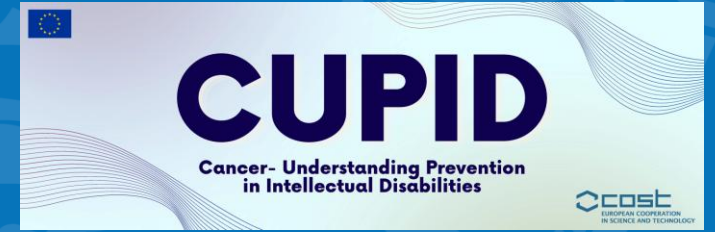




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Coláiste na Tríonóide, Baile Átha Cliath
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The numbers behind the needs: cancer statistics, screening uptake, and cancer inequalities

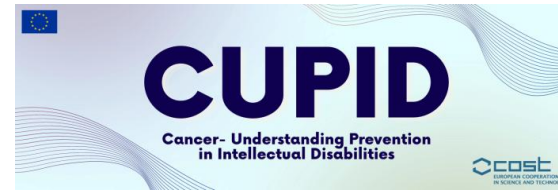
Cancer-screening and prevention for people with intellectual disability (CUPID)- Lunch and learn –
Webinar series

29th April 2026

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Acknowledgement



**Trinity Centre for Ageing
and the Life Course in
Intellectual Disability**



Funded by the Horizon 2020 Framework Programme
of the European Union

Acknowledgement

This article/publication is based upon work from COST Action CUPID supported by COST (European Cooperation in Science and Technology).

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Conflict of Interest Statement



**Trinity Centre for Ageing
and the Life Course in
Intellectual Disability**

- Before we begin, we would like to declare that we have no conflicts of interest to disclose in relation to this presentation.
- The content presented is based on our professional, academic, and/or research perspectives, and no financial or personal interests have influenced the material being shared.

Presentation Outline

- ✓ Overview of the evidence base
- ✓ Cancer incidence in people with intellectual disability
- ✓ Mortality, survival and premature death
- ✓ Diagnosis patterns (stage, delays, emergency presentation)
- ✓ Screening uptake and coverage
- ✓ Barriers to early detection
- ✓ Healthcare inequalities across the cancer pathway

Rising Cancer Burden in People with Intellectual Disabilities

Trinity Centre for Ageing
and the Life Course in
Intellectual Disability



Support needs

Declining physical
function

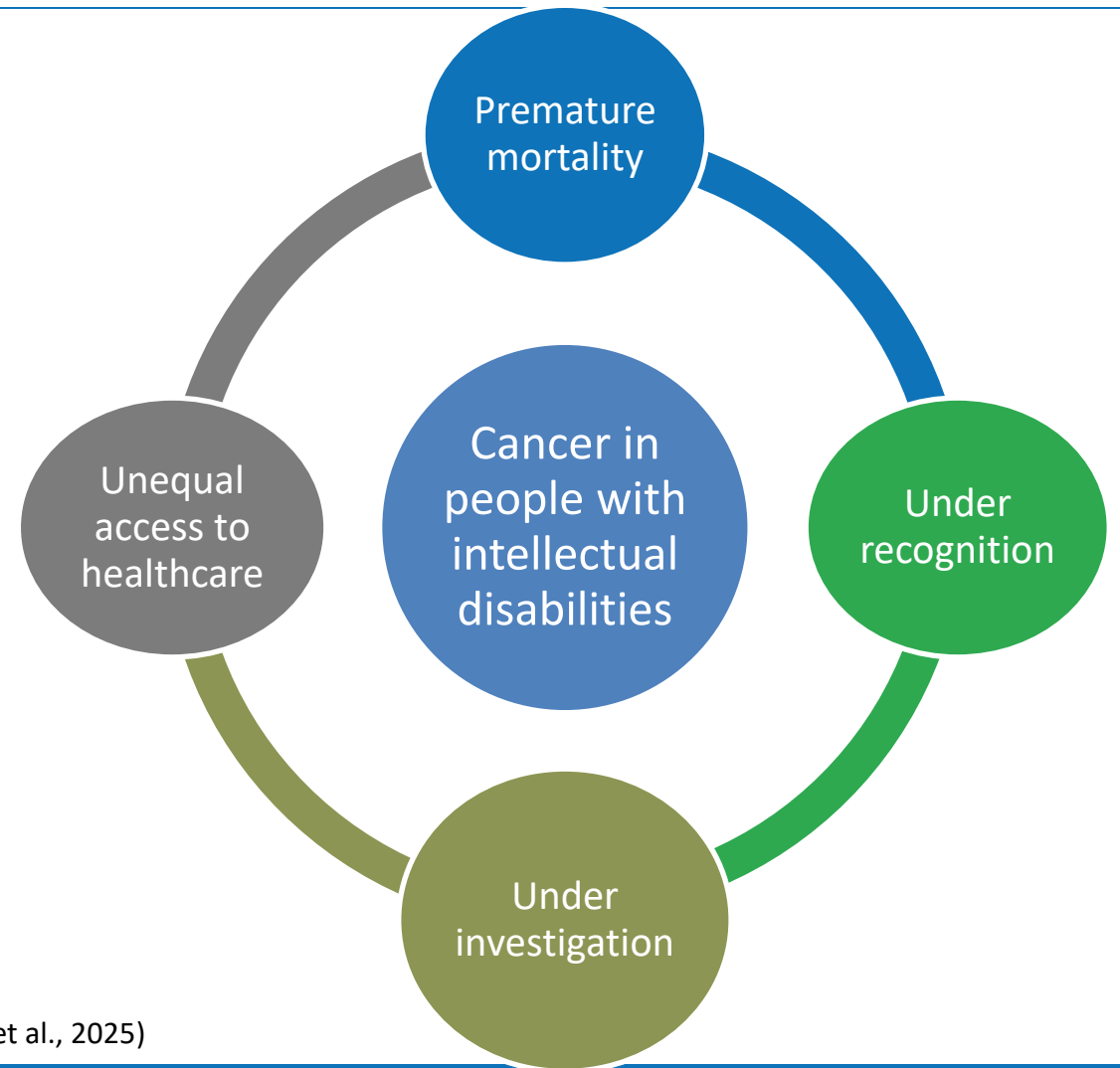
Slower metabolic
process

Higher risk of
chronic conditions
-cancer

(Dolan et al., 2019; McCarron et al., 2018)

Cancer inequalities in intellectual disabilities

Adults with intellectual disabilities face a cancer pattern that is easy to misread if incidence is considered on its own.



(McMahon et al., 2025; Stirling et al., 2021; Cuyppers et al., 2021; Ward et al., 2024; Kennedy et al., 2025)

What the evidence base shows

Overall cancer burden

Recorded overall incidence is often similar to lower than the general population.

Under
diagnosis

Younger age
structure

Competing
mortality

(McMahon et al., 2025; Cuypers et al., 2021; Ward et al., 2024)



A simple claim that cancer is less common in adults with intellectual disabilities does not fit the full evidence.



What the evidence base shows

Dutch cohort (Dutch national cohort)

Open access Original research

BMJ Oncology

Cancer incidence and diagnostic characteristics in people with intellectual disabilities in the Netherlands: a national registry-based cohort study

Maarten Cuypers^{1,2}, Jenneke Naaldenberg^{1,2}, Amina Banda^{1,2}, Lynette Oost^{1,2}, Haiko Bloemendaal³, Geraline Leusink^{1,2}

ABSTRACT
Objective People with intellectual disabilities (ID) face notable health disparities, also affecting cancer care. This study is among the first to use nationwide population and cancer registry databases to compare cancer incidence in the population with ID and the general population.
Methods and analysis A population-based cohort study enrolled all Dutch adults (18+) with indicators of ID (N=187 149) and a 1:4 random general population sample without ID (N=760 907). All cancer diagnoses from 1 January 2015 until 31 December 2020 were collected from the national cancer registry to compare incidence and diagnostic details.
Results Overall, fewer incident cancer cases were found among individuals with ID than without ID (51.0 vs 104.1/10 000 person-years; adjusted OR (aOR) 0.79 (0.76–0.81)), with cases occurring at younger ages and being diagnosed more often at a more advanced stage than in the general population. Key distinctions from the general population include reduced odds of skin cancer (aOR 0.29 (0.38–0.43)) and elevated odds of cancer of unknown primary (OR 1.60 (1.29–1.98)). The fewest cancer diagnoses occurred among those entitled to long-term ID care (aOR 0.63 (0.60–0.66)), with those living independently being at greater risk for cancers of digestive, respiratory and female genital organs.
Conclusion Although the overall incidence of cancer in the population with ID appears lower than in the general population, significant variations exist across ID subgroups and cancer types. These differences indicate varying exposures, lower cancer awareness and barriers to healthcare for individuals with ID. Addressing these differences requires customised strategies for public health, long-term care and oncology care.

INTRODUCTION
 Cancer is a significant health concern for individuals both with and without intellectual disabilities (ID), with the population

WHAT IS ALREADY KNOWN ON THIS TOPIC
 ⇒ People with intellectual disabilities (ID) experience significant health disparities, including challenges in cancer-care access and outcomes. Existing research indicates variable cancer risks in this population, but comprehensive, population-based data are limited.

WHAT THIS STUDY ADDS
 ⇒ This study provides a large-scale, population-based analysis using Dutch registry data, enabling stratification within the population with ID by residency status and need for supportive care. Findings reveal distinct cancer risks among ID subgroups, with the lowest incidence in those with access to long-term residential care and higher risks for certain cancers among individuals with ID living independently.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY
 ⇒ The findings enhance understanding of the cancer burden in the population with ID and differential patterns relative to the general population. Conclusions can inform policy and clinical practice by highlighting the importance of accessible cancer-care pathways and targeted public-health interventions for individuals with ID.

Defined as limitations in cognitive and adaptive functioning, ID is caused predominantly by genetic or developmental disorders emerging before adulthood.¹ Individuals with ID experience health differences due to genetic and biological vulnerabilities, as well as social and systemic barriers that limit their access to equitable healthcare.^{2,3} These barriers contribute to shorter life expectancy and higher rates of avoidable mortality.⁴

To cite: Cuypers M, Naaldenberg J, Banda A, et al. Cancer incidence and diagnostic characteristics in people with intellectual disabilities in the Netherlands: a national registry-based cohort study. *BMJ Oncology* 2025;4:e000686. doi:10.1136/bmjnc-2024-000686

Additional supplemental material is published online only. To view, please visit the journal online (<https://doi.org/10.1136/bmjnc-2024-000686>).

Received 27 November 2024
 Accepted 23 April 2025

Linked
<https://doi.org/10.1136/bmjnc-2025-000685>

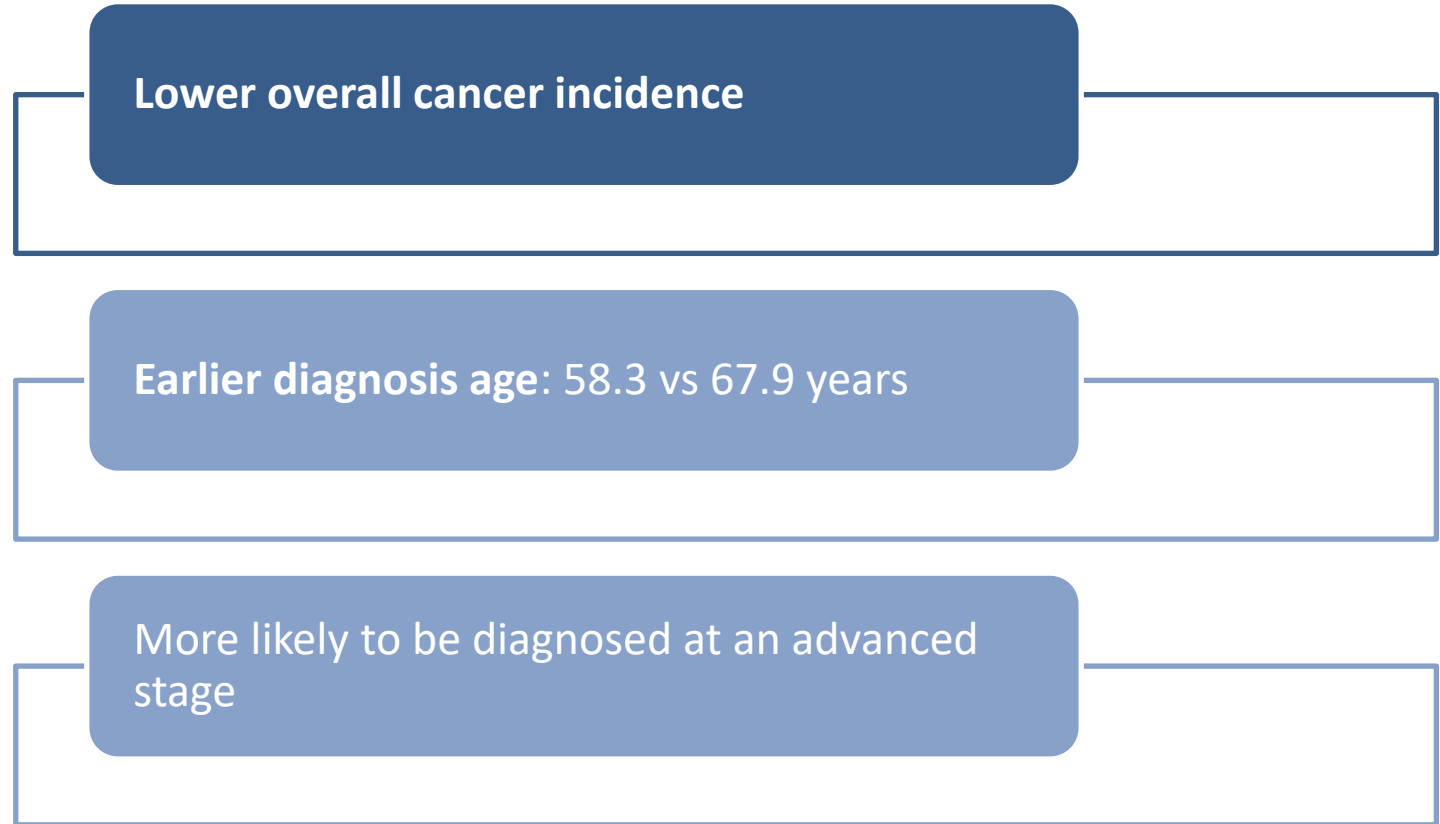
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(Cuypers et al., 2025)



What the evidence base shows

Cancer Incidence vs Mortality (Scotland)

BMJ Open Population-based cancer incidence and mortality rates and ratios among adults with intellectual disabilities in Scotland: a retrospective cohort study with record linkage

Laura McKernan Ward^{1,2} Sally-Ann Cooper² Filip Sosenko² David Morrison² Michael Fleming² Colin McCowan² Katie Robb² Catherine R Hanna² Laura Hughes-McCormack² Kirsty Dunn² David Conway² Angela Henderson² Gill Smith² Maria Truesdale² Deborah Cairns²

To cite: Ward LMCK, Cooper SA, Sosenko F, et al. Population-based cancer incidence and mortality rates and ratios among adults with intellectual disabilities in Scotland: a retrospective cohort study with record linkage. *BMJ Open* 2024;14:e004421. doi:10.1136/bmjopen-2024-004421

► Publication history and additional supplemental material for this paper are available online. To view these files, please visit the journal online (<https://doi.org/10.1136/bmjopen-2024-004421>).

Received 18 January 2024
Accepted 19 July 2024

ABSTRACT
Objective To provide contemporary data on cancer mortality rates within the context of incidence in the population with intellectual disabilities.
Methods Scotland's 2011 Census was used to identify adults with intellectual disabilities and controls with records linked to the Scottish Cancer Registry and death certificate data (March 2011–December 2019). The control cohort without intellectual disabilities and/or autism were used for indirect standardisation and calculation of crude incident rates/crude mortality rates, and age–sex standardised incident rate ratios/standardised mortality ratios (SIR/SMR), with 95% CIs.
Results Adults with intellectual disabilities were most likely diagnosed cancers of digestive, specifically colorectal (14.2%), lung (9.3%), breast (female 22.9%), body of the uterus (female 9.3%) and male genital organs (male 17.6%). Higher incident cancers included 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=1.65) and testicular (male SIR=2.40). SMRs were higher, regardless of a higher, similar or lower incidence (female SMR=1.34, male SMR=1.07). Excess mortality risk was found for colorectal (total SMR=1.54, male SMR=1.59), kidney (total SMR=2.01, female SMR=2.85), female genital organs (SMR=2.34 (ovarian SMR=2.86), body of uterus SMR=2.11), breast (female SMR=1.58) and metastatic cancer of unknown primary origin (female SMR=2.50, male SMR=2.54).
Conclusions Adults with intellectual disabilities were more likely to die of cancer than the general population. Reasons for this may include later presentation/diagnosis (poorer outcomes), poor treatment/compliance or both. Accessible public health approaches are important for people with

STRENGTHS AND LIMITATIONS OF THIS STUDY
→ Our key strength is the comprehensive coverage of administrative and health records identifying the population with and without intellectual disabilities.
→ By using nationwide robust data linkage of high-quality electronic health records, we provide reliable data with minimal bias.
→ Limitations include our inability to account for cancer incidence before the census data, which was mitigated against by our well-powered person-time for rate calculation, allowing for a meaningful interpretation of mortality rates in the context of incidence.
→ Death certificate data imprecision is considered, but our dual-analysis (underlying cause and all-cause analyses), mitigates differences and indeed have similar interpretations.

INTRODUCTION
Intellectual disabilities are a group of conditions with significant limitations in intellectual functioning and adaptive behaviour, with onset in childhood affecting 1.4% of the world population.¹ People with intellectual disabilities continue to face substantial health inequalities culminating in a 20-year premature mortality gap,² and a higher proportion of avoidable deaths compared with the general population.^{3,4} One of the most common avoidable mortalities is cancer, as many cancers are considered either preventable or treatable.⁵ However, there lacks robust comparative studies of cancer inci-

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Lower cancer incidence

Higher cancer mortality

(Ward et al., 2024)

What the evidence base shows

Cancer Incidence and Early Onset (UK Cohort)

Cancer diagnoses, referrals, and survival in people with a learning disability in the UK: a population-based, matched cohort study

Oliver John Kennedy^{1,2,3,4,5,6,7,8}, Umesh Chauhan,¹ Louise Gorman,¹ Paul Lorigan,^{4,8} Samuel Merriel,⁴ Tjerd Van Staaij,¹ Alison Wright,^{1,6} and Darren Mark Ashcraft^{1,6}

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Summary

Background People with a learning disability (LD, also known as intellectual disability) face poorer health outcomes, yet the burden of cancer in this population is poorly understood. This study investigated cancer-related outcomes in people with a LD compared to the general population.

Methods A matched cohort study was conducted using linked primary care, hospital, mortality, and cancer registry data from Clinical Practice Research Datalink (CPRD) Aurum. In total, 180,911 individuals with a LD were matched with 3,405,467 controls. Outcomes included urgent suspected cancer (USC) referrals, cancer diagnoses, treatment within six months, and overall survival (OS) post-diagnosis.

Findings Individuals with a LD had fewer USC referrals within 28 days of possible cancer symptoms (adjusted risk ratio [aRR] 0.52, 95% confidence interval [CI] 0.49–0.55). LD was associated with several cancers, including sarcoma (adjusted hazard ratio [aHR] 1.98, 1.65–2.39), central nervous system (aHR 3.42, 2.99–3.90), testicular (aHR 2.06, 1.61–2.62), and uterine cancers (aHR 1.69, 1.40–2.05) as well as cancer before age 50 years (aHR 1.74, 1.63–1.86). Absolute incidence was lower in individuals with a LD compared to without (3396 [1.9%] vs 67,506 [2.0%]) due to increased all-cause mortality (aHR 3.19, 3.12–3.27). LD was associated with fewer diagnoses via USC referrals (aRR 0.81, 0.76–0.86), fewer treatments within six months (aRR 0.83, 0.80–0.85) and shorter OS (median 4.4 years, 95% CI 3.9–5.1 vs 9.1 years, 8.8–9.5; aHR 1.73, 1.65–1.83). Melanoma, breast, and prostate cancers were less common but had up to a fourfold increased risk of death after diagnosis in individuals with a LD.

Interpretation Individuals with a LD have higher cancer risk, more diagnoses outside USC pathways, fewer treatments, and poorer prognosis. Fewer diagnoses of some cancers, alongside worse outcomes, may indicate under-investigation. As premature all-cause mortality improves, cancer burden in this population may rise disproportionately.



The Lancet Regional
Health - Europe
2026;60: 101519
Published Online 14
November 2025
<https://doi.org/10.1016/j.lanpep.2025.101519>

Slightly lower overall cancer incidence (1.9% vs 2.0%)

Slightly higher risk of cancer diagnosis

Markedly higher risk of cancer before age 50

(Kennedy et al., 2025)

What the evidence base shows

Cancer Risk in Younger Cohort (Sweden)

PLOS MEDICINE

RESEARCH ARTICLE

Cancer risk in individuals with intellectual disability in Sweden: A population-based cohort study

Qianwei Liu^{1*}, Hans-Olov Adami^{2,3,4}, Abraham Reichenberg^{5,6}, Alexander Kolevzon^{5,6,7}, Fang Fang^{1†}, Sven Sandin^{2,3,4†}

1 Institute of Environmental Medicine, Karolinska Institutet, Stockholm, Sweden, **2** Department of Medical Epidemiology and Biostatistics, Karolinska Institutet, Stockholm, Sweden, **3** Institute of Health and Society, University of Oslo, Oslo, Norway, **4** Department of Epidemiology, Harvard T.H. Chan School of Public Health, Boston, Massachusetts, United States of America, **5** Department of Psychiatry, Icahn School of Medicine at Mount Sinai, New York, New York, United States of America, **6** Seaver Autism Center for Research and Treatment, Icahn School of Medicine at Mount Sinai, New York, New York, United States of America, **7** Department of Pediatrics, Icahn School of Medicine at Mount Sinai, New York, New York, United States of America

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Citation: Liu Q, Adami H-O, Reichenberg A, Kolevzon A, Fang F, Sandin S (2021) Cancer risk in individuals with intellectual disability in Sweden: A population-based cohort study. *PLoS Med* 18(10): e1003840. <https://doi.org/10.1371/journal.pmed.1003840>

Academic Editor: Wei Zheng, Vanderbilt University
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Abstract

Background

A knowledge gap exists about the risk of cancer in individuals with intellectual disability (ID). The primary aim of this study was to estimate the cancer risk among individuals with ID compared to individuals without ID.

Higher overall cancer risk in younger individuals with ID

Increased cancer risk

(Liu et al., 2021)



Important

Findings are not contradictory

Lower recorded incidence can occur alongside **higher mortality**

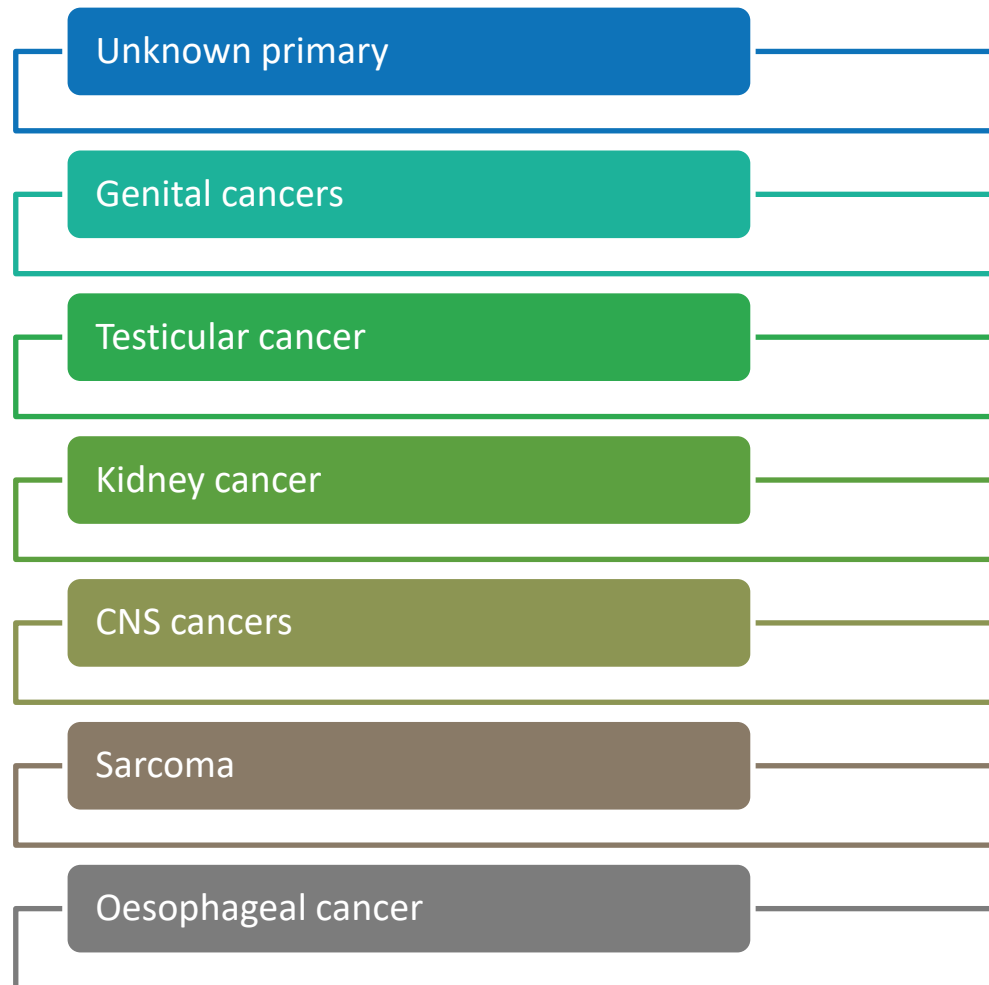
✓ Possible explanations:

- **Late diagnosis** of cancer
 - **Age** structure
- **Underdiagnosis or missed cases**
- **Higher all-cause and competing mortality**, reducing chance of cancer being detected at older ages.

(McMahon et al., 2025; Cuypers et al., 2025; Kennedy et al., 2025)

What the evidence base shows

Specific cancer types



Patterns vary by cohort age, case mix, and whether syndromic subgroups are included.

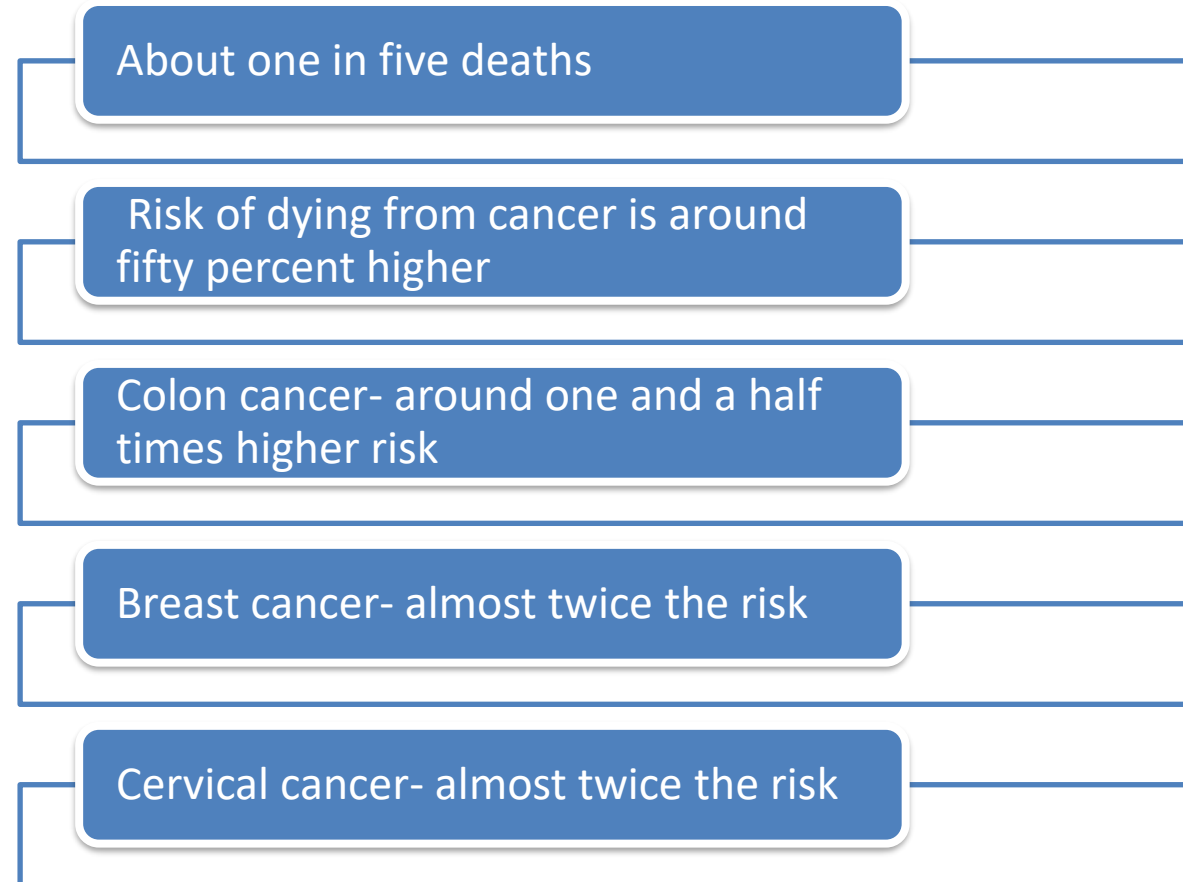
(Banda et al., 2024; McMahon et al., 2025)

What the evidence base shows

Pattern	Headline finding	Sources
Earlier burden	Cancer diagnosis and cancer death occur at younger ages	Cuypers et al., 2021;2025; Kennedy et al., 2025
Unknown primary	Higher incidence and much higher mortality suggest late recognition	Cuypers et al., 2021;2025; Ward et al., 2024
Female genital cancers	Uterine and ovarian cancers are repeatedly elevated in some cohorts	Ward et al., 2024; Kennedy et al., 2025; Cuypers et al., 2025
Testicular cancer	Raised incidence appears across large national studies	Ward et al., 2024; Kennedy et al., 2025
CNS and sarcoma	Higher risks are especially clear in the UK cohort	Kennedy et al., 2025
Lower recorded breast, prostate, and skin cancers	Likely shaped at least in part by under detection and lower screening or case finding	Cuypers et al., 2025; Ward et al., 2024; Kennedy et al., 2025

Mortality, late diagnosis, and pathway failure

Netherlands



People with intellectual disabilities died 10 years younger than in the general population

(Cuypers et al., 2021)

Mortality, late diagnosis, and pathway failure

UK, Canada

About 50% less likely to get an urgent cancer referral

Lower treatment rates and shorter survival

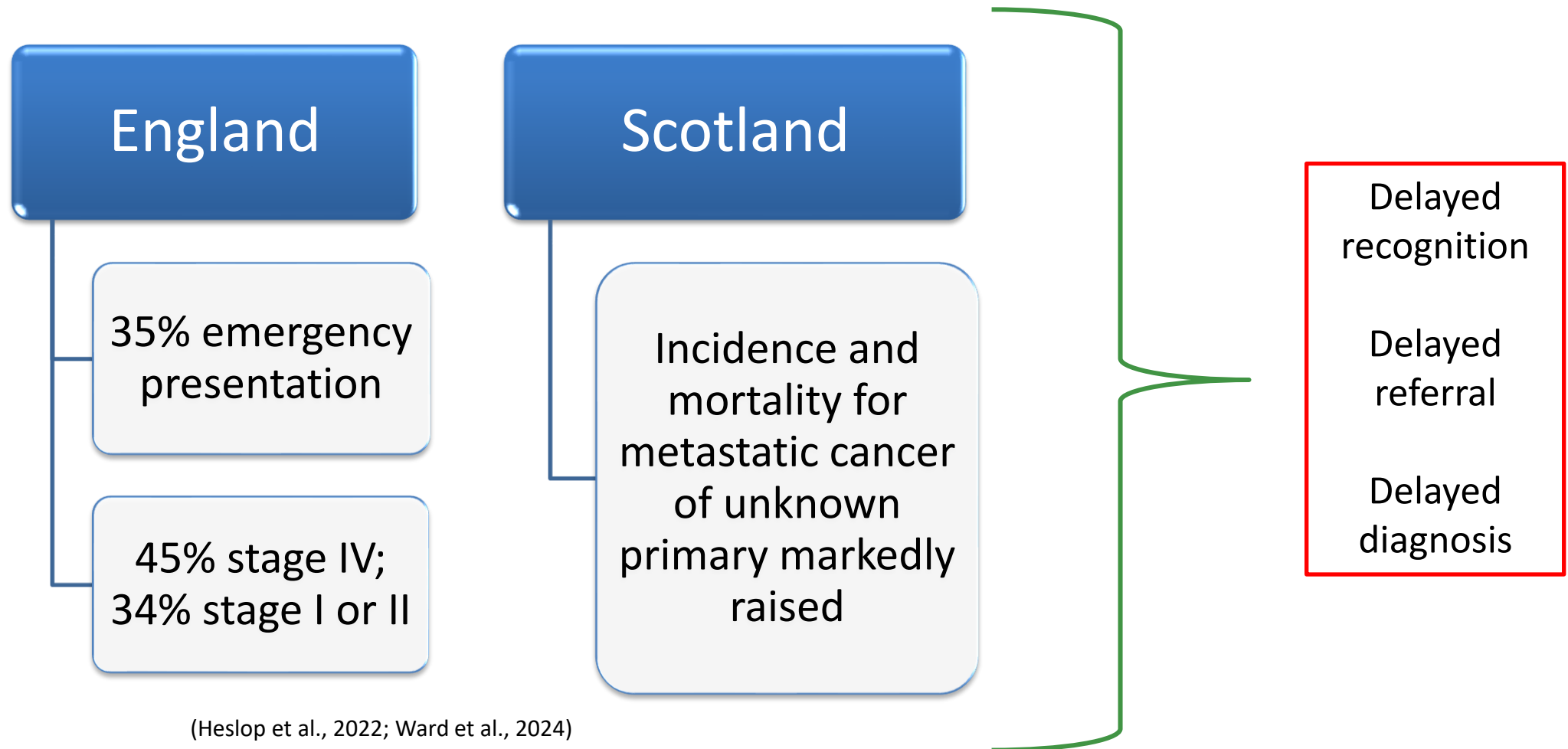
Higher risk of death after diagnosis

Additionally, in Manitoba, mixed intellectual or developmental disability cohorts showed a 20 percent higher risk of metastatic disease at diagnosis and a 53 percent higher risk of death after cancer diagnosis

(Kennedy et al., 2025)

Hansford et al., 2023)

Mortality, late diagnosis, and pathway failure



What the evidence base shows

Mortality and prognosis

Cancer mortality is higher and survival is worse.

More likely to be diagnosed at an advanced (metastatic) stage
Mortality after cancer diagnosis is about fifty percent higher
Survival differences vary by sex

Overall cancer mortality is higher, particularly among females.
Excess deaths in:
Colorectal and kidney cancers
Female cancers (ovarian, uterine, breast)
Metastatic cancers (unknown primary)

So the question becomes...



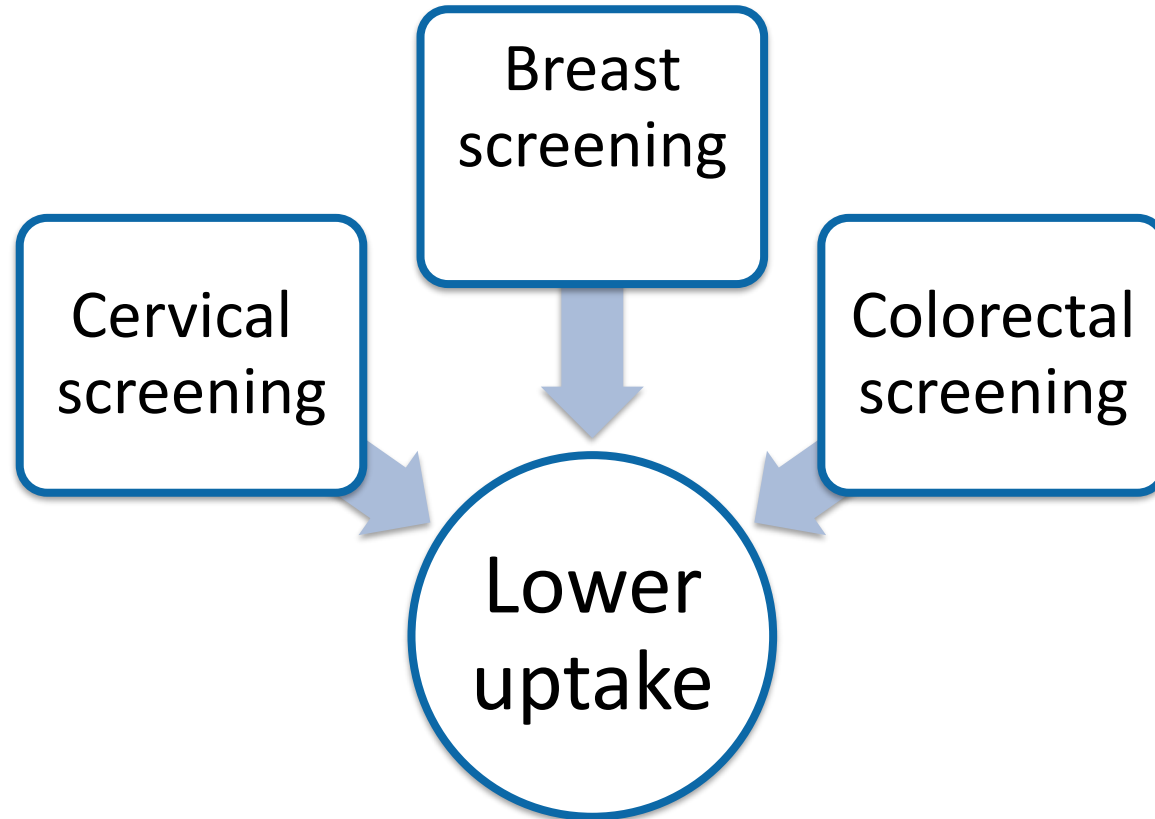
Where in the pathway are these inequalities arising?



One of the most important aspects is the surveillance of
symptoms and screening

What the evidence base shows

Screening



Most evidence is from organised screening programmes in high income settings

(McMahon et al., 2025; Power et al., 2024)

What the evidence base shows

Screening

Lower cervical
screening
uptake- 35%

Much less
likely to be
screened

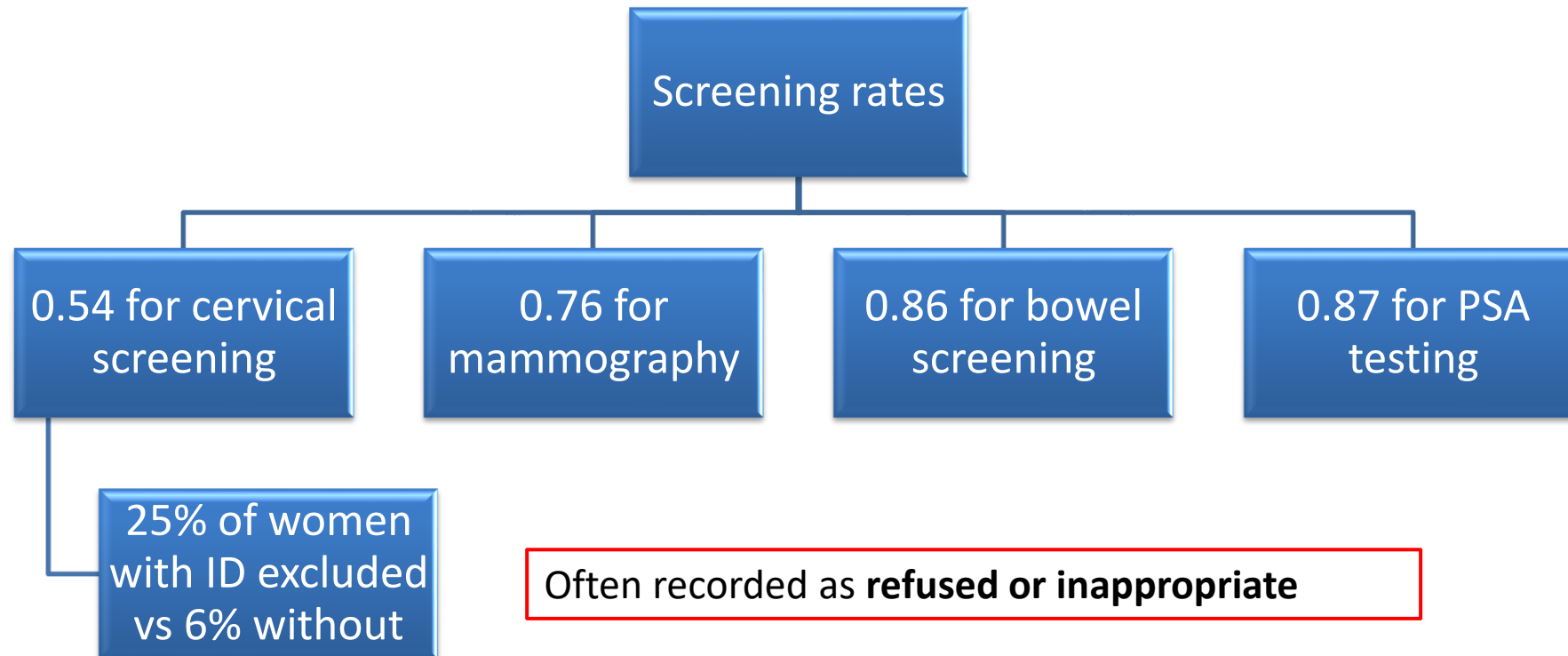
Studies reported that adults with IDD experienced inequities at various points along the cancer continuum.

Numerous social and physical determinants of health influenced the experiences and outcomes of adults with IDD.

(Banda et al., 2024; Osborn et al., 2012; Ouellette-Kuntz et al., 2015; Power et al., 2024)

Screening participation gaps

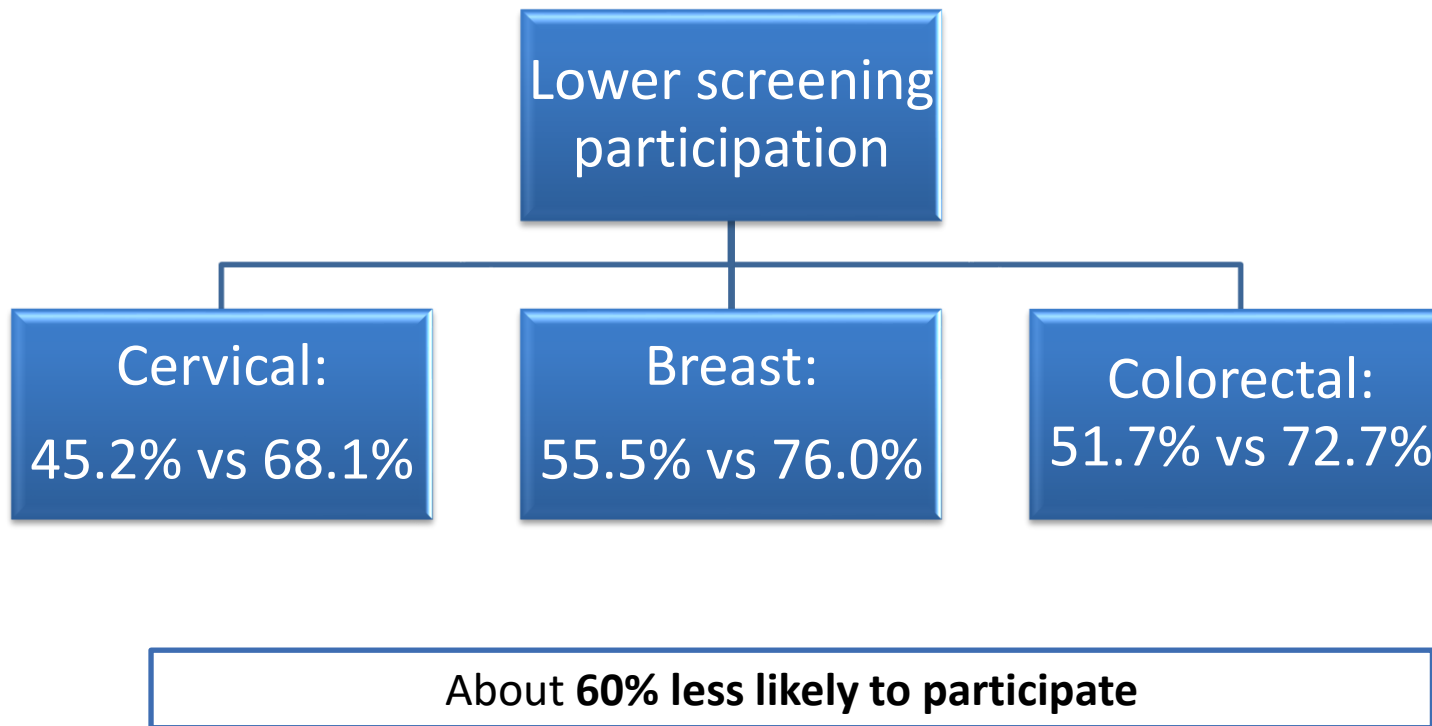
UK



(Osborn et al., 2012)

Screening participation gaps

Netherlands



Quality of Screening

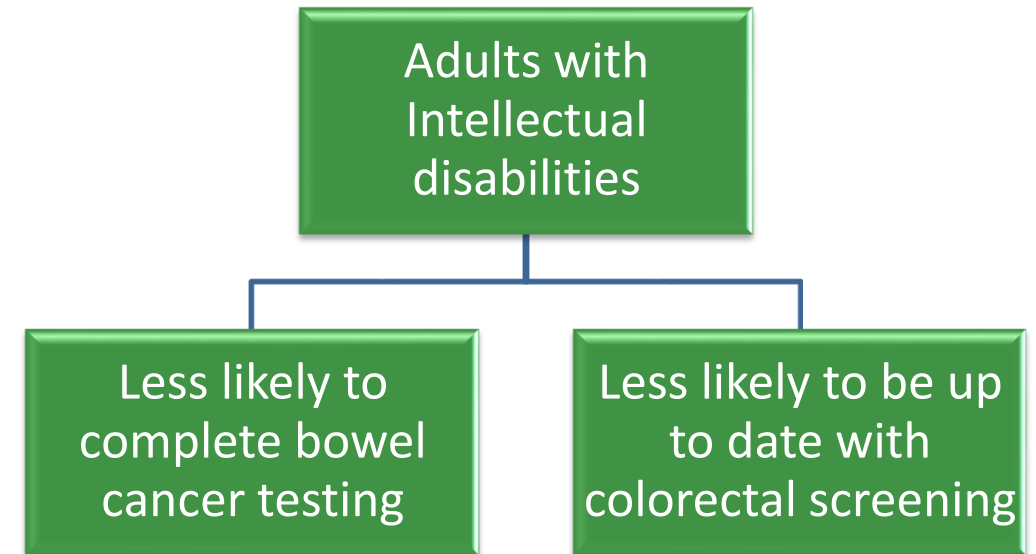
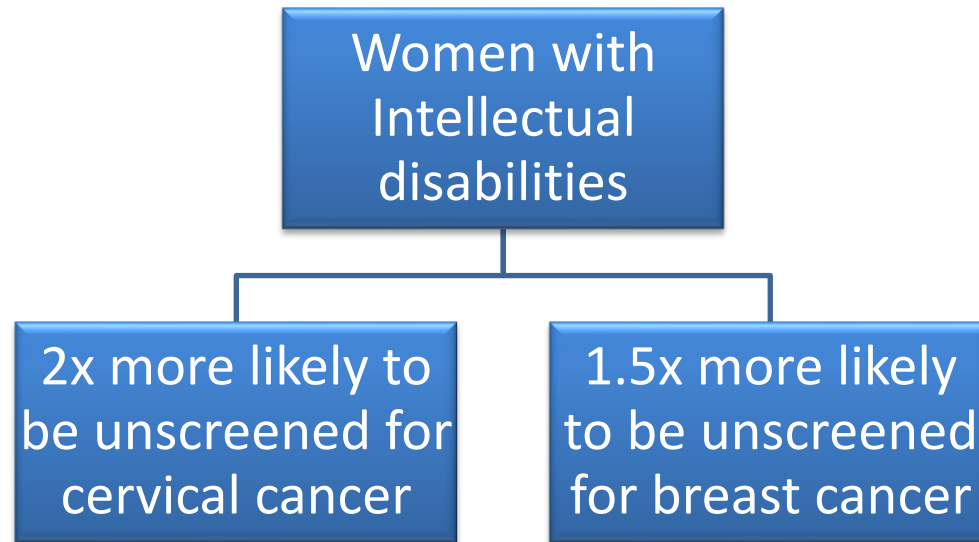
More invalid/unreliable results

Suggests **ongoing accessibility and quality issues**, even after attendance

(Banda et al., 2025)

Screening participation gaps

Ontario



(Cobigo et al., 2013; Ouellette-Kuntz et al., 2015)

So the key question now is...

Why do these gaps persist?

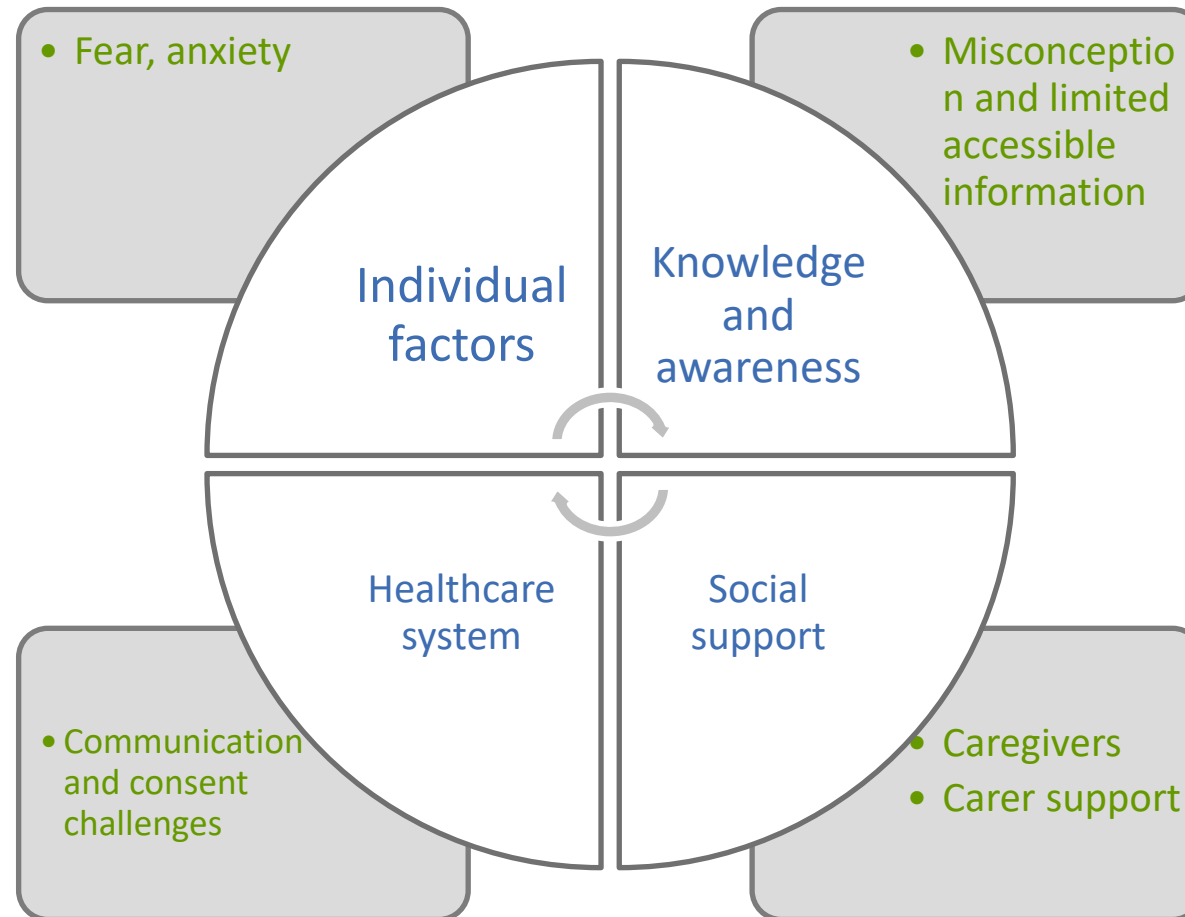


And that brings us to the barriers to screening and
early detection



What the evidence base shows

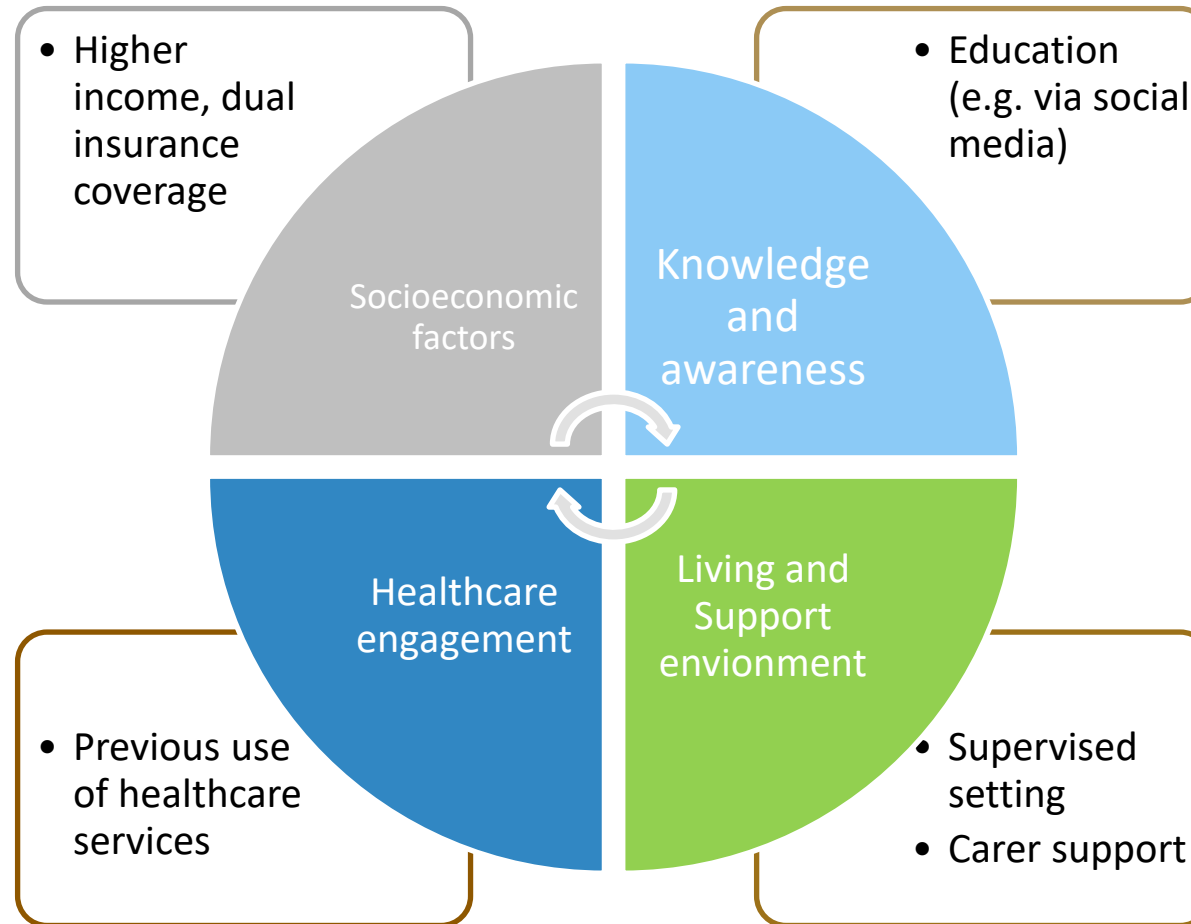
Screening – Key barriers



(Banda et al., 2025; Osborn et al., 2012; Ouellette-Kuntz et al., 2015; Power et al., 2024)

What the evidence base shows

Screening – Facilitators



(Arana-Chicas et al., 2020; Chan et al., 2021; Power et al., 2024)

What the evidence base shows

Service access

Referral, treatment, and pathway access are worse.

Survivorship and palliation remain under studied.

Less cancer-related care
Inequalities **increase with age**
Greater **disparities in females**
Lower use of screening programs

Fewer urgent referrals
Less treatment within 6 months
Shorter survival after cancer diagnosis
Some cancers **less common but higher risk of death**
after diagnosis

(Cuypers et al., 2020; 2004; Kennedy et al., 2025; Stirling et al., 2021)

Why the inequalities are so persistent

Barriers to Cancer Screening and Across the Cancer Care Pathway



(Chan et al., 2021; Cuypers et al., 2024; Power et al., 2024; Ouellette-Kuntz et al., 2015; Stirling et al., 2021)

So if inequalities are built into the system, the next question is — how do we change that?



Implications for clinicians and policy

The evidence supports a shift from generic equality language to concrete service design.

Cancer risk assessment should go beyond incidence, incorporating mortality, age at diagnosis, stage, emergency presentation, and route to diagnosis to better capture inequalities.

Organised screening programmes should make reasonable adjustments standard, including accessible information, supported decision-making, longer appointments, service navigators, staff training, and transport or support funding.

Primary care and referral pathways should use lower investigation thresholds when symptoms are nonspecific or communication is difficult, making this a clear clinical priority.

(Cuypers et al., 2021; Heslop et al., 2022; Kennedy et al., 2025; Weise et al., 2024; Marriott et al., 2015)

Implications for clinicians and policy

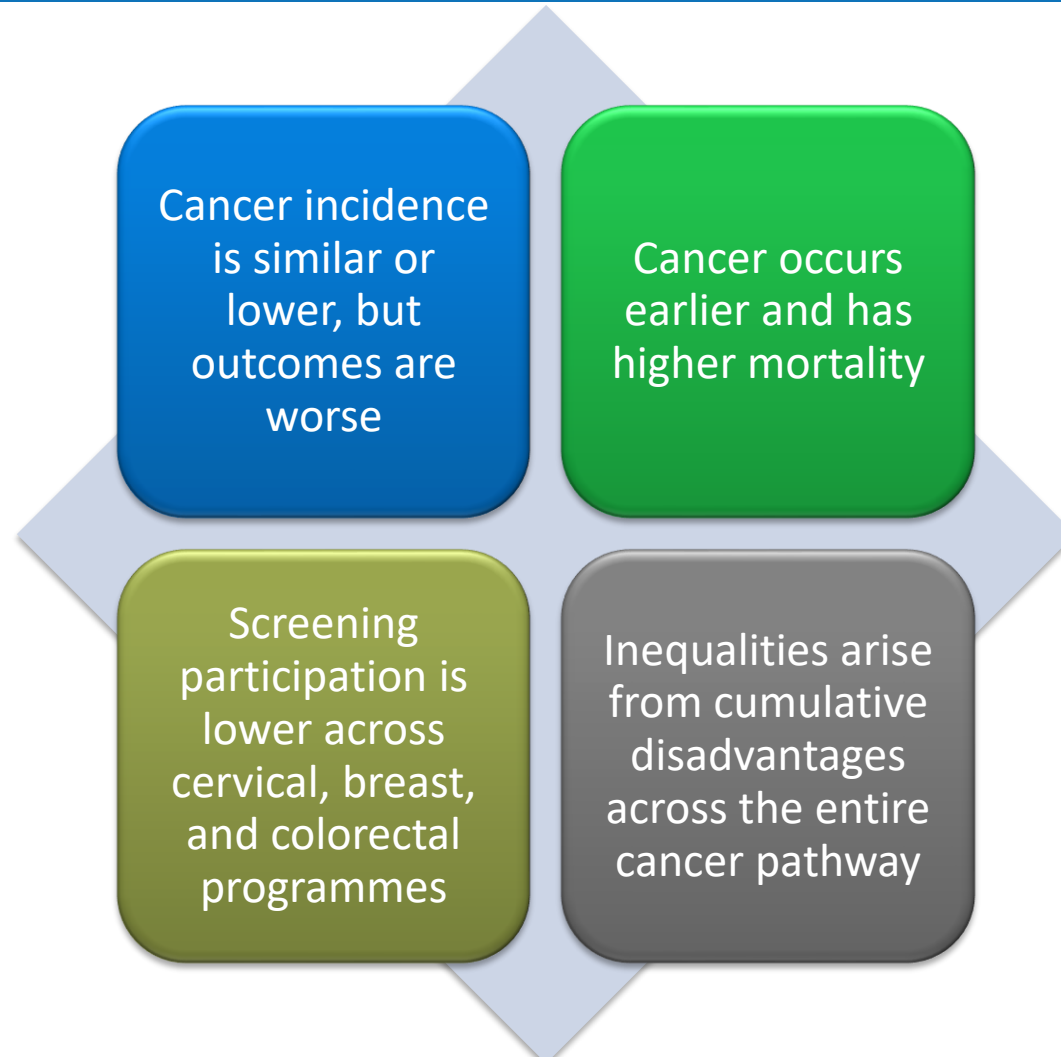
Screening policy may need tailoring, not just improved uptake, with consideration of earlier start ages and alternative test methods for groups with earlier onset or difficulty tolerating standard procedures.

Cancer registries, screening systems, and routine records should record intellectual disability more reliably. Without that, inequities remain partly hidden and hard to act on.

Guidelines should address treatment adaptation explicitly. Current evidence suggests lower treatment rates and unwarranted variation, but guidance on how to adapt care safely is still thin.

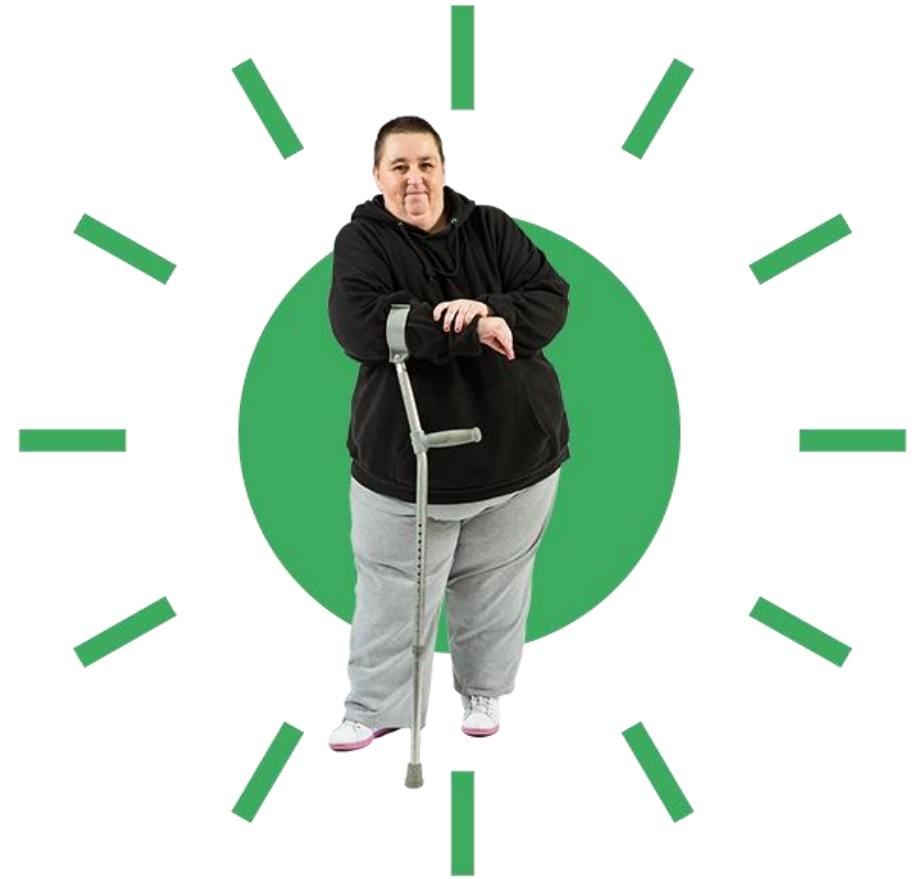
(Heslop et al., 2022; Cuypers et al., 2004; 2024b; Kennedy et al., 2025; McMahon et al., 2025)

Main Takeaways



Main Takeaways

This is not just about access to care — it is about ensuring that care is designed to meet the needs of everyone.



CANCER-SCREENING AND PREVENTION FOR PEOPLE WITH INTELLECTUAL DISABILITY (CUPID): LUNCH & LEARN - WEBINAR SERIES

CUPID
CANCER-SCREENING AND PREVENTION
FOR PEOPLE WITH INTELLECTUAL DISABILITY



06 May 2026

13:00 to 13:45 (GMT)
14:00 to 14:45 (CET)



Dr. Oliwia Kowalczyk

Dr. Margaret Denny

BEYOND WORDS: A FOCUS ON AUGMENTATIVE COMMUNICATION

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