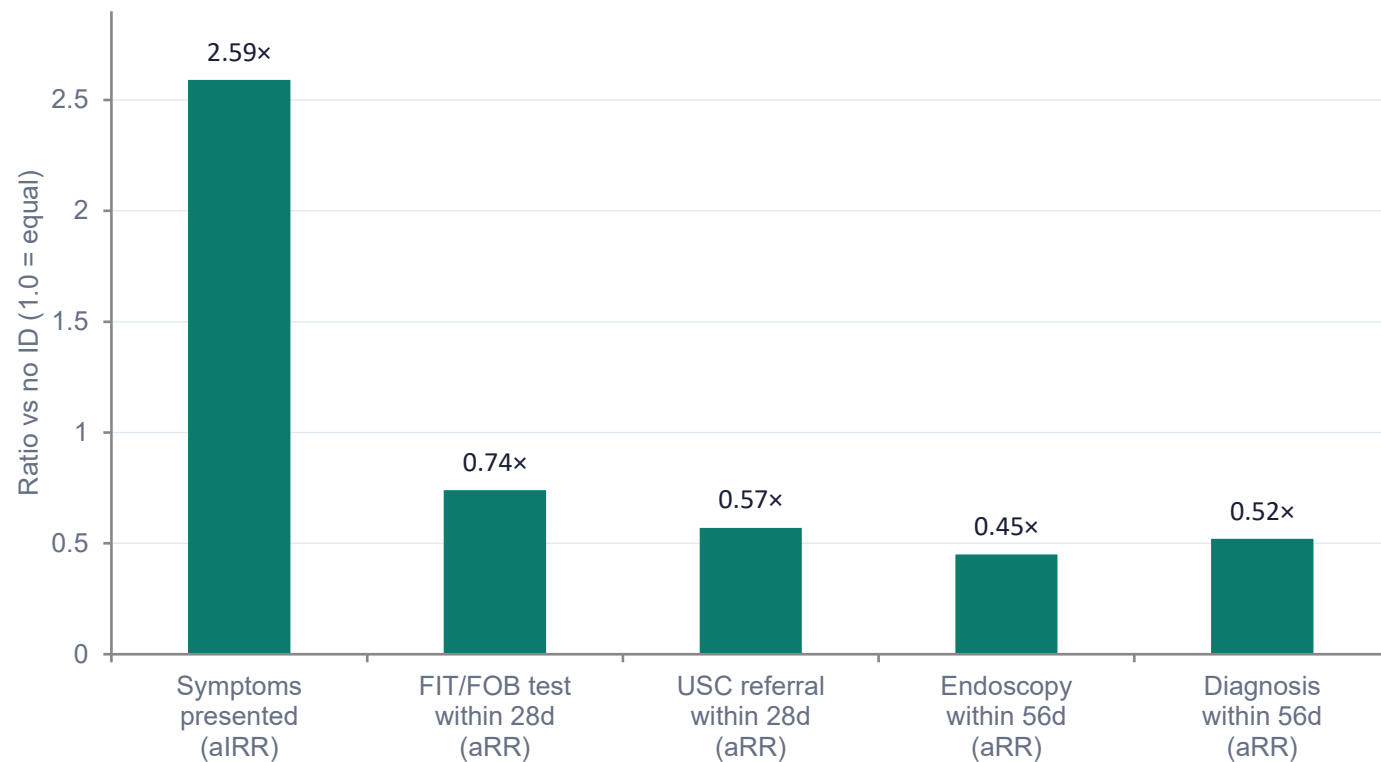
This is especially true for younger people.

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×

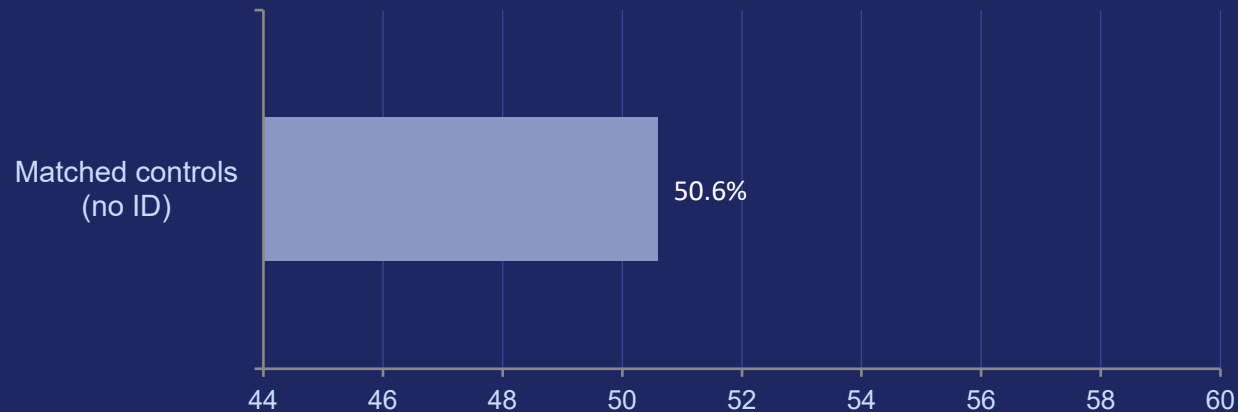
More likely to be diagnosed with stage IV disease

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).

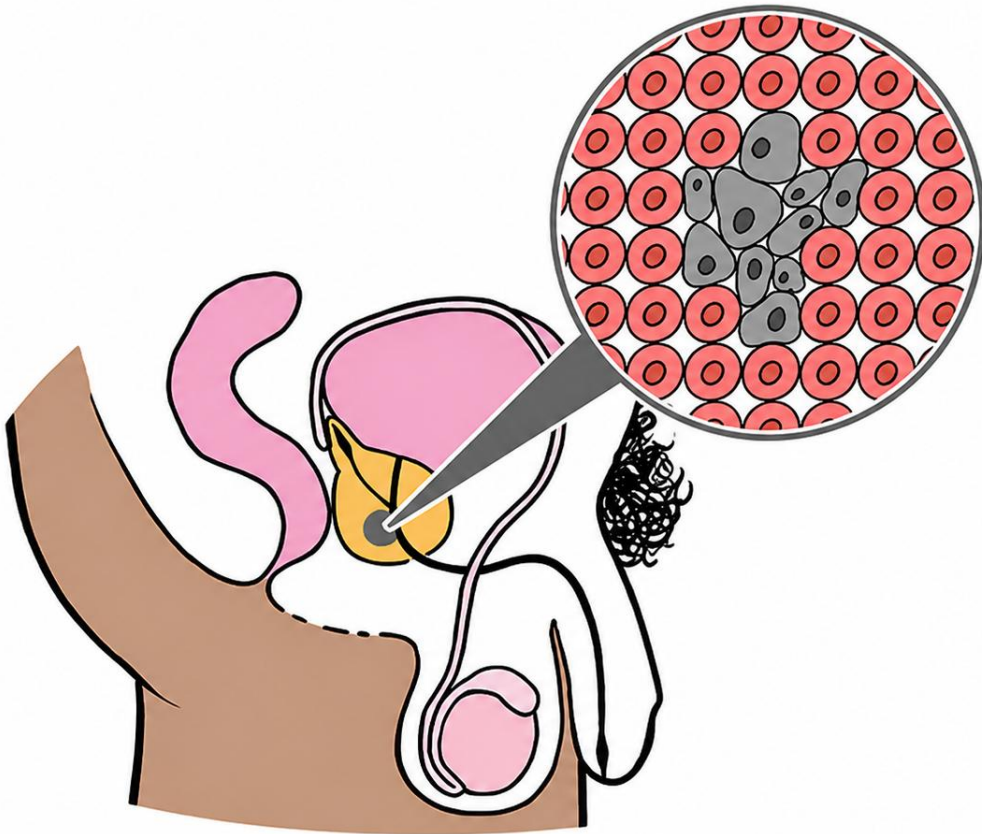
Prostate cancer: getting checked

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.



Scale of the problem

Cases

52,254



New cases of
prostate cancer each
year, 2016-2018
average, UK

Deaths

12,039



Deaths from prostate
cancer, 2017-2019,
UK.

Survival

78%



Survive prostate
cancer for 10 or more
years, 2013-2017,
England

Prevention

Not clearly
linked to any
preventable
risk factors

Preventable cases of
prostate cancer are
not known as it is not
clearly linked to any
preventable risk
factors

Health inequalities in prostate cancer

- Black men have **double the risk of both diagnosis with and dying from prostate cancer and develop it younger.**¹
- **Metastatic disease on presentation is associated with deprivation:** patients in the **most deprived** areas were 29% more likely to be diagnosed with metastatic prostate cancer than those in the least deprived.²
- There is wide **geographical inequity.**²

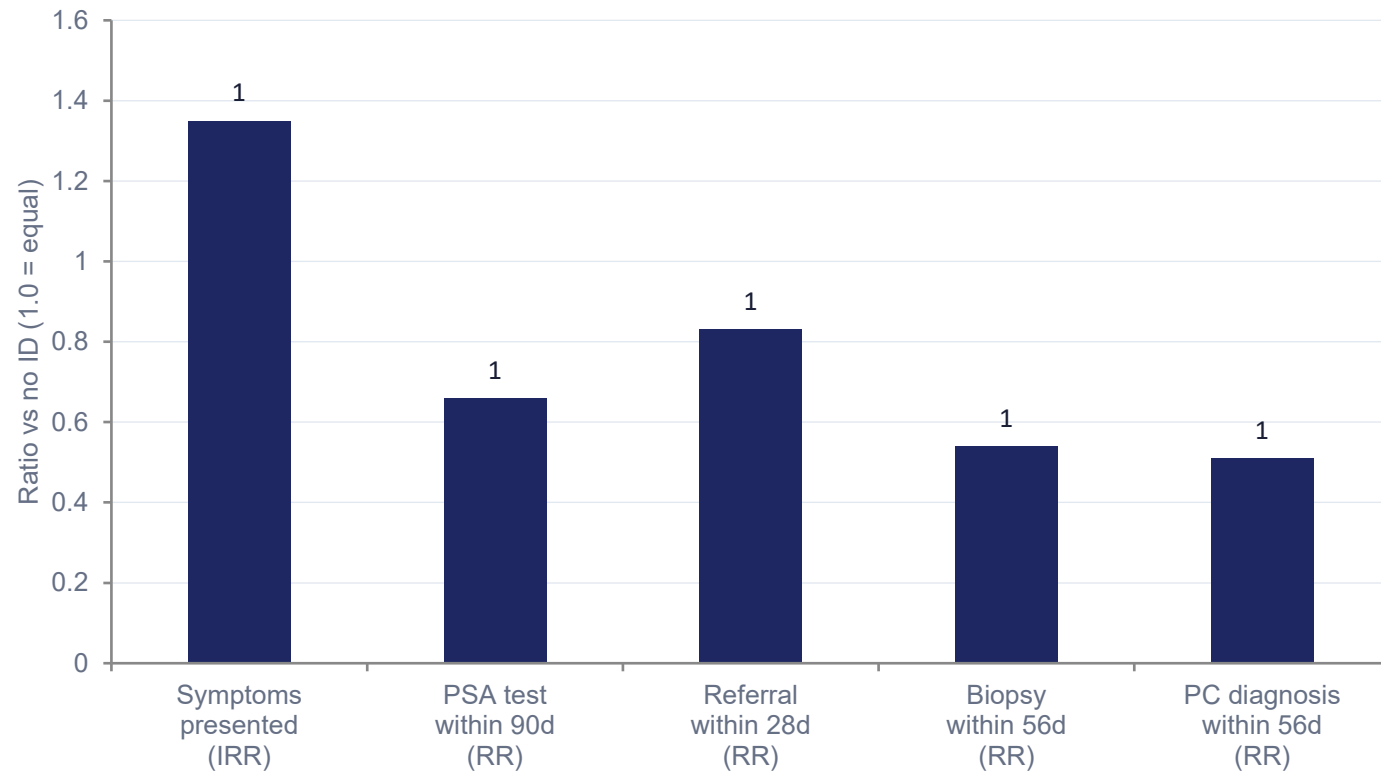


Black men are more likely to get prostate cancer than other men. In the UK, about 1 in 4 black men will get prostate cancer at some point in their lives. If you're black, you may be more likely to get prostate cancer if you're aged 45 or over.

1. Lloyd T, Hounscome L, Mehay A, Mee S, Verne J, Cooper A. Lifetime risk of being diagnosed with, or dying from, prostate cancer by major ethnic group in England 2008–2010. BMC medicine. 2015 Dec;13(1):1-0.
2. <https://www.npca.org.uk/reports/npca-short-report-2022/>

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)

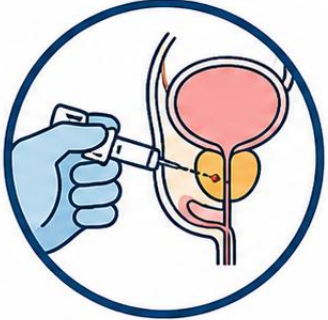
0.51×

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 once diagnosed.

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×

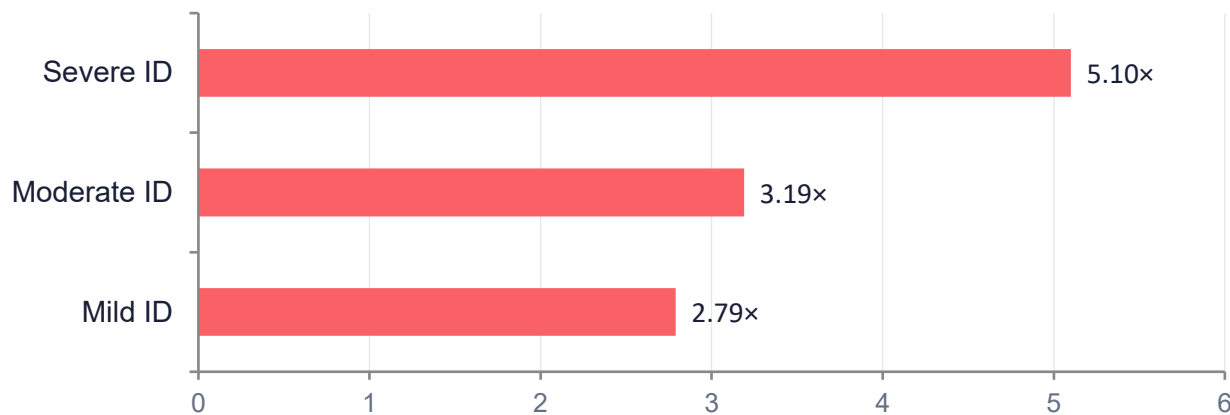
Less likely to receive
radical treatment for
non-metastatic disease

2.11×

Higher risk of death
from prostate cancer
after diagnosis

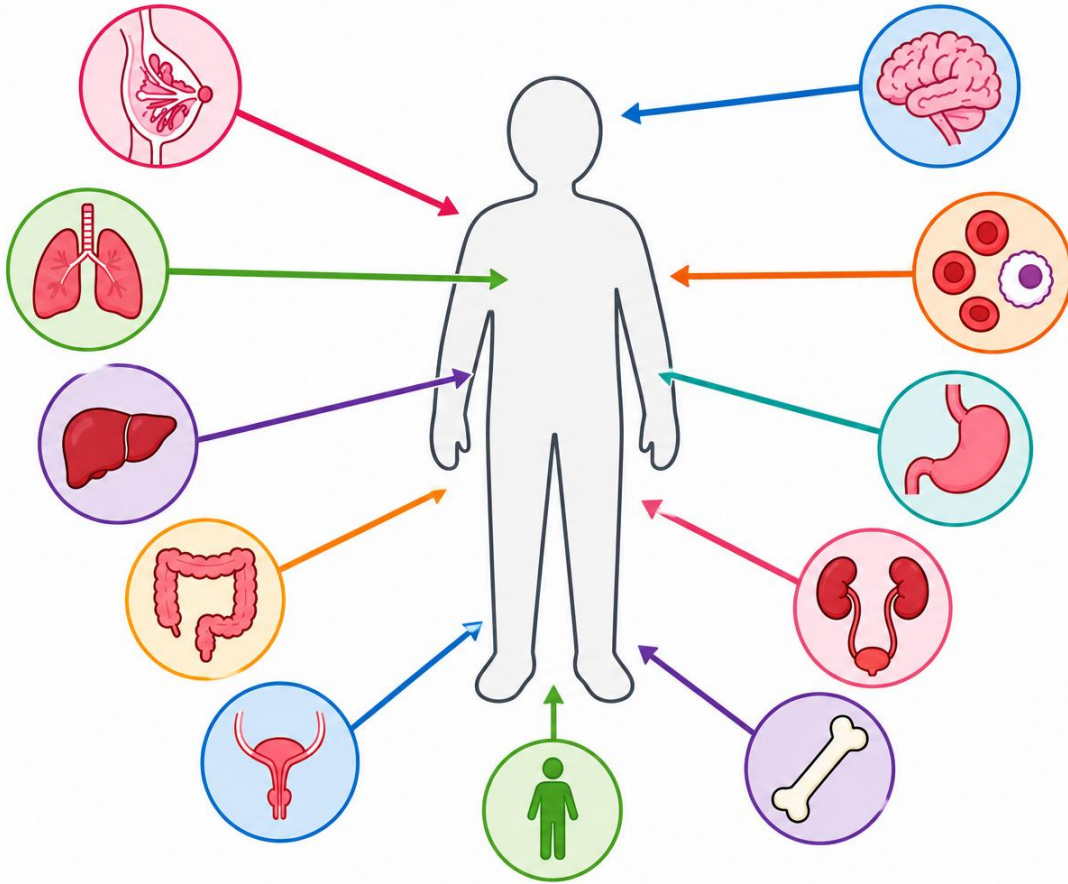
Risk of death rises with ID severity

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.

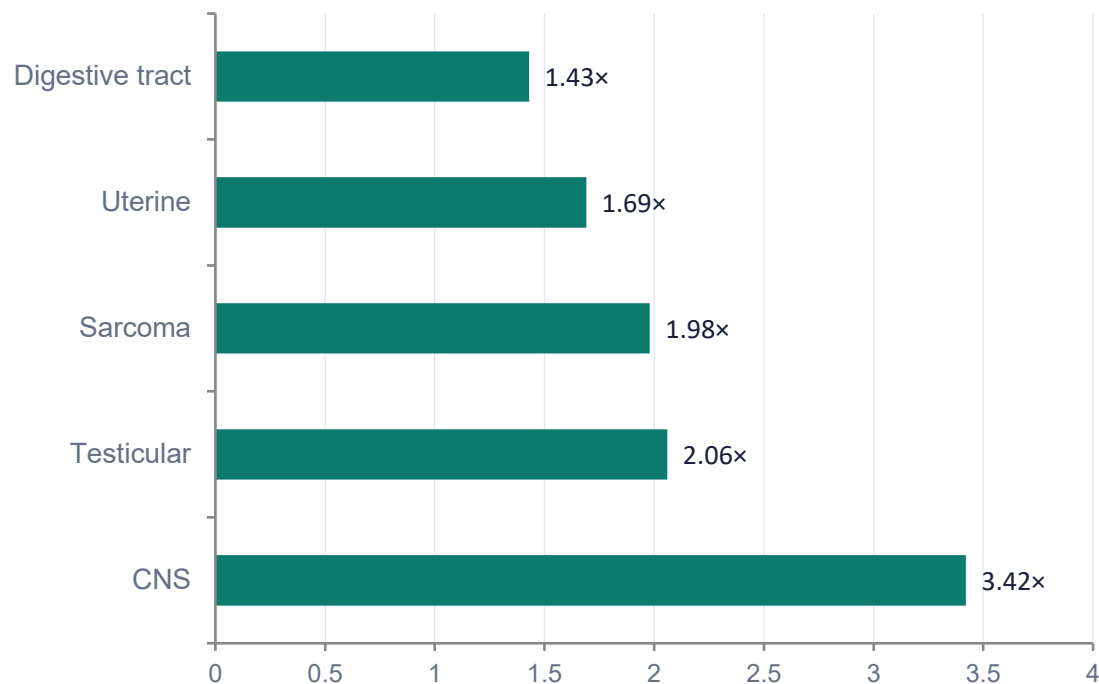
Some types of cancer happen more often in people with a learning disability.

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

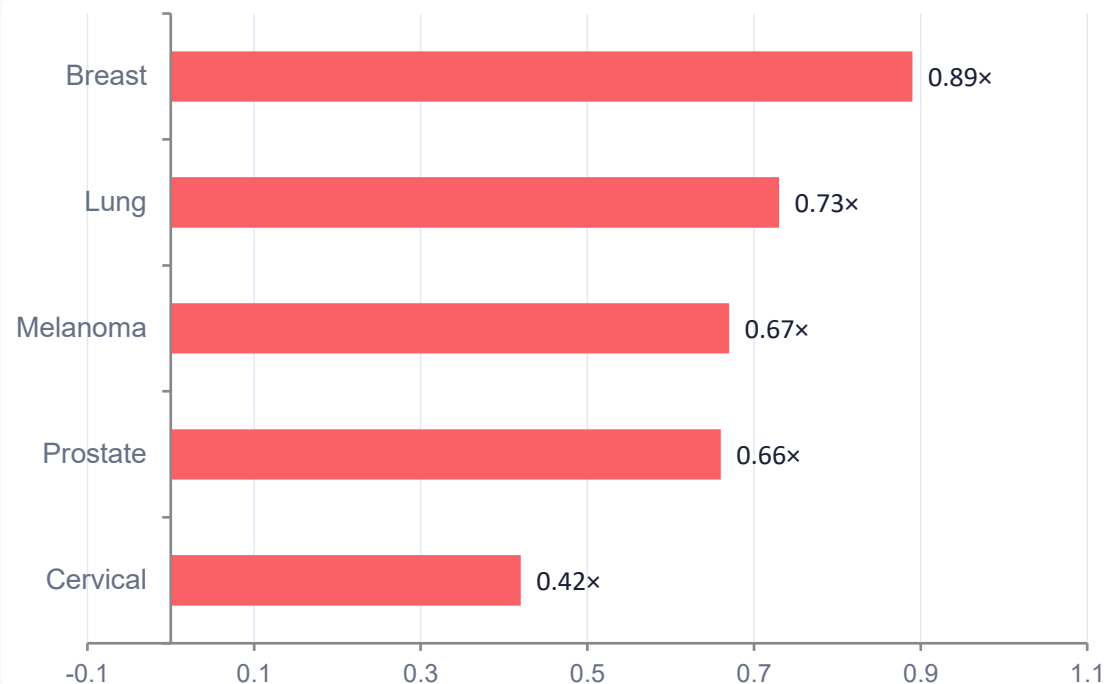
All cancers: a mixed risk picture

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

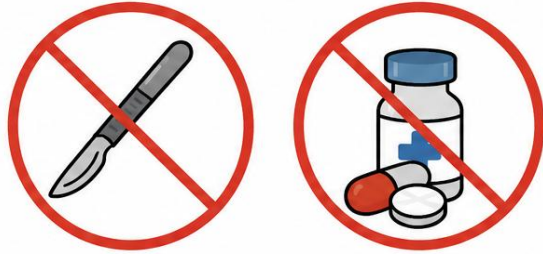
HIGHER RISK (aHR vs no LD)



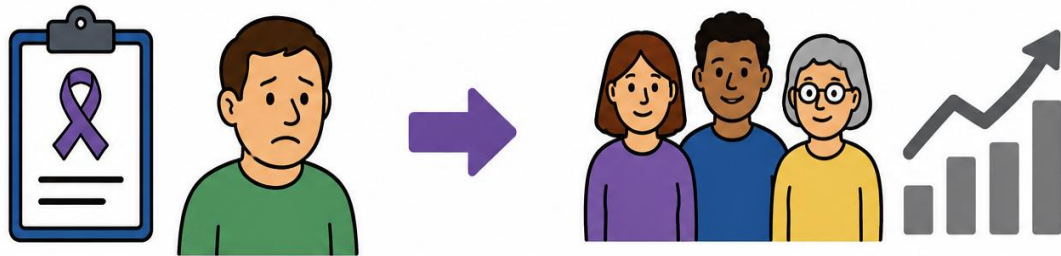
LOWER DIAGNOSIS RATE (aHR vs no LD)



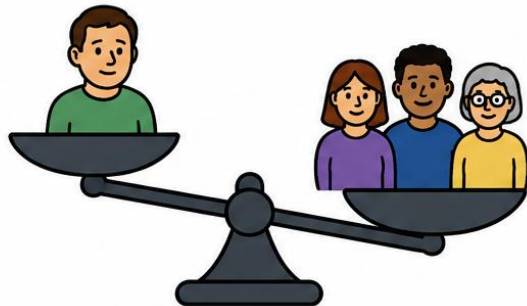
All cancers: findings



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)

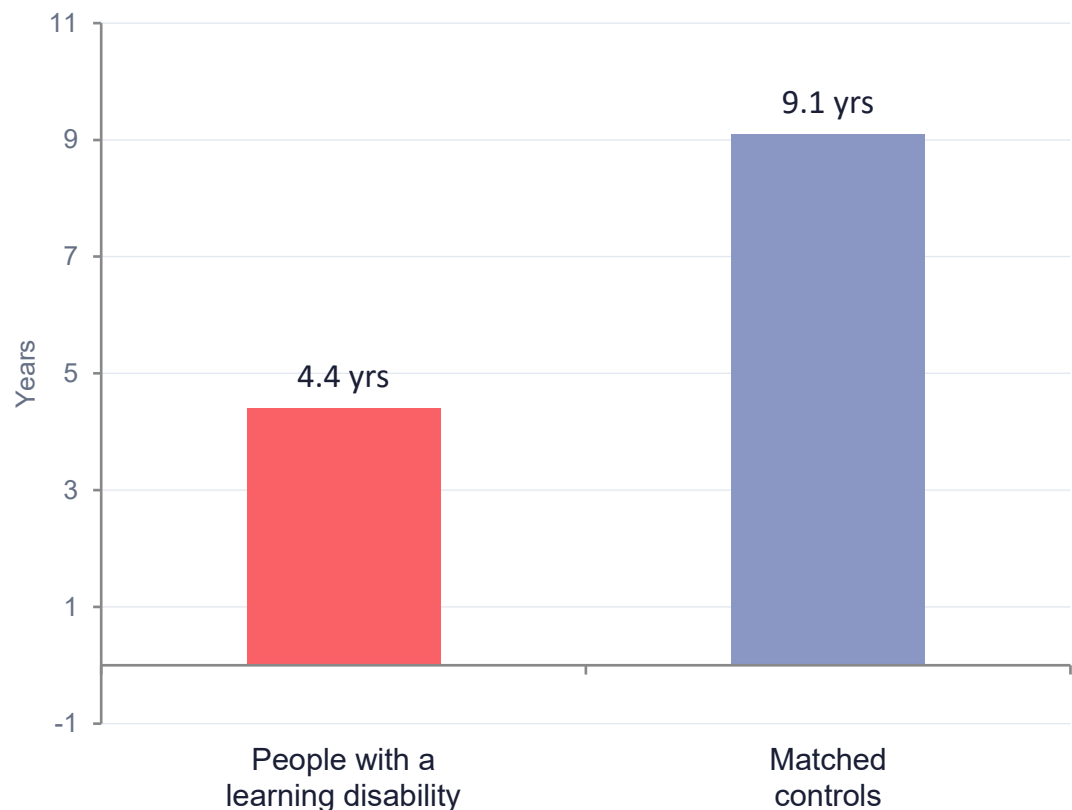
1.30×

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.

People with a learning disability - A hidden inequality

1

Higher risk, worse outcomes

Elevated risk of several cancers and poorer outcomes once diagnosed.

2

Screened less often

Inaccessible information, adjustments not made, anxiety about clinics, and reliance on carers/supporters to attend.

3

Absent from the evidence

Under-represented in cancer screening research and in the trials that shape screening policy.

Screening is not designed with people with LD in mind, compounding health inequalities.



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The TRANSFORM Trial

- We are looking at four different ways to screen for prostate cancer:

- 1:** $\text{PSA} \geq 3\text{ng/mL}$ - standard used for referral leading to MRI recommendation

(Standard = 3ng/mL , unless family history or Black ethnicity)

- 2:** Protagram MRI in all

3: Protagram MRI in men who have a $\text{PSA} \geq 1\text{ng/mL}$

4: Polygenic risk score to decide who gets more screening tests (risk stratification)



THE QUESTION

How can patient and public involvement make trial information accessible for people with intellectual disabilities?

*Designed **with** people, not **for** them, with experts by experience shaping the materials.*

What we have done so far

1

Focus groups

Healthcare experiences, then specific trial concepts.

2

Co-design

Contributors supported redesigning the draft materials.

3

Iterative feedback

Revised between sessions, then brought back.

4

Refine

Themes carried forward and tested again.

Participatory action research · reported against GRIPP2

Who took part

November 2025

4 self-advocates · 1 family · 1 worker

December 2025

8 self-advocates · 1 family · 1 worker

February 2026

3 self-advocates · 2 family · 2 workers

*23 attendances across three sessions,
recruited through Pathways Associates and
Learning Disability England.*

What we heard: six themes

1

**Making information
comprehensible**

2

Format and design

3

Risk communication

4

**Reasonable
adjustments**

5

Personalising results

6

**Equity, culture and
trust**

1 · Making information comprehensible

Plain English: explain, don't remove

Terms like PSA, MRI, biopsy, randomisation and prostate enlargement explained rather than removed, with a definition box where a term must stay.

'Screening' is a problem word

Many people confuse screening with diagnosis or treatment. The difference has to be stated directly.

Use 'you'

Second person for decisions and actions because it speaks to the reader.

**Simplification is not
superficiality.**

Complex concepts can be understood when they are explained clearly and without talking down to PWID.

2 · More than easy read

Easy read alone is not enough

Not everyone with an intellectual disability can use easy read/ finds it helpful. Offer it and check, don't presume.

Multiple formats

Audio, short animation, real-life video of what happens at a visit, and a website, plus an accessible way to request another format.

Show what actually happens at each stage of the patient journey

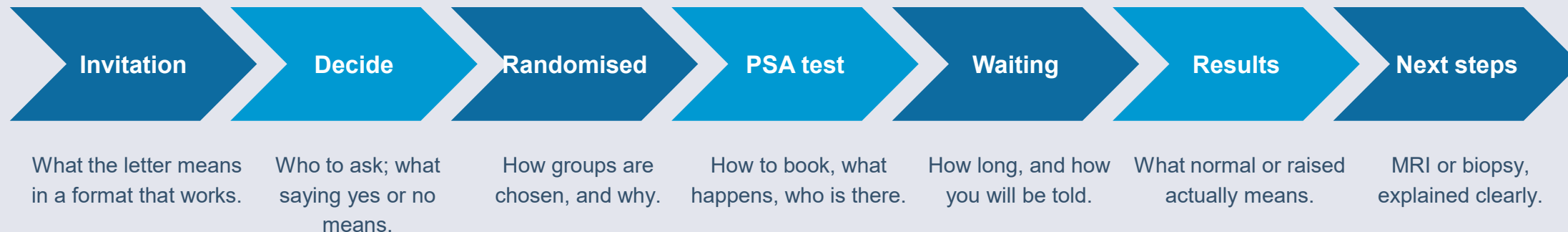
Realistic images (e.g. a nurse taking a blood sample) rather than abstract or unclear icons.

Designed to be seen

Strong colour contrast, smaller chunks, more white space, and photosymbols from a single source.

A clear patient journey

'What happens first, next, after that', mapped from invitation to results, with the adjustments each stage might need.



Right to ask questions · right to withdraw repeated at every step.

3 · Randomisation explained



The wording that caused confusion

‘You might not get any tests’

Read as unfair, as being judged, excluded, ‘not chosen’.

The single concept that generated the most concern of any in the materials.

Their redesign suggestions

Every good trial needs a comparison group.

A computer allocates fairly, at random.

No one is left out.

You are always told which group you are in.

You cannot choose your group.

Taking part matters even without the test.

3 · Communicating risk

A high PSA does not mean cancer.

Say it and repeat it

Many men with a raised PSA do not have cancer.
Contributors wanted this stated explicitly, more than once.

Levels rise for many reasons

Naturally with age, and for other reasons, including some medications.

The test is imperfect

It can miss cancers and raise false alarms. Say so, and explain any next steps calmly.

Not less information, but kinder delivery.

Plus a 'common worries' section to normalise the anxiety.

4 & 5 · Adjustments, and getting results right

4 · Reasonable adjustments

Knowing in advance what will happen

Seeing the space beforehand

Longer slots, and time to process

A quiet place to wait; privacy at reception

A same-sex clinician; a carer present

Continuity of staff; interpreters or BSL

Record needs early so every later contact works for the person.

5 · Personalising results

‘One size does not fit all’ said repeatedly

Record preferences at the outset

Phone, virtual, letter or in person

Face-to-face offered whatever the result

Information to take away and revisit

Shareable with family and supporters

Never simply send results- check understanding, don’t assume it.

Supporters have communication needs of their own, and the materials have to work for them too.

6 · Equity, culture and trust

Trust isn't given

Some minority communities hold greater distrust of screening and of GP systems.

Language and literacy

Translation and interpreters where needed and never assume someone can read/understand.

Higher risk, said with care

Black men face higher prostate cancer risk. The group debated openly how to state it so it informs without stigmatising.

Systemic enablers

The GP learning disability register, default SMS reminders, NHS App signposting.

And a plain-language account of why the research matters at all and how the evidence will guide national decisions.

Recommendations made

In the materials

- ✓ Key sections to be rewritten: simpler language, acronyms explained, 'you' kept for prompts
- ✓ Randomisation rewritten to the group's specification
- ✓ A new PSA section: the test's limits, and what next steps mean
- ✓ A step-by-step pathway visual, with adjustments mapped to each stage
- ✓ Unclear icons to be replaced with realistic images from one source

Around the materials

- ✓ Short animations and an FAQ booklet
- ✓ Multiple formats, plus an accessible way to request alternatives
- ✓ A 'common worries' section, at the group's suggestion
- ✓ A plain-language section on the trial's role in national screening decisions
- ✓ An information pack and scripts for GPs, so messaging is consistent

Not a consultation, but a redesign brief.

Why it matters

1

It is feasible

With good facilitation, accessible methods and enough time, people with intellectual disabilities can engage with and take part in cancer clinical trials.

2

Need for meaningful co-production

Easy read produced without the intended audience is often not good enough to support informed consent.

3

Consent depends on understanding

Genuine understanding is what makes consent genuine and that is what underpins autonomy.

4

Evidence for everyone

If trials cannot recruit people with intellectual disabilities, the evidence that shapes national screening will not apply to everyone.



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Founding partners

The Freddie
Green and
Family
Charitable
Foundation



Major supporters

The John Black
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Foundation



Delivery partners



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Thank you.



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Any questions?