

A Canadian research perspective on cancer among adults with intellectual or developmental disabilities

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en santé du Canada

Conflicts of Interest

- Funding from the Canadian Institutes of Health Research and the Canadian Cancer Society

Take Home Messages

In Canada, adults with intellectual or developmental disabilities are more likely to be diagnosed with an unknown or advanced stage cancer and more likely to die following a cancer diagnosis.

Lower rates of cancer screening, delays during the diagnosis period, and lower rates of treatment contribute to these worse outcomes.

Addressing these disparities is possible requires making changes at the policy and system level, clinically, and in research.

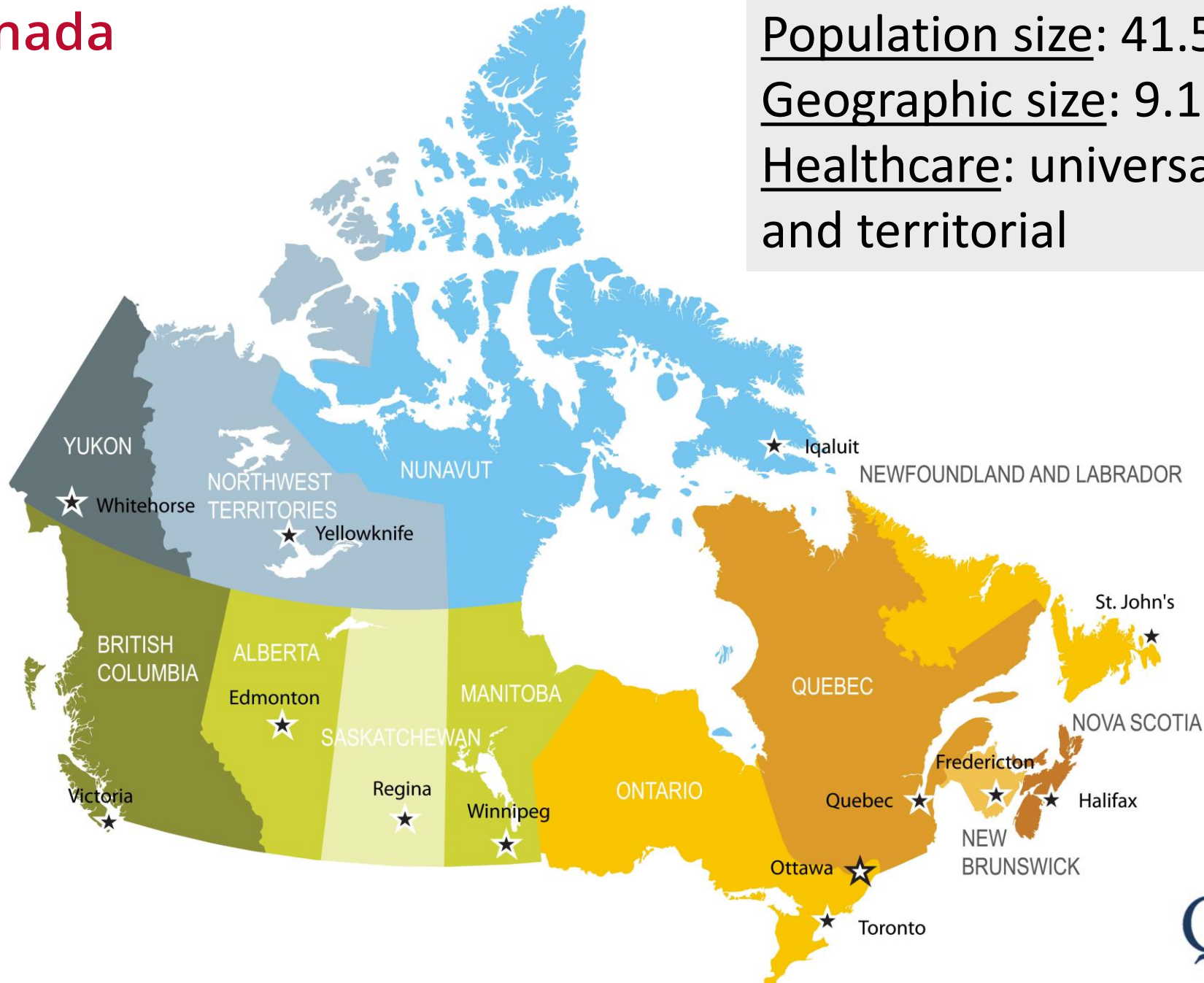
The time is now to act on existing evidence and improve outcomes.

Canada

Population size: 41.5 million (2024)

Geographic size: 9.1 million km²

Healthcare: universal system, provincial and territorial



The Autism Project: Pamela Button



November 2012
LUCAS OLENIUK / TORONTO STAR

Toronto Star six-part series in 2012

https://www.thestar.com/news/investigations/the-autism-project-aging-with-autism/article_41bbad7f-b0bd-5f27-86bd-e8e1d94e3de6.html

2019-2029

CANADIAN STRATEGY FOR CANCER CONTROL

Doing together what cannot be done alone



CANADIAN PARTNERSHIP
AGAINST CANCER
PARTENARIAT CANADIEN
CONTRE LE CANCER

Advancing Health Equity Through Cancer Information and Support Services

Report on communities that are underserved

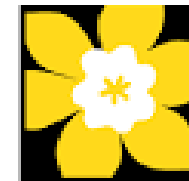
October 2023

Ontario Cancer Plan 6

2024 – 2028



Ontario Health
Cancer Care Ontario



Canadian
Cancer
Society

Société
canadienne
du cancer

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Why haven't adults with intellectual or developmental disabilities been emphasized in Canadian cancer planning?

A lack of evidence to inform policy and service provision?



Contents lists available at ScienceDirect

European Journal of Oncology Nursing

journal homepage: www.elsevier.com/locate/ejon



A scoping review documenting cancer outcomes and inequities for adults living with intellectual and/or developmental disabilities

Morgan Stirling^{a,b}, Alexandra Anderson^a, Helene Ouellette-Kuntz^c, Julie Hallet^{d,e},
Shahin Shooshtari^a, Christine Kelly^a, David E. Dawe^{b,g,h}, Mark Kristjanson^{b,f},
Kathleen Decker^{a,g}, Alyson L. Mahar^{a,g,*}

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Are cervical and breast cancer screening programmes equitable? The case of women with intellectual and developmental disabilities

V. Cobigo,¹ H. Ouellette-Kuntz,^{2,3} R. Balogh,^{3,7} F. Leung,⁵ E. Lin^{3,6} & Y. Lunsky^{3,4}



AMERICAN JOURNAL ON INTELLECTUAL AND DEVELOPMENTAL DISABILITIES
2018, Vol. 123, No. 6, 499–513

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DOI: 10.1352/1944-7558-123.6.499

The Association Between Continuity of Primary Care and Preventive Cancer Screening in Women With Intellectual Disability

Natasha Plourde, Hilary K. Brown, Simone Vigod, and Virginie Cobigo

Brief Report

Brief report: cervical cancer screening in women with intellectual and developmental disabilities who have had a pregnancy

H. K. Brown,^{1,2,3} N. Plourde,⁴ H. Ouellette-Kuntz,^{2,5} S. Vigod^{1,2,3} & V. Cobigo^{2,4}

RESEARCH ARTICLE

Uptake of Colorectal Cancer Screening among Ontarians with Intellectual and Developmental Disabilities

Hélène Ouellette-Kuntz^{1,2,3*}, Helen Coe¹, Virginie Cobigo^{3,4}, Andrew S. Wilton³

¹ Department of Public Health Sciences, Queen's University, Kingston, Ontario, Canada, ² Ongwanada Resource Centre, Kingston, Ontario, Canada, ³ Institute for Clinical Evaluative Sciences (ICES), Toronto, Ontario, Canada, ⁴ School of Psychology, University of Ottawa, Ottawa, Ontario, Canada

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What did we learn?

Inequities across all studied milestones along the cancer continuum

Lack of connection of inequities to broader systems of intersecting oppression.



- Challenges accessing support.
- Gatekeeping role of healthcare providers, caregivers.
- Significant limitations in methods used to create existing evidence.
- Significant gaps in evidence used to support decision-making.

Our Team's Motivation

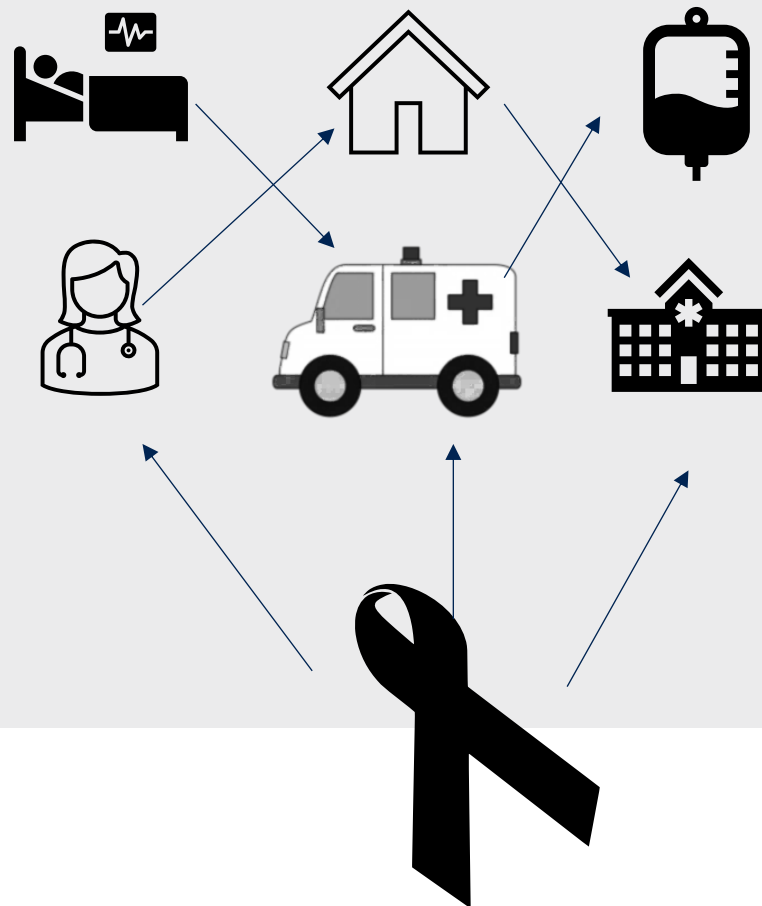
- Inequity exists within Canadian healthcare systems.
- Address the lack of high-quality data to support cancer control for people with intellectual or developmental disabilities.
- Justice and advocacy for people living with intellectual or developmental disabilities in Canada and their friends, families, and caregivers.

Do Canadians with intellectual or developmental disability experience cancer disparities within provincial, universal healthcare systems?

HOW IS OUR TEAM DOING RESEARCH IN CANADA?

Administrative health
data

Provincial cancer
registry data



HOW IS OUR TEAM DOING RESEARCH IN CANADA?

Administrative health
data
Provincial cancer
registry data

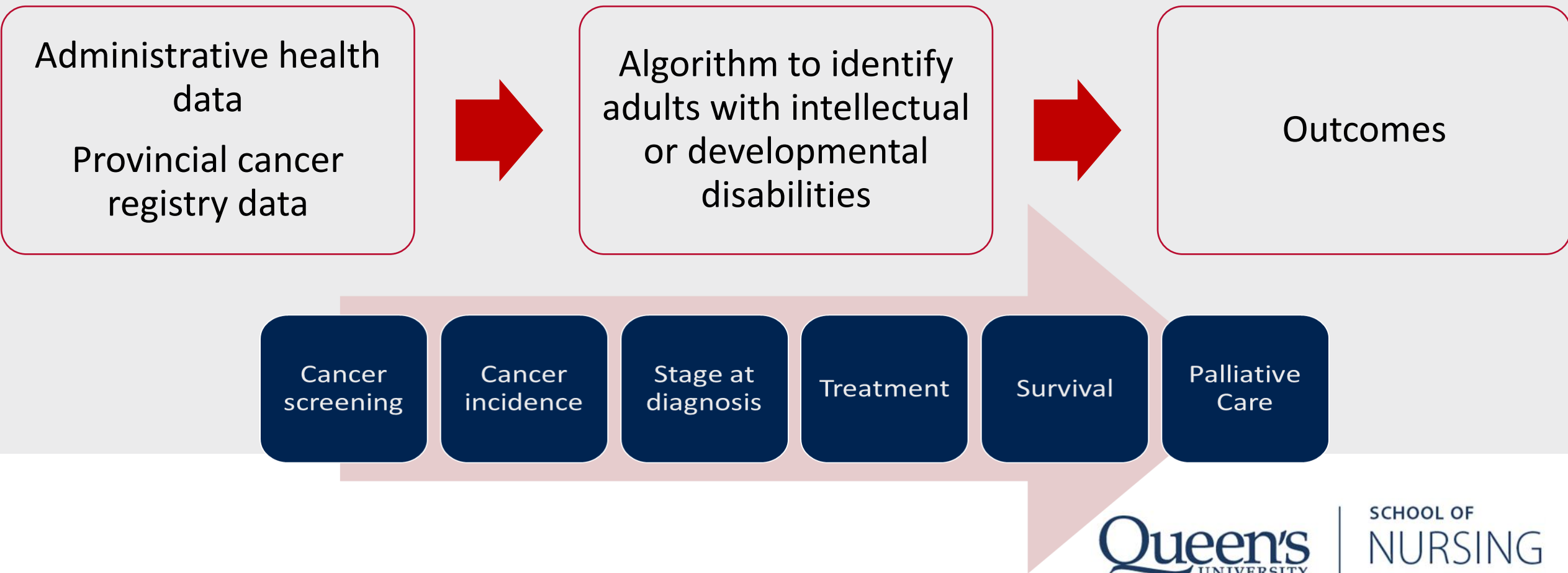


Algorithm to identify
adults with intellectual
or developmental
disabilities



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HOW IS OUR TEAM DOING RESEARCH IN CANADA?



Today's Talk?

Administrative health data
Provincial cancer registry data



Algorithm to identify adults with intellectual or developmental disabilities

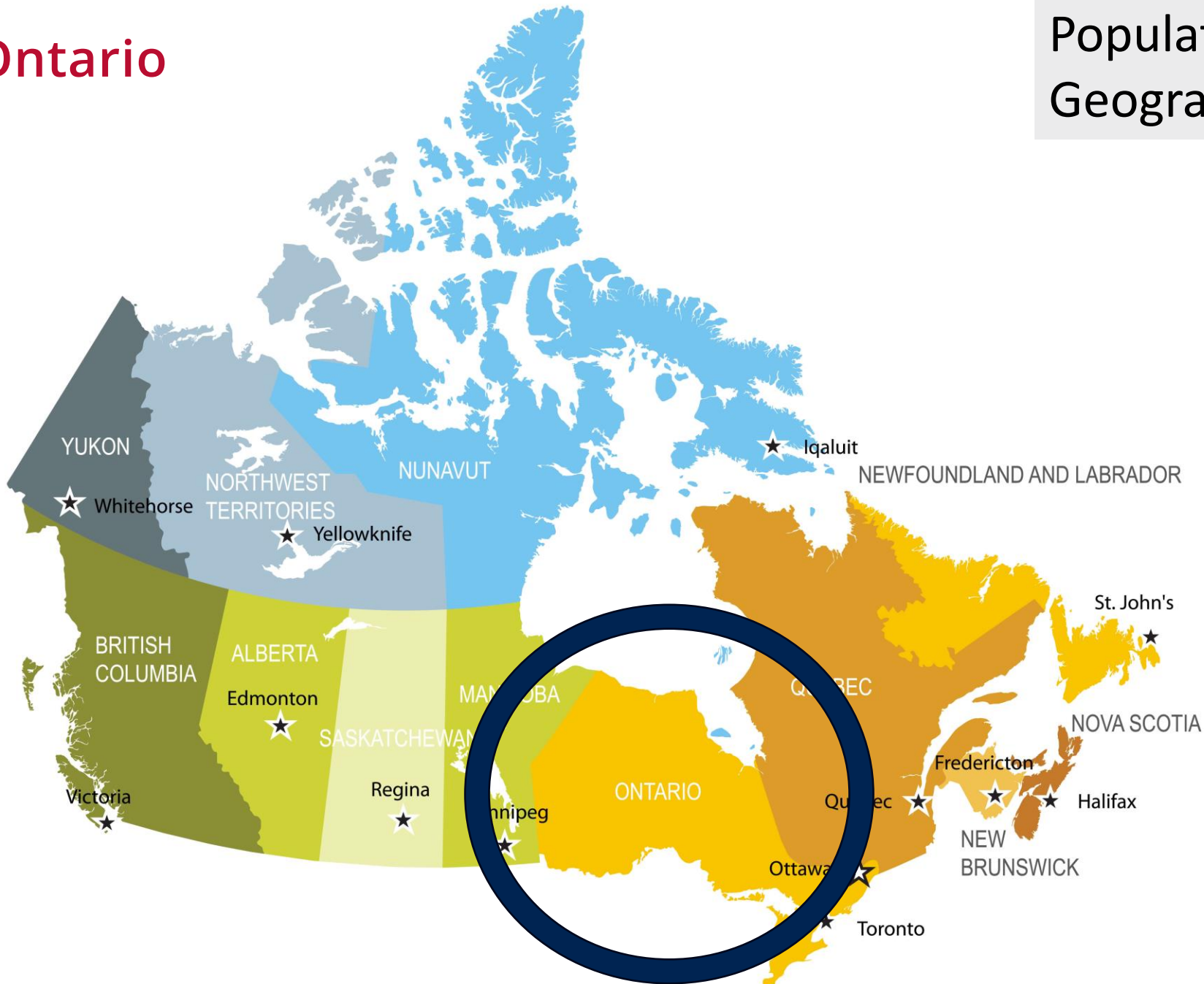


Outcomes



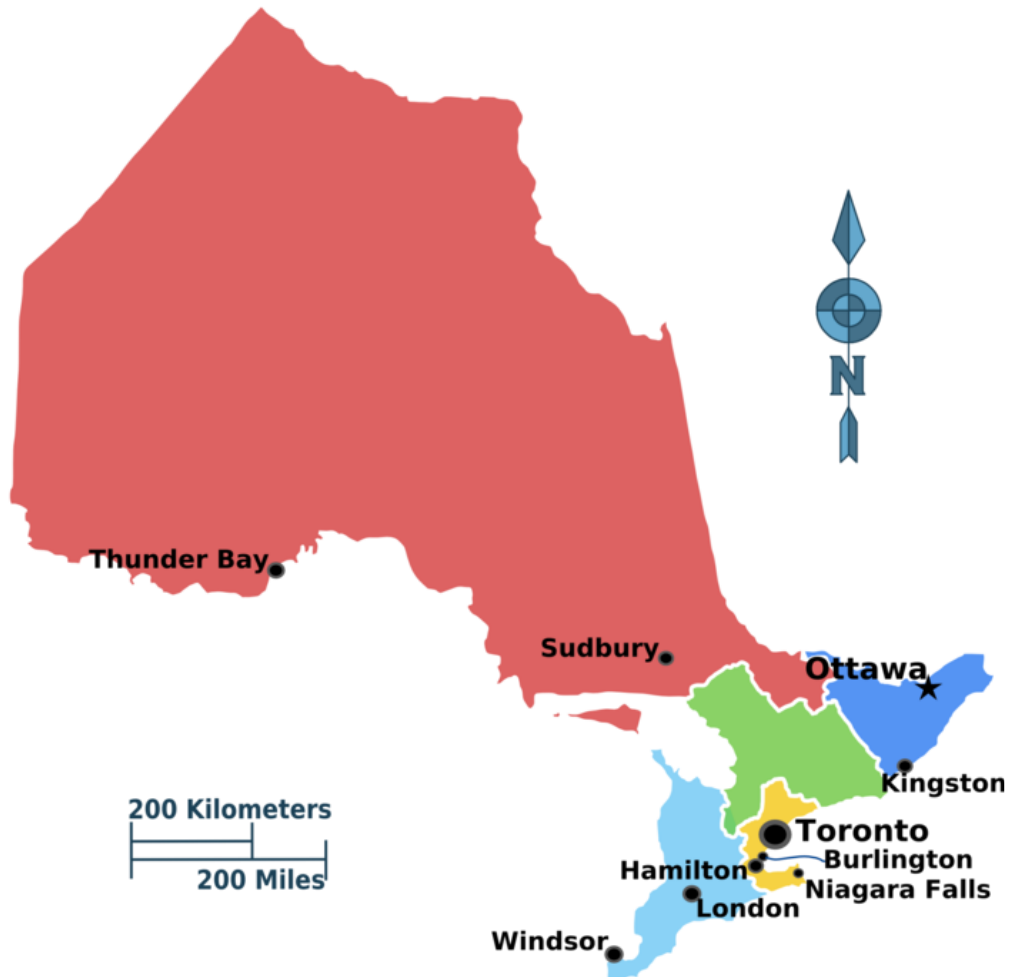
Ontario

Population size: 16.1 million
Geographic size: 892,000km²



Ontario

- 6 transitional health regions
- 14 regional cancer centres (5 in the Greater Toronto Area)



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Who has an intellectual or developmental disability and cancer in Ontario (2007-2019) ?

Breast cancer: 123,695 Ontarians, 486 with IDD (0.39%)

Colorectal cancer: 98,809 Ontarians, 506 with IDD (0.51%)

Lung cancer: 116,232 Ontarians, 385 with IDD (0.33%)

Compared to people with cancer who were not living with intellectual or developmental disability



**More likely to
be younger**



**Greater
burden of
comorbid
disease**

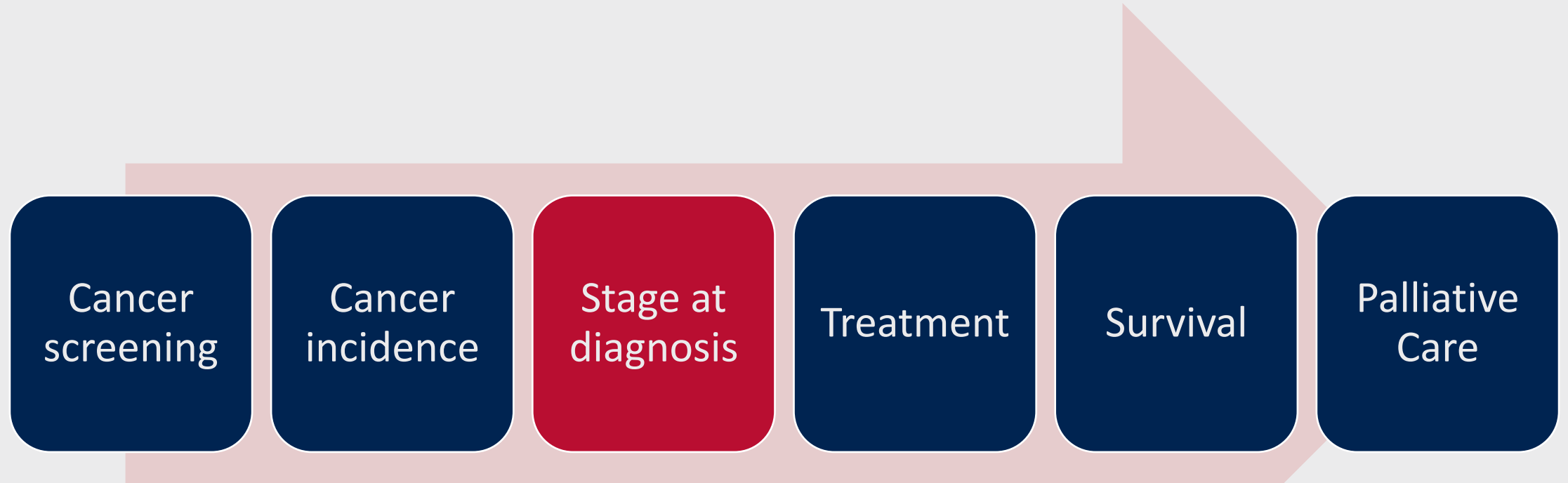


**More likely to
be in the
lowest
income
communities**

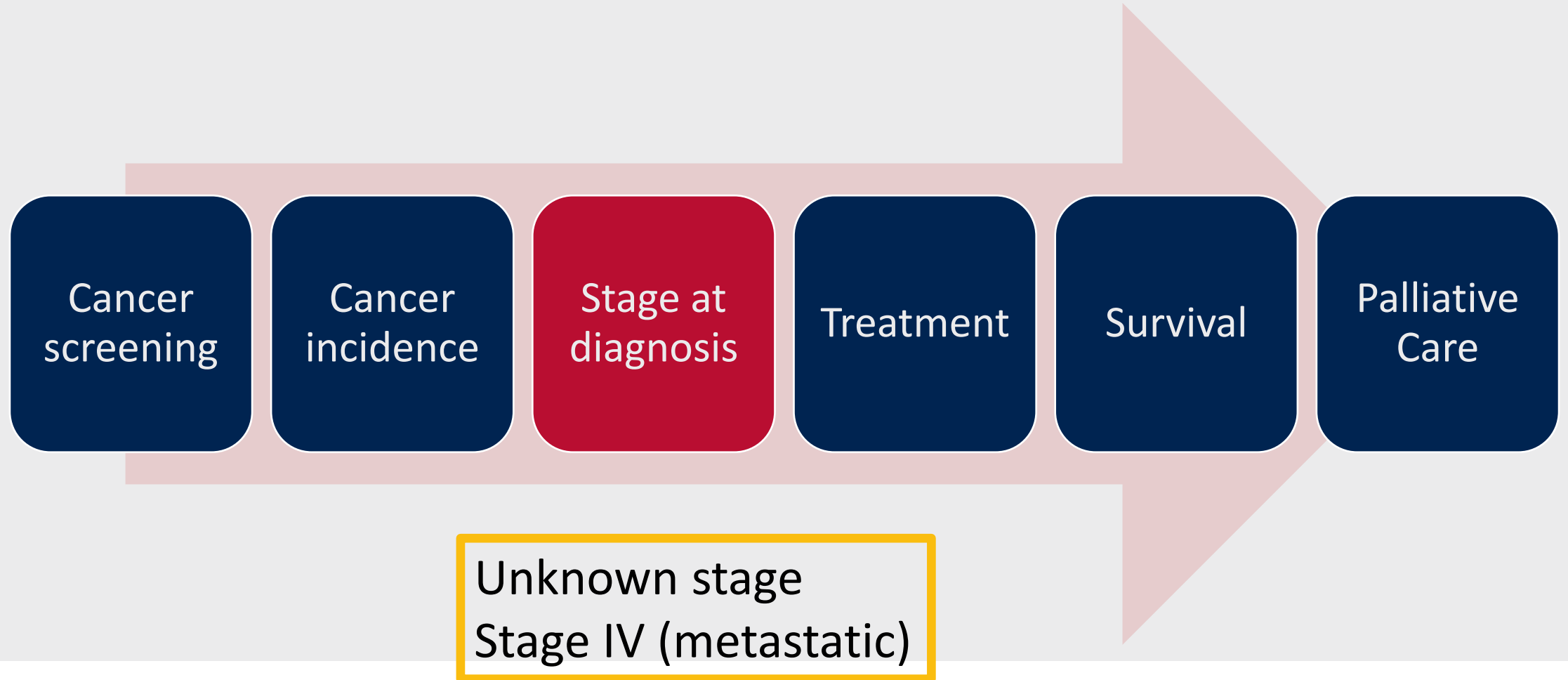


**More likely
to live in
rural settings**

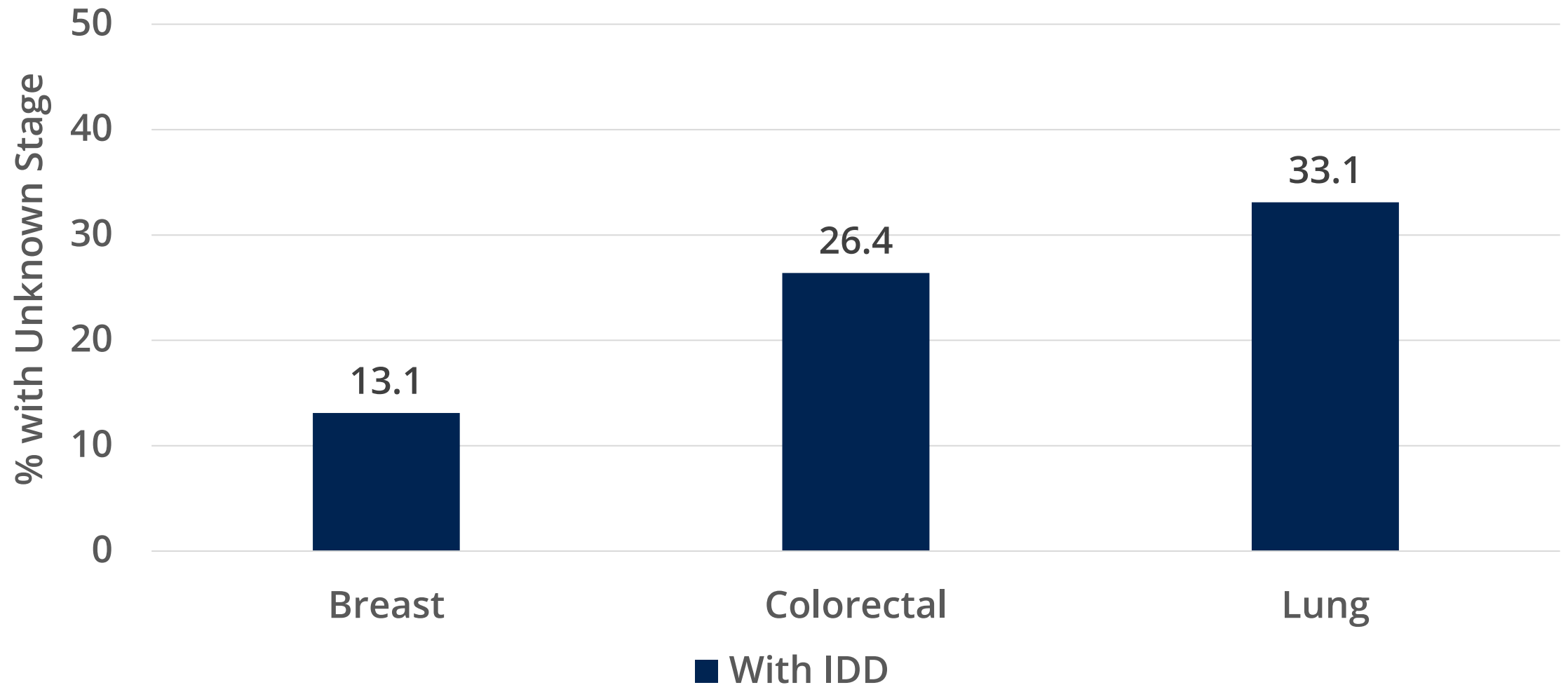
Stage at diagnosis



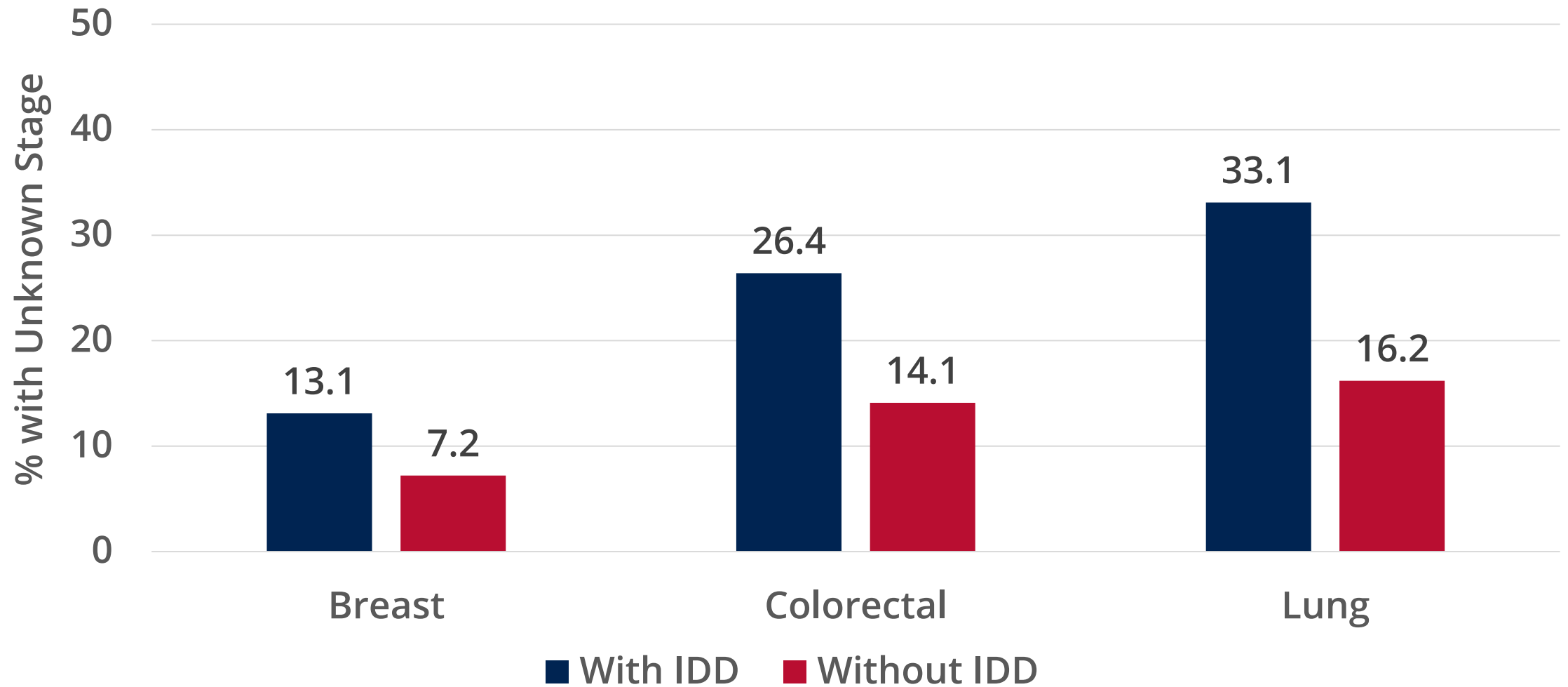
Stage at diagnosis



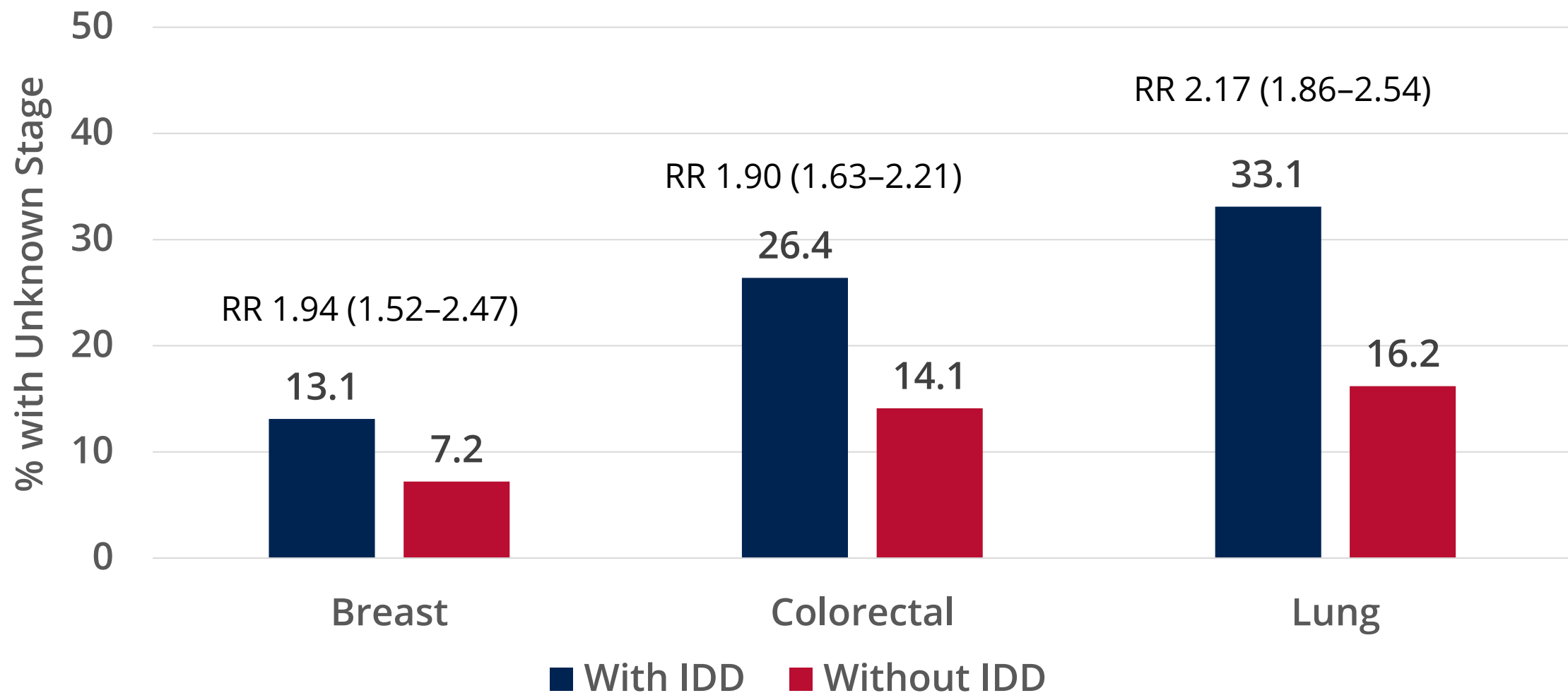
Unknown Stage



Unknown Stage



Unknown Stage

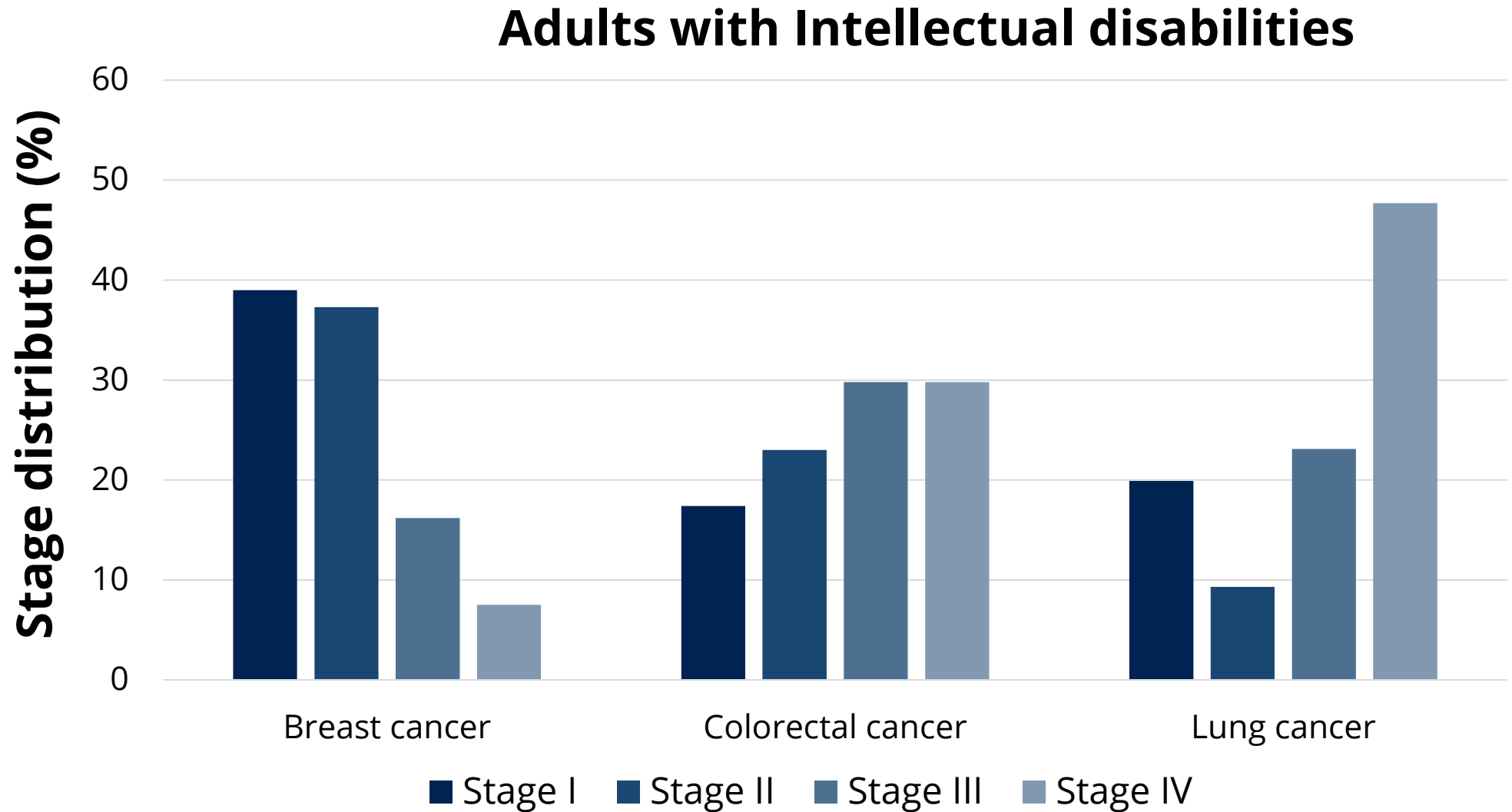


Why is this happening???

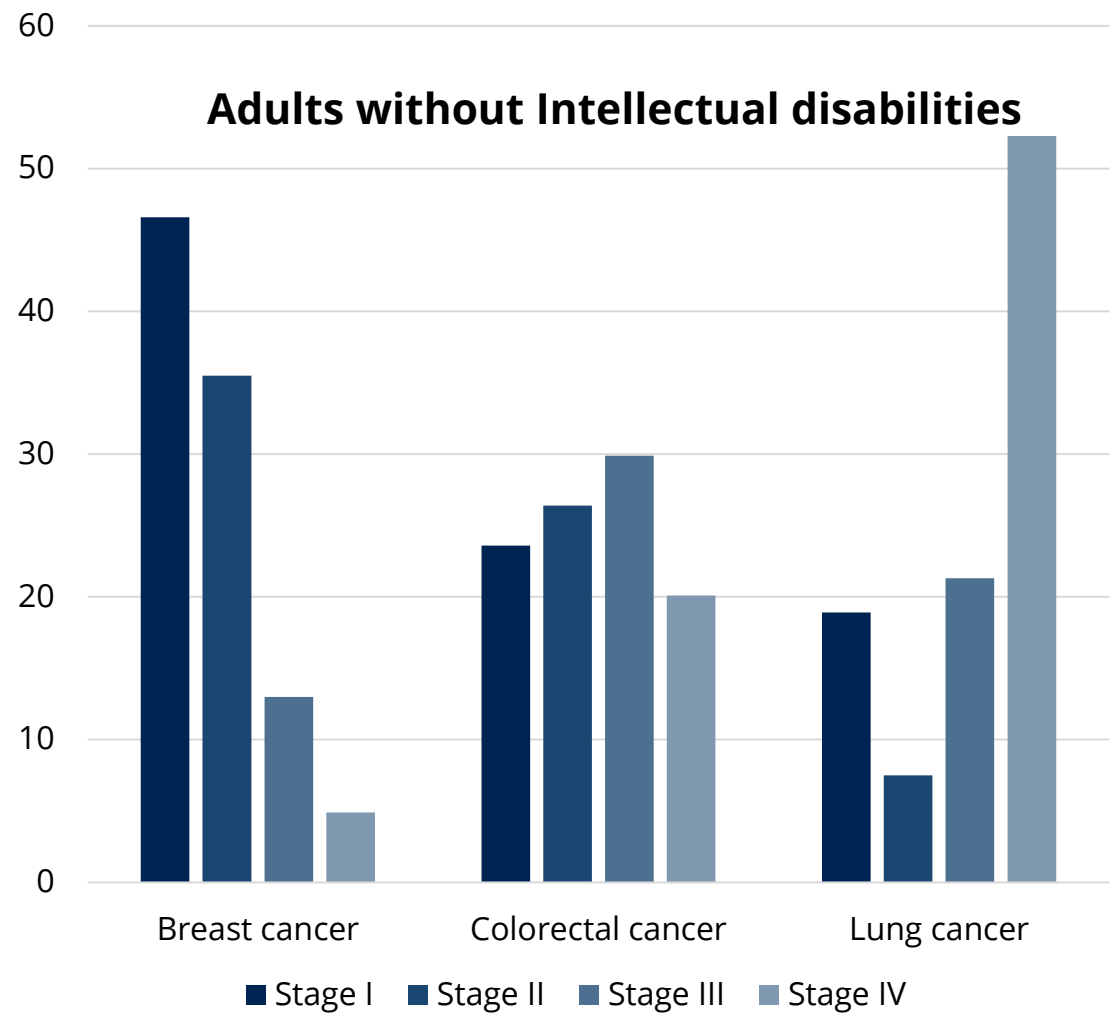
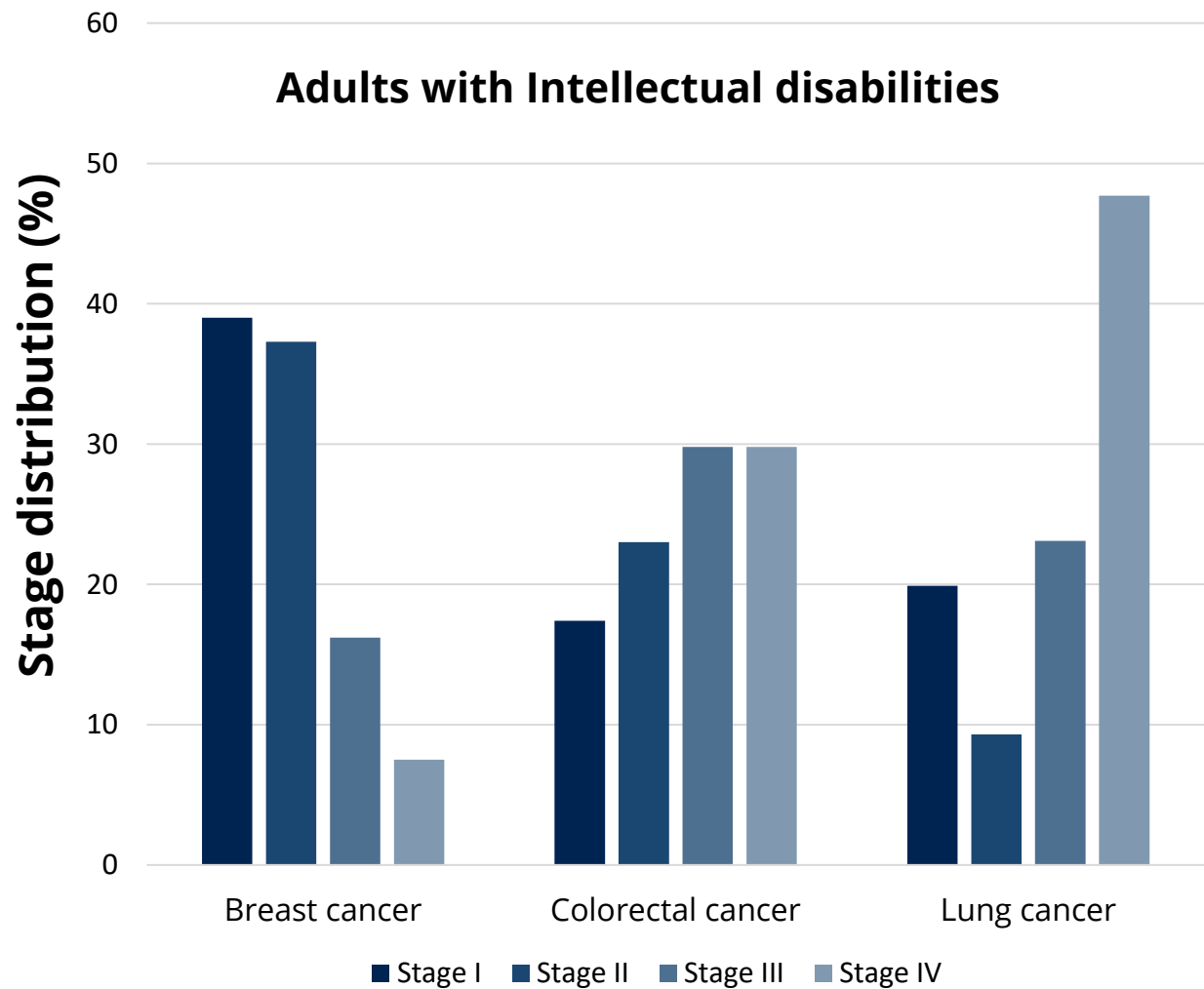
Pathways to unknown stage at diagnosis

- No plans for treatment, why continue staging?
- Frank metastatic disease, staging not recorded.
- Access to regional cancer centres.

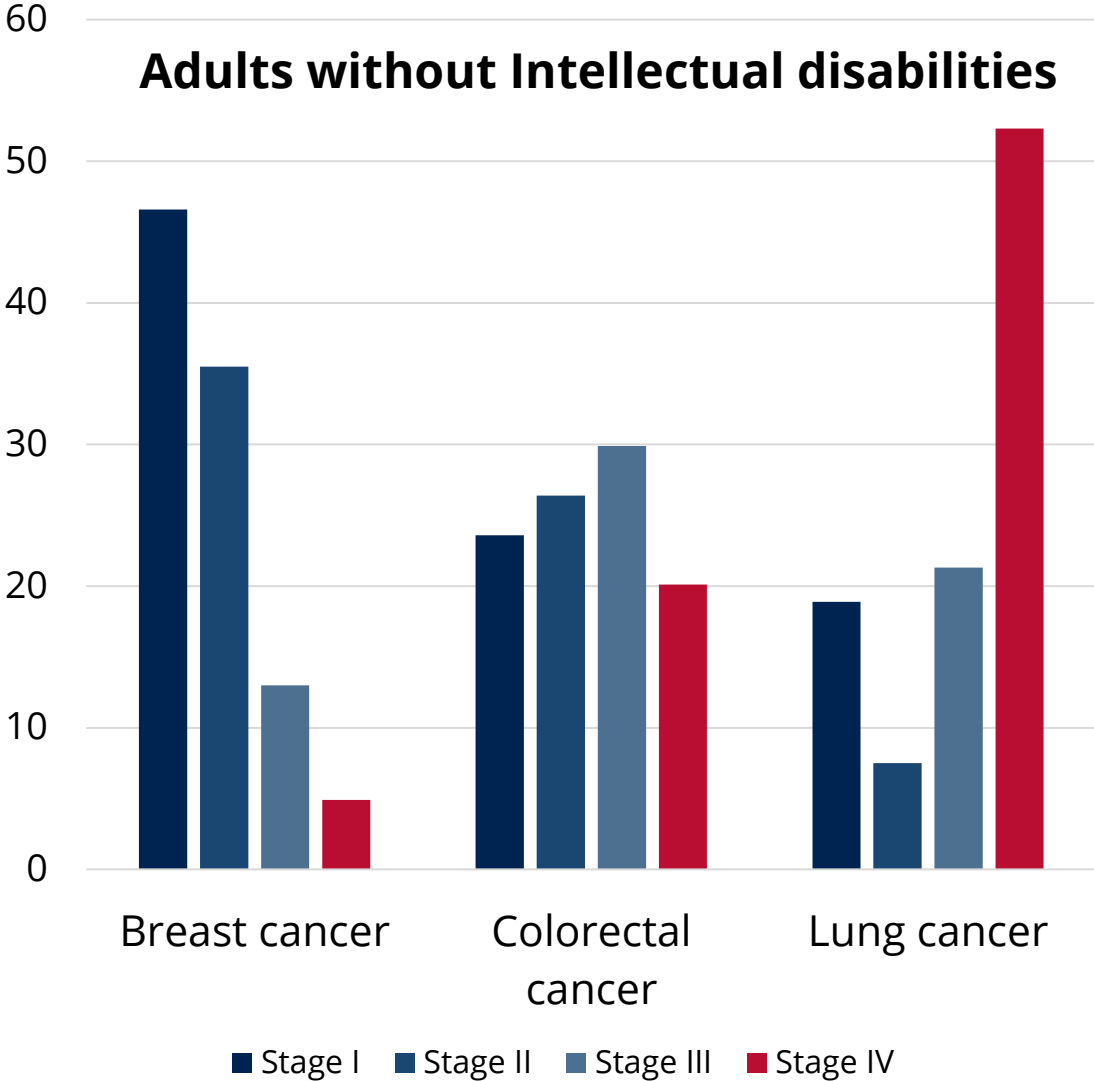
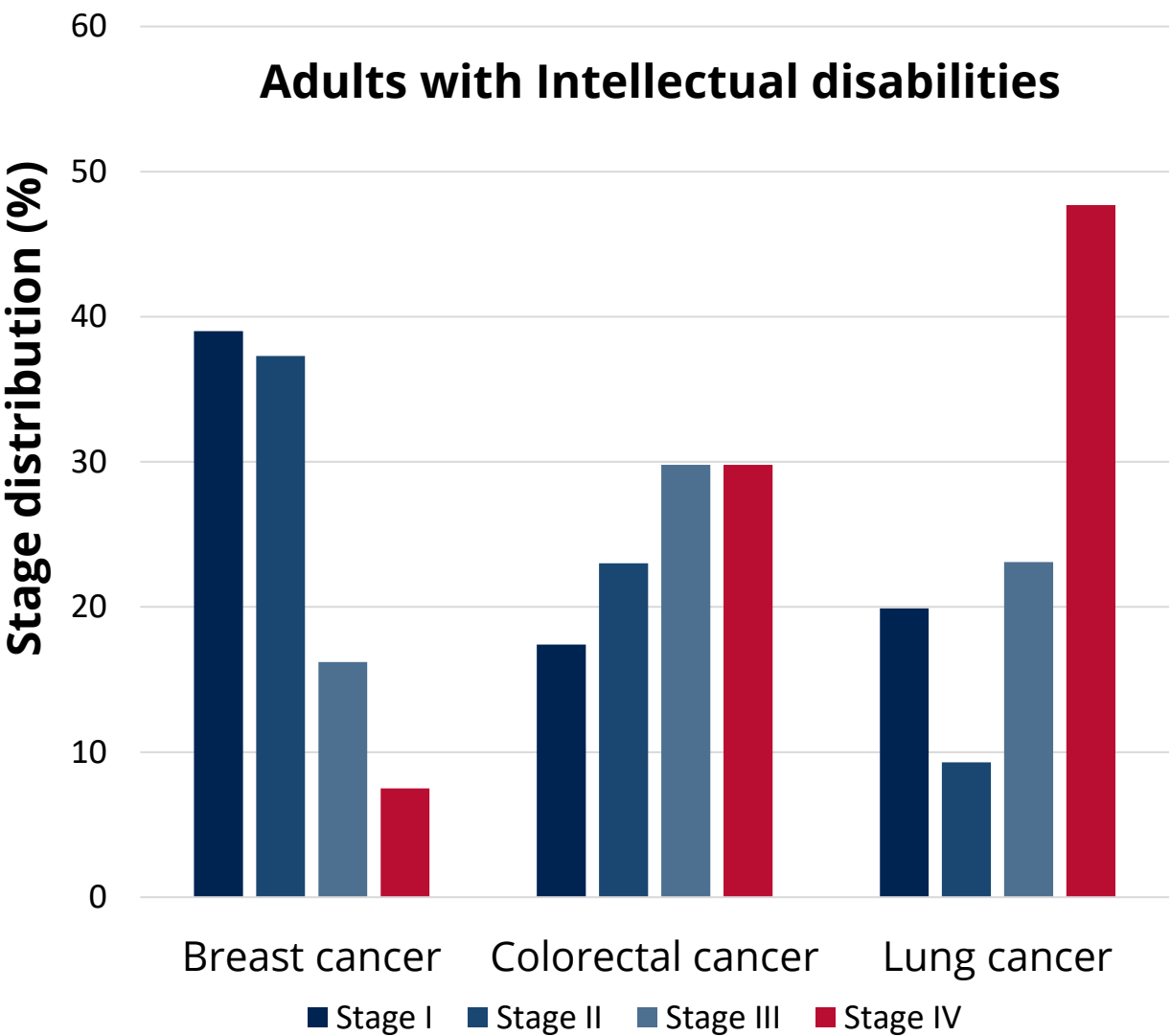
Metastatic Stage



Metastatic Stage



Metastatic Stage



Metastatic Stage

Ontarians living with intellectual or developmental disability were...

**1.56 times as
likely**

to be diagnosed with
**metastatic breast
cancer**

RR 1.56 (1.08-2.27)

**1.45 times as
likely**

to be diagnosed with
**metastatic
colorectal cancer**

RR 1.45 (1.23-1.72)

**0.91 times as
likely**

to be diagnosed with
**metastatic lung
cancer**

RR 0.91 (0.85-1.08)

Why is this happening???

Pathways to unknown stage at diagnosis

- No plans for treatment, why continue staging?
- Frank metastatic disease, staging not recorded.
- Access to regional cancer centres.

Pathways to metastatic stage

- Fewer opportunities for cancer screening.
- Challenges in symptom appraisal, detection, and communication,
- How symptoms are acted on by care givers and the health care system.

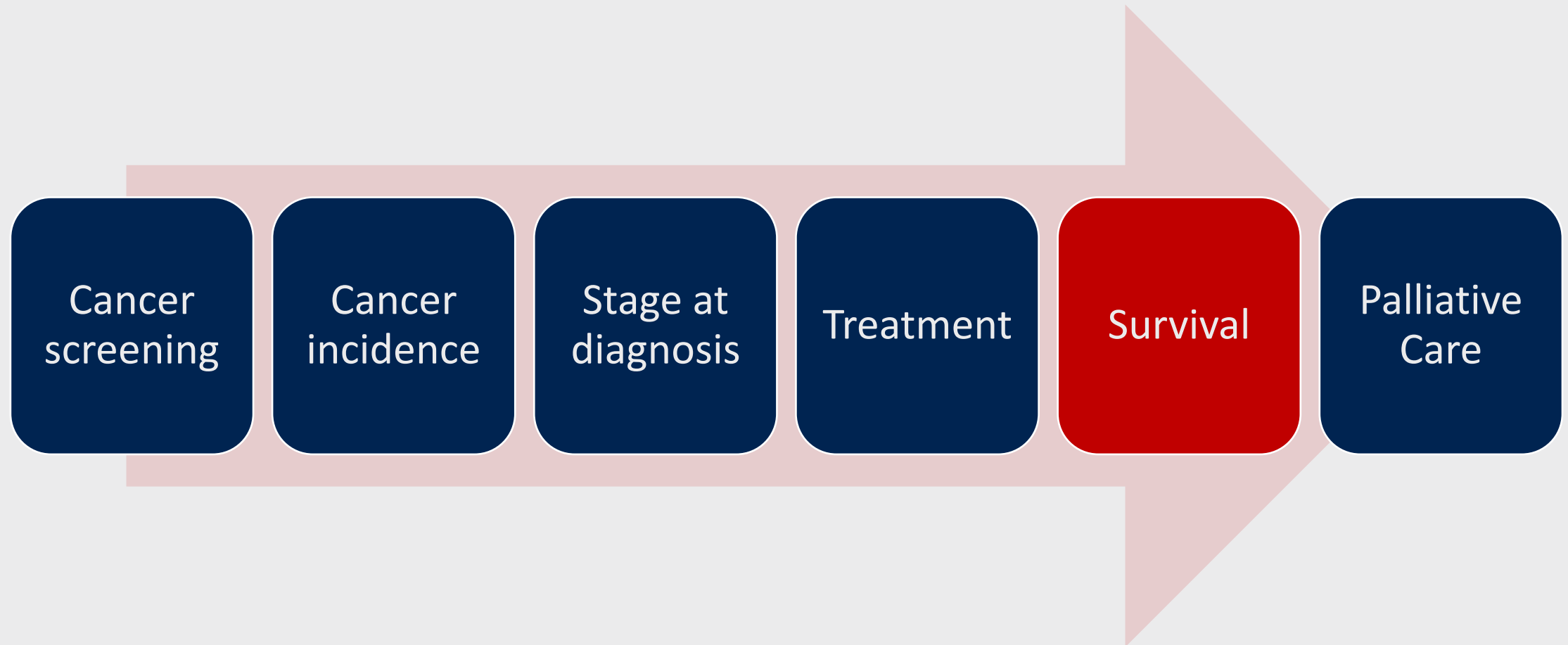
We then explored the diagnostic interval for colon cancer:

- How long does it take to get diagnosed?
- Are the appropriate diagnostic and staging investigations occurring?
- Is gate keeping to potentially curative treatment occurring at the time of diagnosis?

Colon cancer diagnosis interval

Content embargoed- please connect with Alyson for more information.

Cancer survival



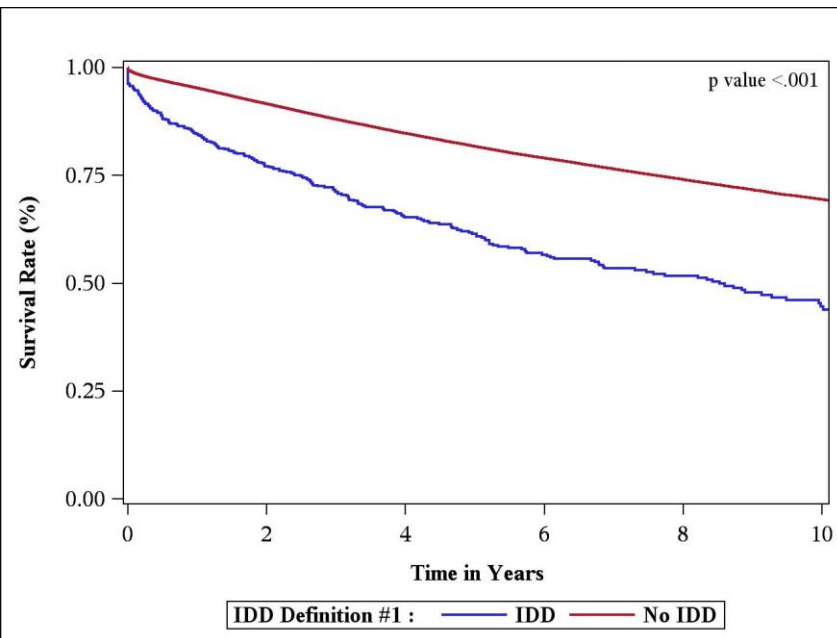
Cancer survival

Death from any cause
Death from cancer

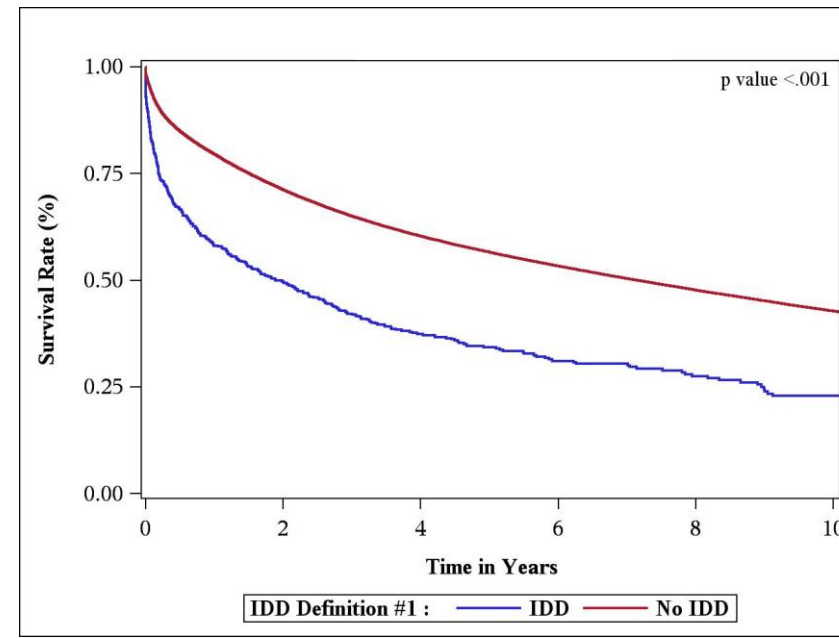


Cancer survival

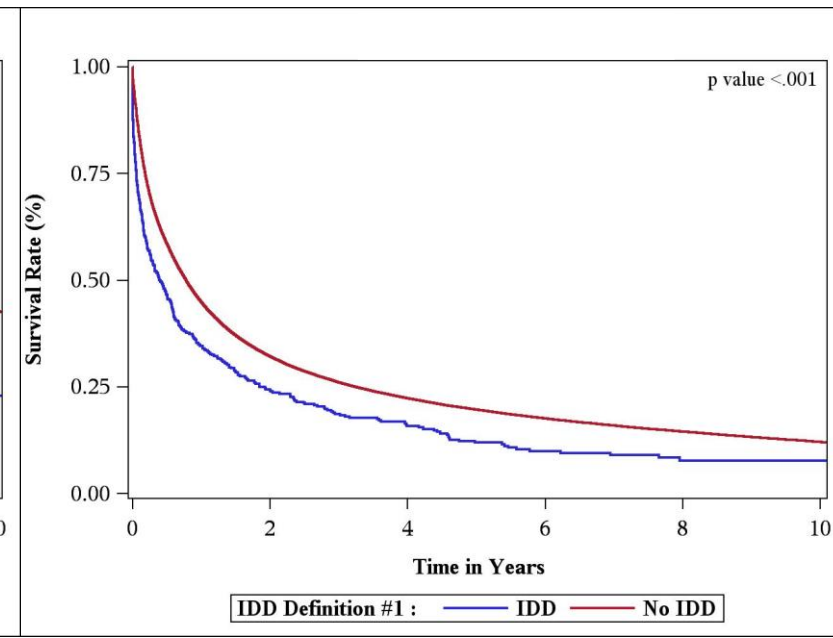
Breast cancer



Colorectal cancer



Lung cancer



Ontarians living with intellectual or developmental disability were...

**2.74 times as
likely**

to die following
breast cancer

HR 2.74 (2.41–3.12)

**2.42 times as
likely**

to die following
colorectal cancer

HR 2.42 (2.18–2.68)

**1.49 times as
likely**

to die following
lung cancer

HR 1.49 (1.34–1.66)

*Adjusted for relevant confounders

Why is this happening?

Pathways to worse survival

- More people diagnosed with unknown or metastatic cancer?

Evidence that worse cancer survival for people living with intellectual or developmental disability, regardless of stage of cancer at diagnosis.

Stage specific survival: Colorectal cancer (Ontario)

	Adjusted Hazard Ratio (95% CI)	P -value
Stage		0.02
0/I	2.06 (1.17-3.63)	
II	2.10 (1.35-3.26)	
III	2.60 (1.96-3.44)	
IV	2.02 (1.63-2.51)	
Unknown	3.49 (2.74-4.43)	

Why is this happening?

Pathways to worse survival

- People are dying for reasons other than their cancer? Other chronic health conditions, injuries, or other means?

Ontarians living with intellectual or developmental disability were...

**2.28 times as
likely**

to die of their breast
cancer.

HR* 2.28 (1.86-2.78)

**2.57 times as
likely**

to die of their
colorectal cancer.

HR* 2.57 (2.26-2.92)

**1.38 times as
likely**

to die of their lung
cancer.

HR* 1.38 (1.21-1.57)

*Adjusted for relevant confounders

Why is this happening?

Pathways to worse survival

- More aggressive underlying cancer biology? Understaging?
- Contraindications for treatment?
- Not being offered treatment?
- Barriers to receiving treatment?
- Lack of person-centered care?
- Little evidence or resources to support shared decision-making?

We investigated survival disparities further, to understand the potential role of treatment:

- Curative treatment in female breast cancer
- Non-curative treatment in non small cell lung cancer
- Symptom assessment across all cancer treatment settings.

Breast cancer treatment

Content embargoed- please connect with Alyson for more information.

Lung cancer treatment

Content embargoed- please connect with Alyson for more information.

Routine cancer symptom assessment

Content embargoed- please connect with Alyson for more information

How can we effect change?

Subsection Subtitle

“An IDD is not sufficient cause for worse outcomes or poor experiences; rather, it is the complex interplay between one’s abilities and the factors shaping how the cancer care system, caregivers, and cancer care teams respond (or not) to the disease that determines outcomes. It is unjust and irresponsible to suggest differences in health are attributed to one’s disability without being attentive to the social and economic factors that influence how and why adults with IDD access cancer care, especially when these are often well beyond the control of individuals.”

Changes to Systems and Policy

- Bring adults with intellectual or developmental disability forward in cancer policy, making visible within systems, for the cancer community.
- Set priorities for cancer care alongside adults with intellectual or developmental disabilities and their families, carers, service provision organizations.
- Advocate for the use of available evidence to better direct resources, funding, and service provision.



Primary care of adults with intellectual and developmental disabilities

2018 Canadian consensus guidelines

William F. Sullivan, Heidi Diepstra, John Heng, Shara Ally, Elspeth Bradley, Ian Casson, Brian Hennen, Maureen Kelly, Marika Korossy, Karen McNeil, Dara Abells, Khush Amaria, Kerry Boyd, Meg Gemmill, Elizabeth Grier, Natalie Kennie-Kaulbach, Mackenzie Ketchell, Jessica Ladouceur, Amanda Lepp, Samantha Sacks, Sarah Shea, Katherine Stringer, Kyle Sue and Sandra Witherbee

Canadian Family Physician April 2018; 64 (4) 254-279;

Changes to Clinical Pathways and Services

- Empower adults with intellectual or developmental disabilities
- Modify and adapt clinical guidelines, protocols, and service delivery.
- Develop and test accessible resources and tools to support patient-centered care.



OPEN

Collaboration for
Cognitive Accessibility

Self-Advocacy Guide for Cancer Patients on the Autism Spectrum

Co-created by Paula Holmes-Rodman, PhD and Lindsey Holmes, ovarian cancer survivor, and an adult with autism [i]

With input from the autistic community [ii]

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Cancer Types and
Treatments

For Patients and
Families

Research

For Physicians

How Y

[For Patients and Families](#) / [Resources and Support Services](#)

Neuro-Inclusive Oncology Care and Empowerment Program

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Changes to Research

- More, mixed methods research across all points along the continuum- prevention through to palliative care.
- International collaboration.
- Develop and validate inclusive quality metrics for evaluation.
- Engage adults with intellectual or developmental disabilities in research.
- Address barriers to participation in research.
- Conduct accessible clinical trials.



**Follow the conversation:
#BreakingBarriers2025**



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The University of Dublin

**Trinity Centre
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Intellectual Disability**

Take Home Messages

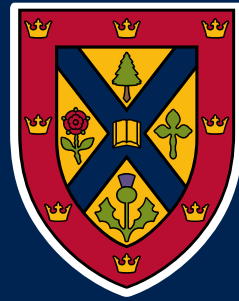
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Addressing these disparities is possible requires making changes at the policy and system level, clinically, and in research.

The time is now to act on existing evidence and improve outcomes.

Thank you!
Go raibh maith agaibh!



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