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Cancer Incidence among People with intellectual Disabilities in The Netherlands

A population-based cohort study

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COI

- No disclosures
- Funding from Dutch Ministry of Health (VWS) and The Netherlands Organisation for Health Research and Development (ZonMw)

Outline

WHY OF INTEREST?

WHAT DO WE ALREADY KNOW?

WHAT DID WE DO?

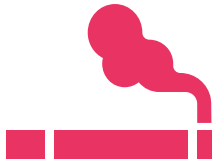
OUR FINDINGS

INTERPRETATION AND DISCUSSION

Why of interest?

Genetics

Potential causal link between syndrome and tumor development



Lifestyle

Less aware of health risks, less prevention

Health(care) disparities

Communication

Health skills and literacy

Diagnostic overshadowing

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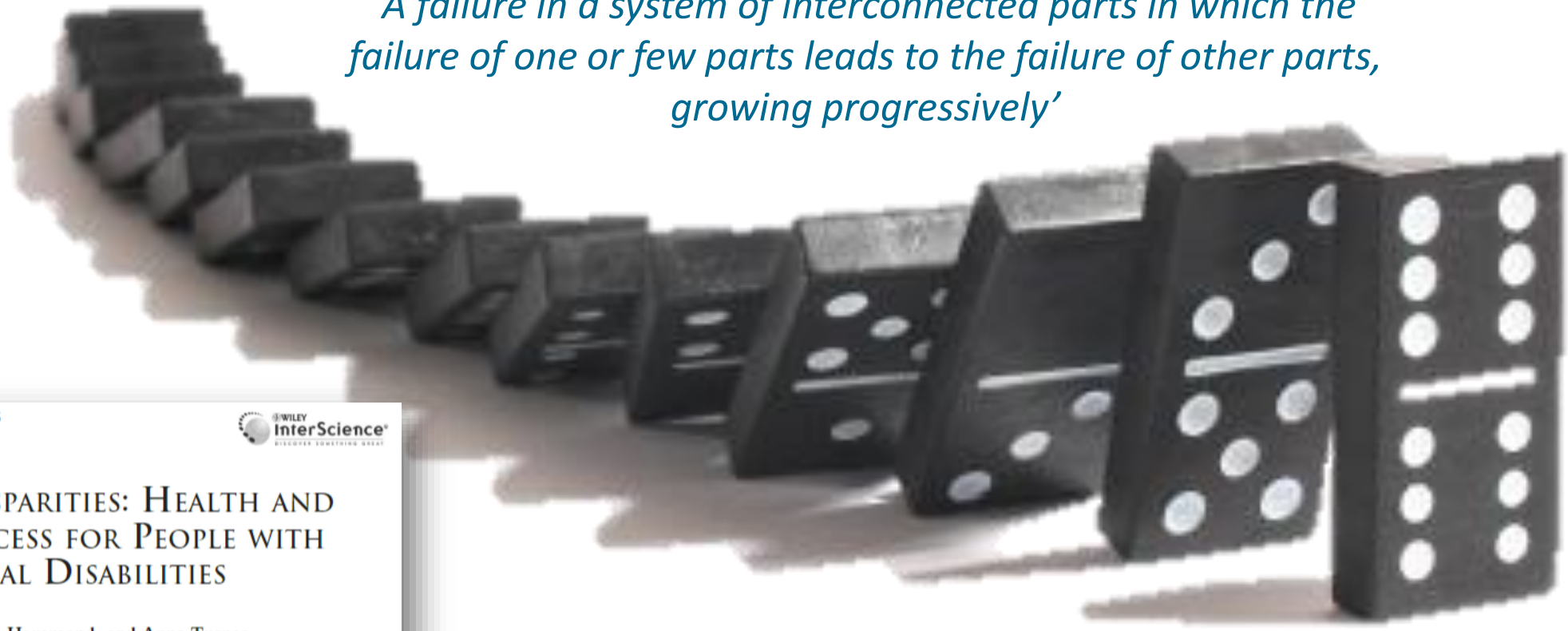
Cascading problems

'A failure in a system of interconnected parts in which the failure of one or few parts leads to the failure of other parts, growing progressively'

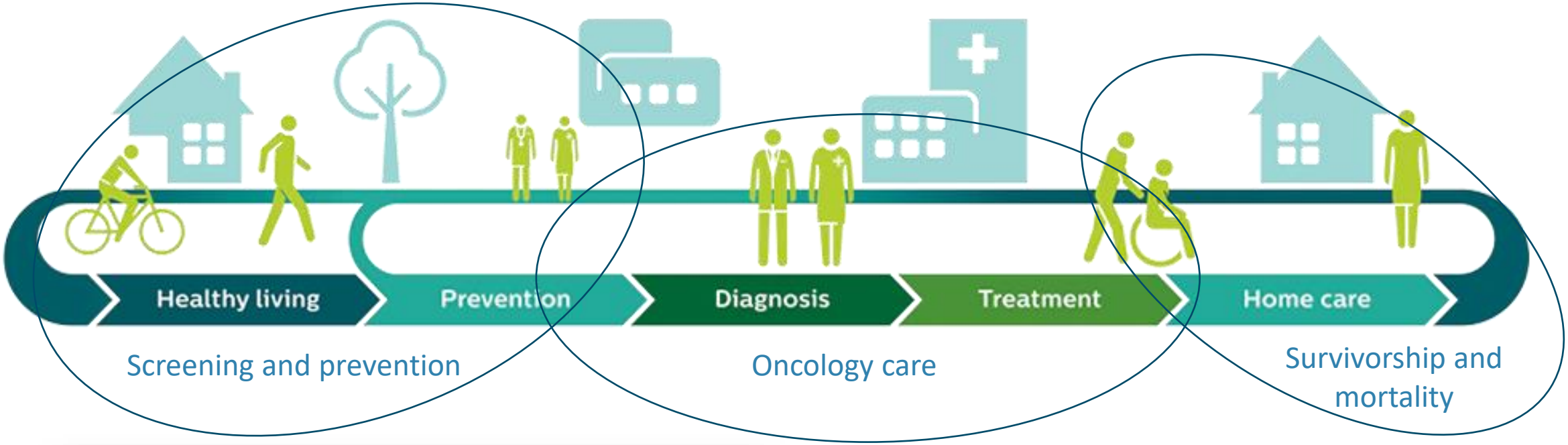


MENTAL RETARDATION AND DEVELOPMENTAL DISABILITIES RESEARCH REVIEWS 12: 70–82 (2006)

A Cascade of Disparities: Health and Health Care Access for People with Intellectual Disabilities

Gloria L. Krahn,* Laura Hammond, and Anne Turner
Child Development and Rehabilitation Center, Oregon Health & Science University, Portland, Oregon

Challenges throughout cancer continuum




Open access Editorial

BMJ Oncology

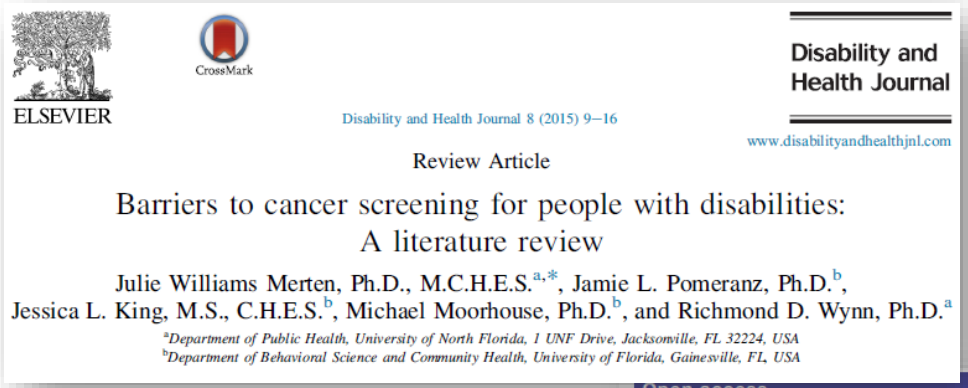
Research priorities to improve cancer care for people with intellectual disabilities across the cancer continuum

Maarten Cuypers,[1] Deborah Cairns,[2] Kathryn A Robb [2]

https://doi.org/10.1136/bmjonc-2024-000395

(early) detection

- Low participation and barriers in population screening
  - Consistent findings across Europe, North America, Australia, and Asia
- Diagnosis at more advanced stages



ELSEVIER

CrossMark

Disability and Health Journal

Disability and Health Journal 8 (2015) 9–16

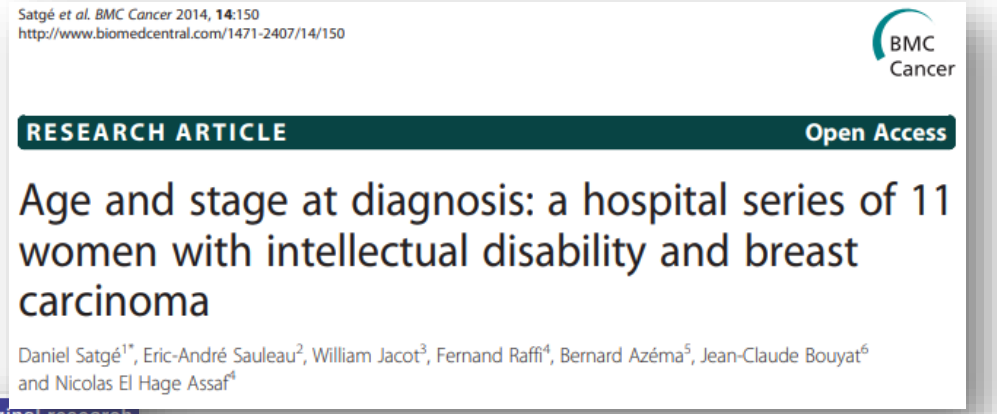
www.disabilityandhealthjnl.com

Review Article

Barriers to cancer screening for people with disabilities: A literature review

Julie Williams Merten, Ph.D., M.C.H.E.S.[a,*], Jamie L. Pomeranz, Ph.D.[b], Jessica L. King, M.S., C.H.E.S.[b], Michael Moorhouse, Ph.D.[b], and Richmond D. Wynn, Ph.D.[a]

[a]Department of Public Health, University of North Florida, 1 UNF Drive, Jacksonville, FL 32224, USA
[b]Department of Behavioral Science and Community Health, University of Florida, Gainesville, FL, USA



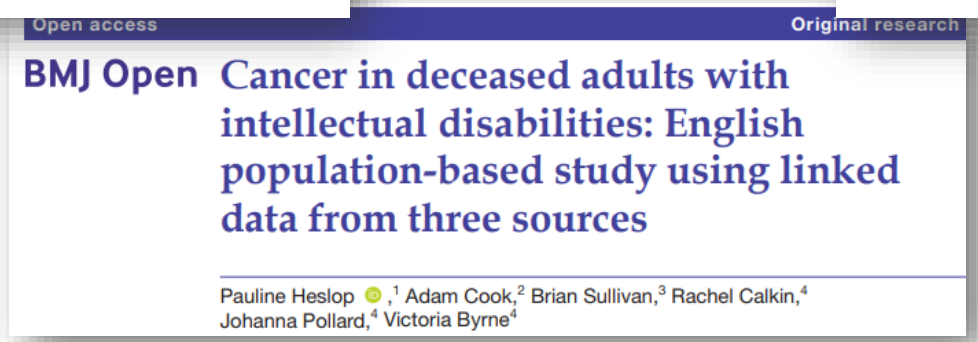
Satgé et al. BMC Cancer 2014, 14:150
http://www.biomedcentral.com/1471-2407/14/150

BMC Cancer

RESEARCH ARTICLE Open Access

Age and stage at diagnosis: a hospital series of 11 women with intellectual disability and breast carcinoma

Daniel Satgé[1*], Eric-André Sauleau[2], William Jacot[3], Fernand Raffi[4], Bernard Azéma[5], Jean-Claude Bouyat[6] and Nicolas El Hage Assaf[4]



Open access Original research

BMJ Open

Cancer in deceased adults with intellectual disabilities: English population-based study using linked data from three sources

Pauline Heslop ,[1] Adam Cook,[2] Brian Sullivan,[3] Rachel Calkin,[4] Johanna Pollard,[4] Victoria Byrne[4]

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Oncology care and mortality

- Based on routine data from The Netherlands, and a literature review:
  - Fewer people with ID receive treatment at oncology department than expected
  - Treatments get adjusted without evidence or reasoning as to why
  - More people with ID die due to cancer than expected

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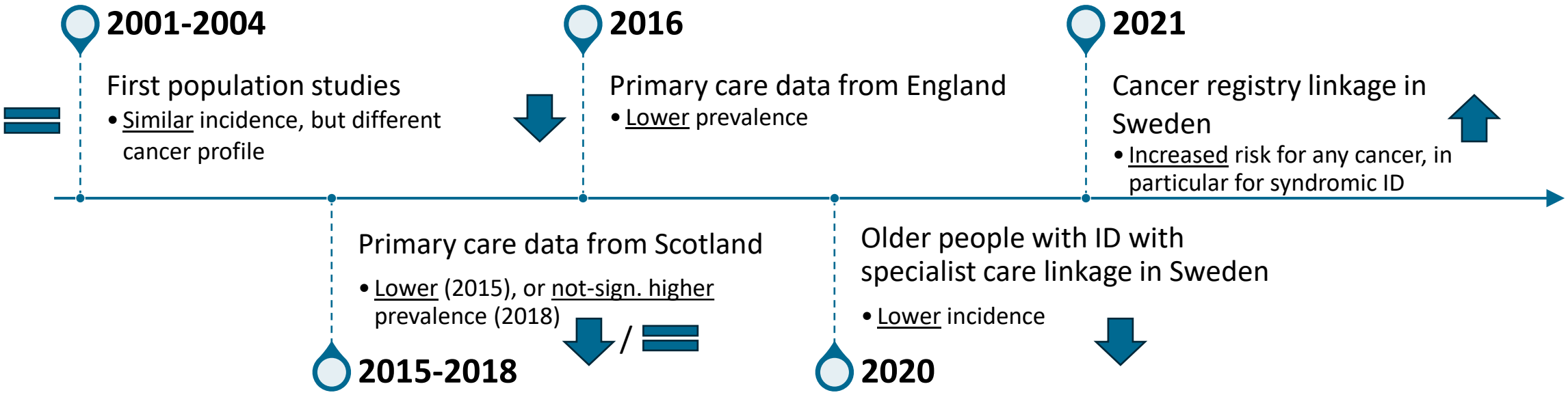
What do we know about cancer incidence?

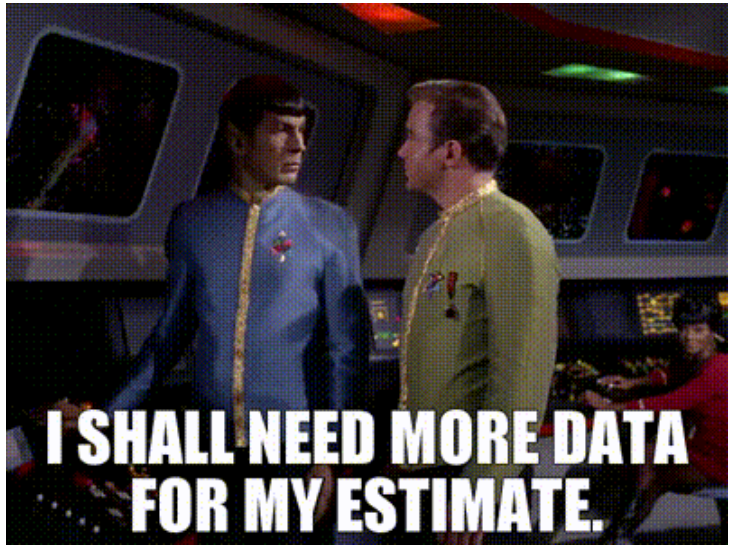
Brief overview of literature

- Since 2000



Patja, 2001; Sullivan, 2004; Carey, 2016; Cooper, 2015 and 2018; Satge, 2020; Liu, 2021

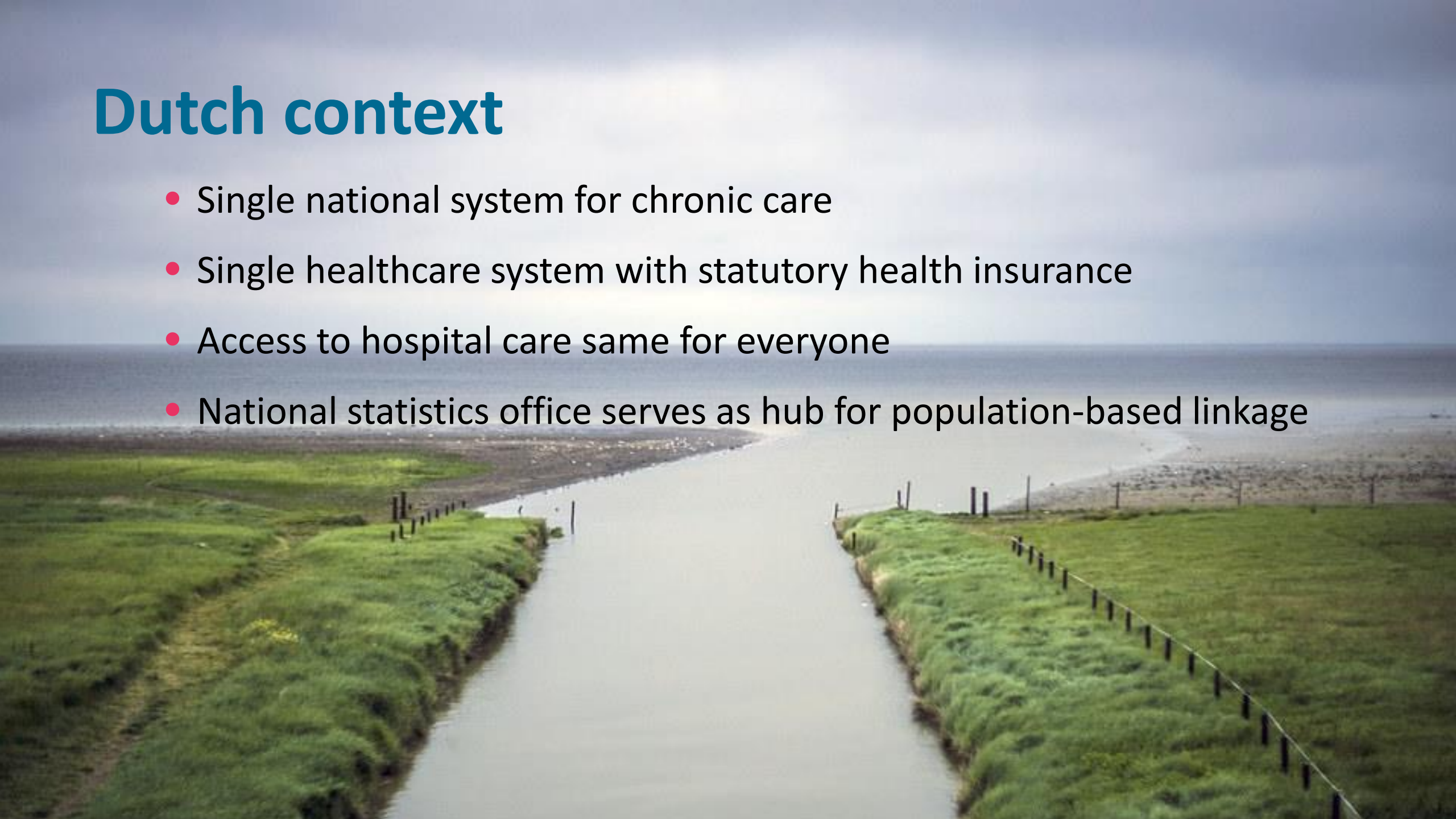
Cancer incidence



- Literature is inconclusive
  - Depends on which groups are studied and compared
- Genetic subgroups can have specific risks
  - Down's syndrome lower risk for solid tumors, increased leukemia risk
- Different age profile
  - Between 5 and 12 years younger at diagnosis
- Different cancer types and stage at diagnosis

Dutch context

- Single national system for chronic care
- Single healthcare system with statutory health insurance
- Access to hospital care same for everyone
- National statistics office serves as hub for population-based linkage



ID definition

- Users of ID-specific long-term care services or social benefits
- No information on aetiology
- But, a formal diagnosis of ID is mandatory to access any of the services
- Service level indicative for ID severity
  - Stratify by residential status

Data sources

Population registry to generate cohort (N=948,056)

Chronic care and welfare databases to identify persons with ID (N=187,149)

New cancer diagnoses in national cancer registry (2015-2020) (N=50,257)

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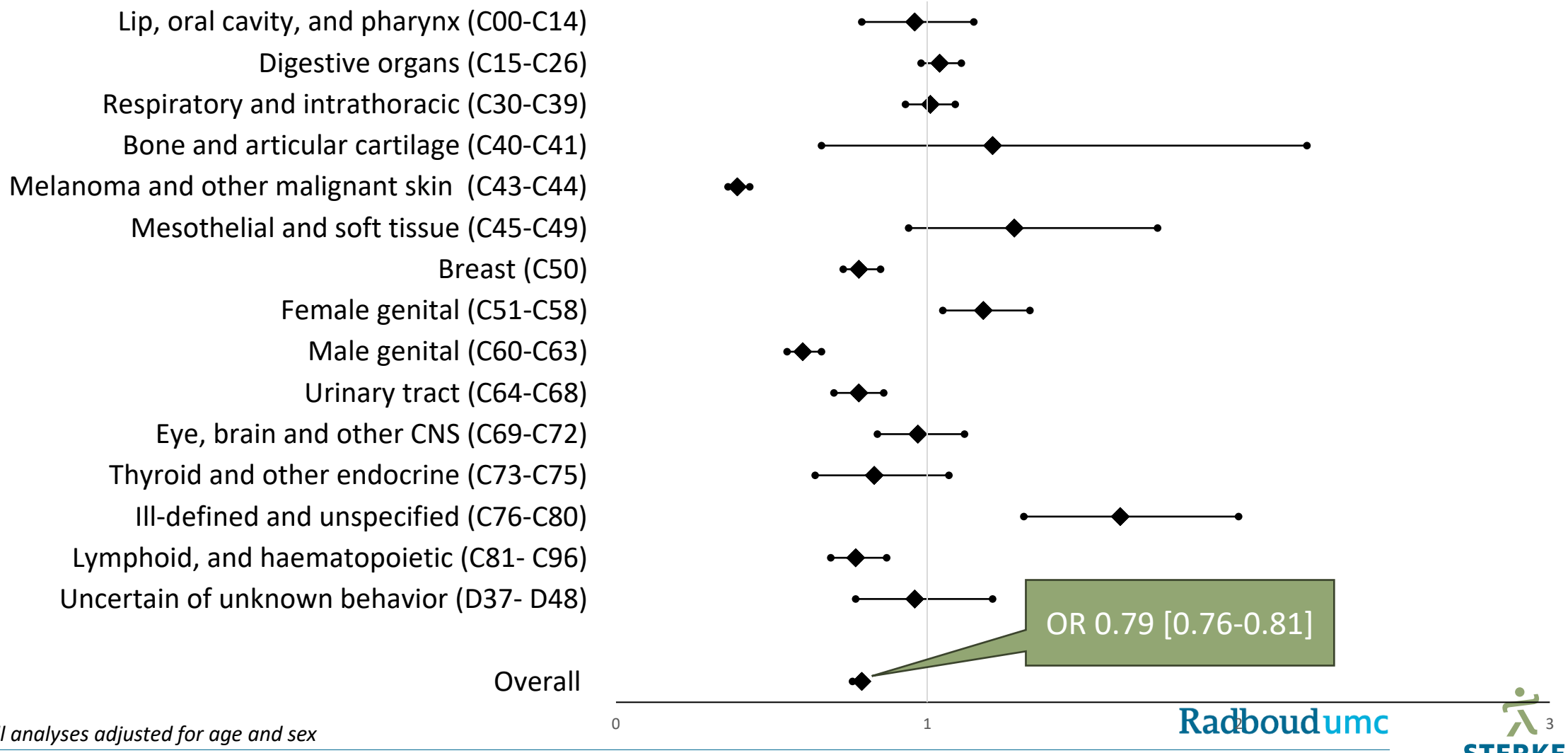
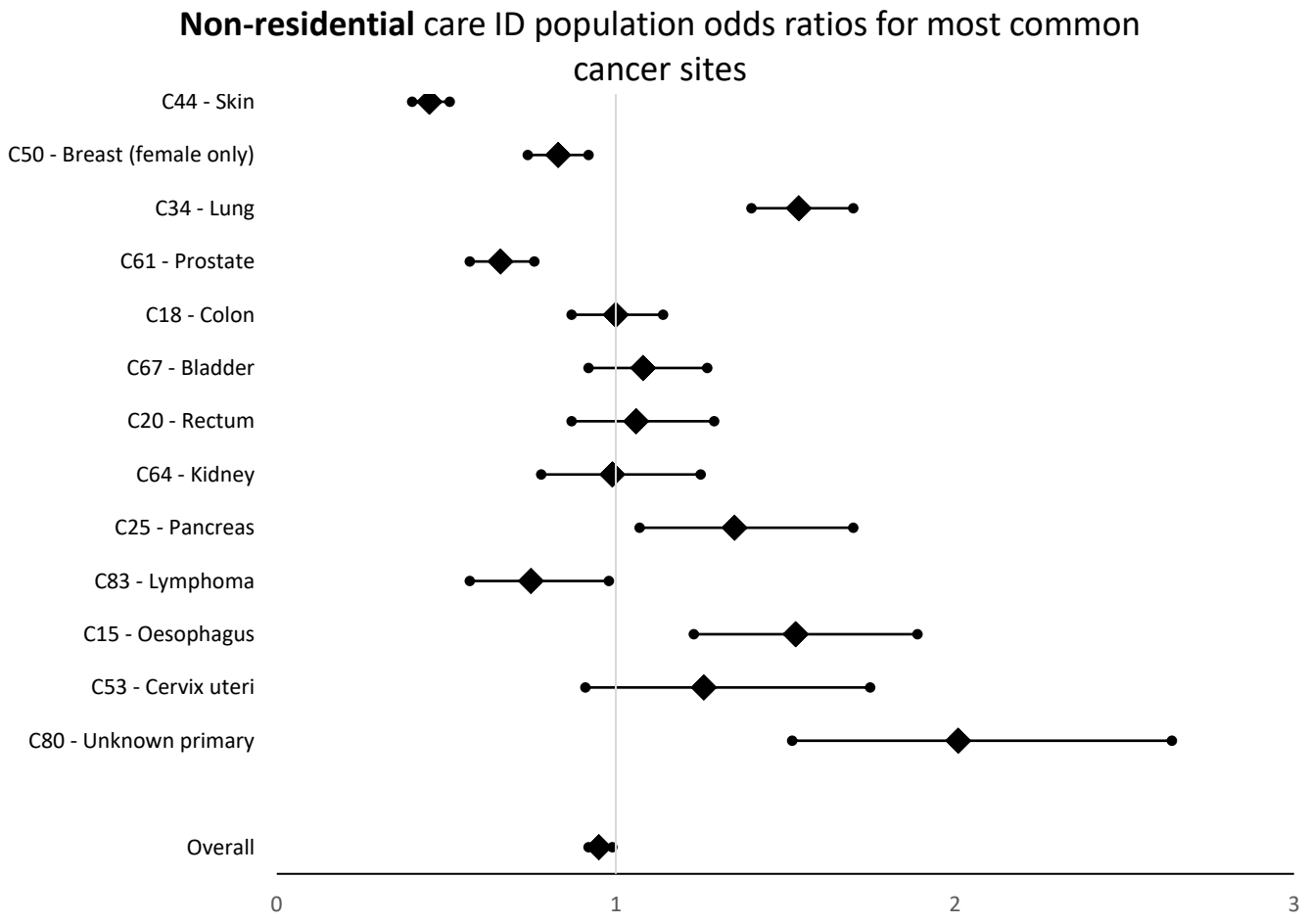
Findings – All cancers by ICD-10 chapter



All analyses adjusted for age and sex

Findings – Most common sites

- Stratified by residency status in long-term care (i.e. proxy for ID severity)



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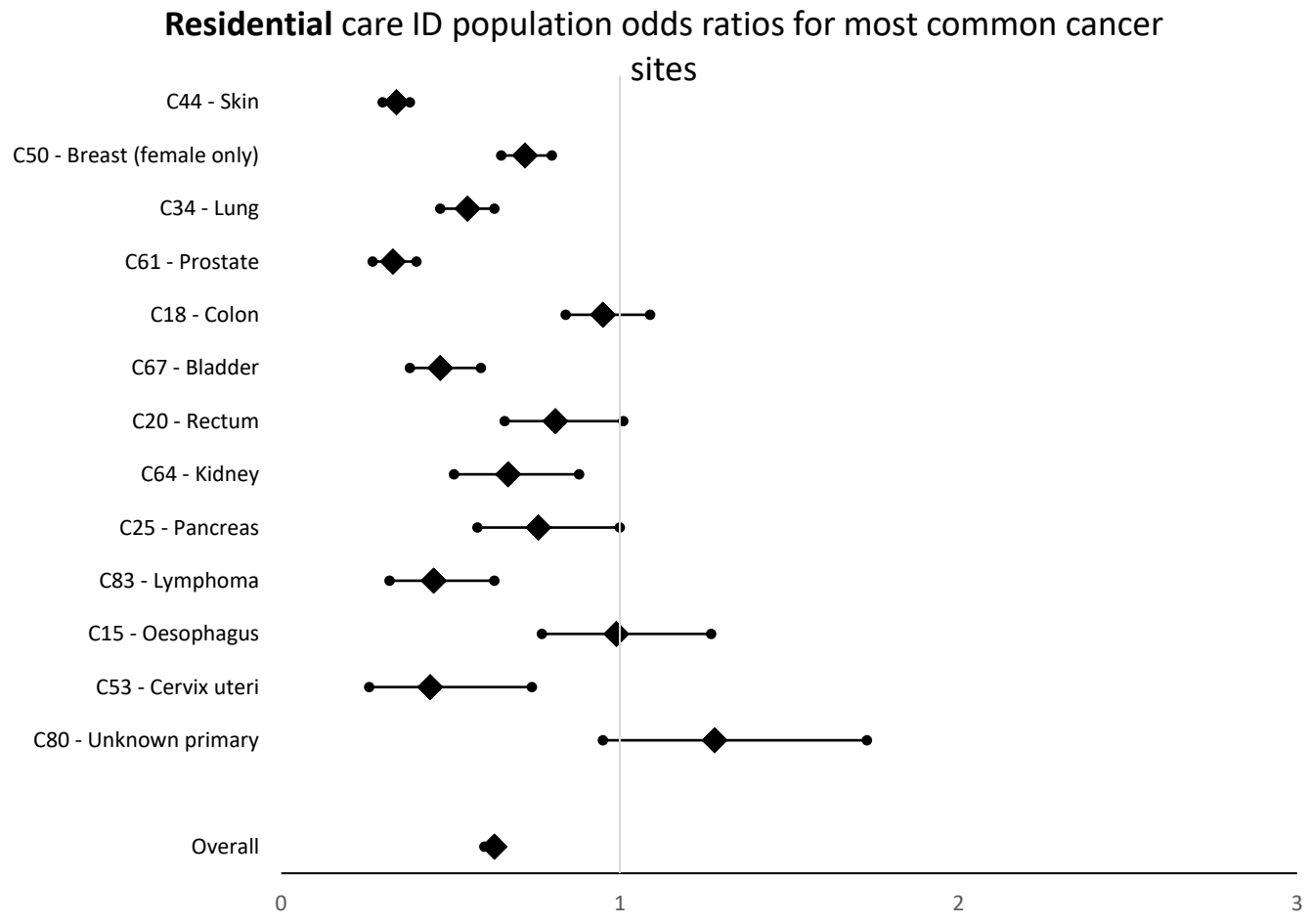
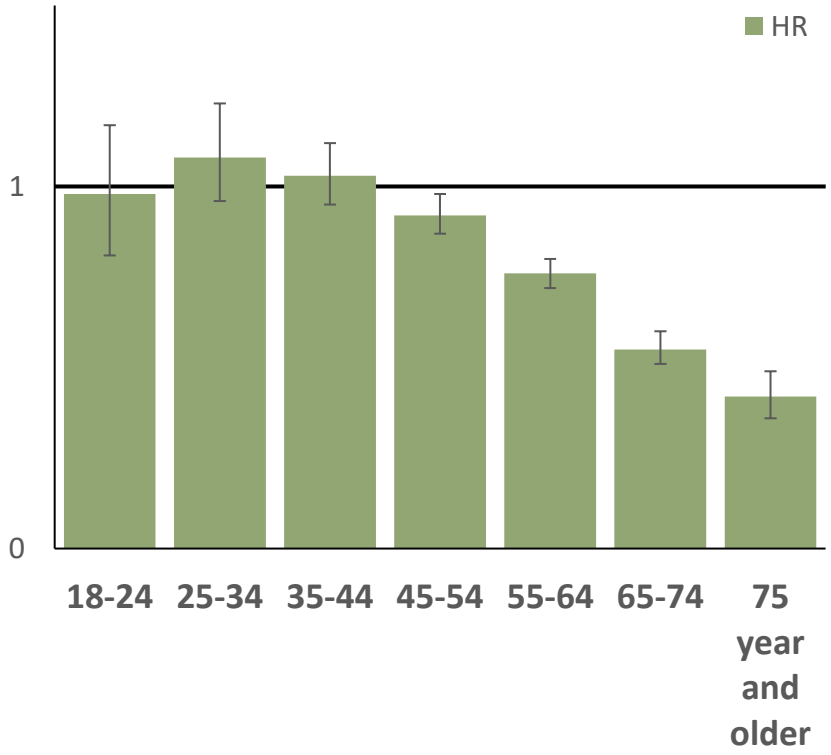
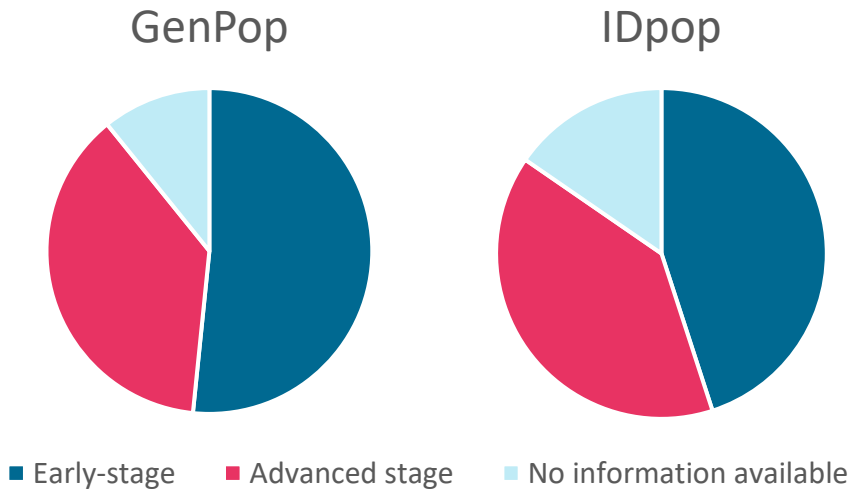


Findings – Age and stageing





Mean age at diagnosis 67,9 (13,0) vs 58,3 (12,7)

Discussion

- Different incidence, at different age, and different sites
- High risk for cancer of unknown primary
  - Indicative for late diagnoses?
- Low risk for skin cancer
  - Underdiagnosis or truly lower risks?
- Lower risks particularly in residential care
- Contributing lifestyle factors outside residential care?
  - Lung, pancreas, oesophaegal

Methodological take-aways

- Large sample and long follow-up preferable
- Be aware of subgroups within the ID population
- Take demograpic differences between both population into account (matched sample or adjust analyses for age and sex)
- Better information on ID aetiology is needed

Roundtable invitation

How Can We Bridge the Cancer Care Gap for People with Intellectual Disabilities?

Tuesday, August 6, 2024
5:30 PM - 7:00 PM
Session F13
Chicago 9 (Level 4)

Image: skschools.org

Thank you for your attention

Collaborators

Jenneken Naaldenberg, Geraline Leusink, Lynette Oost, Amina Banda, Haiko Bloemendal

Contact

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Maarten.Cuypers@radboudumc.nl

Funders and partners