



Deficits and research priorities across the cancer continuum for people with intellectual disabilities

Breaking Barriers: Enhancing Cancer Care for Individuals with ID

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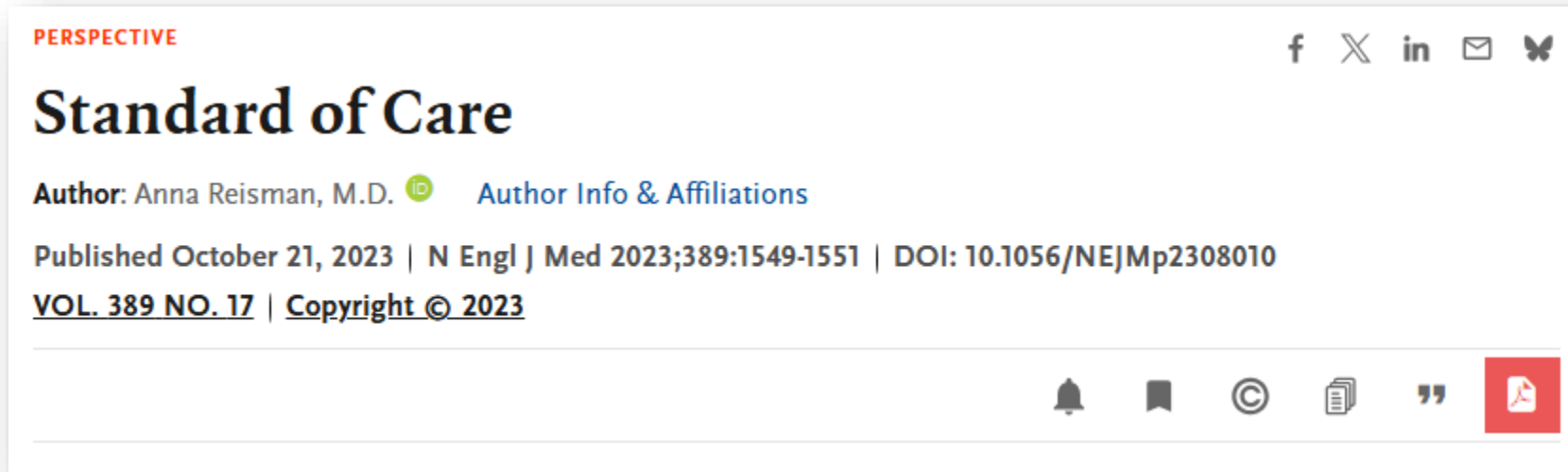
Department of Primary and Community Care

Intellectual Disability and Health

COI

- No disclosures
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Standard of care



'It was becoming distressingly clear that the standard of care — if it were to be responsive to Deborah's needs — was simply out of reach.'

'Neither breast cancer nor intellectual disability is rare.'

Why of interest?



Genetic and biological factors

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

Original Manuscripts | [Full Access](#)

Multimorbidity and lifestyle factors among adults with intellectual disabilities: a cross-sectional analysis of a UK cohort

F. Tyrer ✉, A. J. Dunkley, J. Singh, C. Kristunas, K. Khunti, S. Bhaumik, M. J. Davies, T. E. Yates, L. J. Gray

First published: 28 November 2018 | <https://doi.org/10.1111/jir.12571> | Citations: 35

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DOI: 10.1002/cam4.7210

REVIEW

Cancer Medicine WILEY

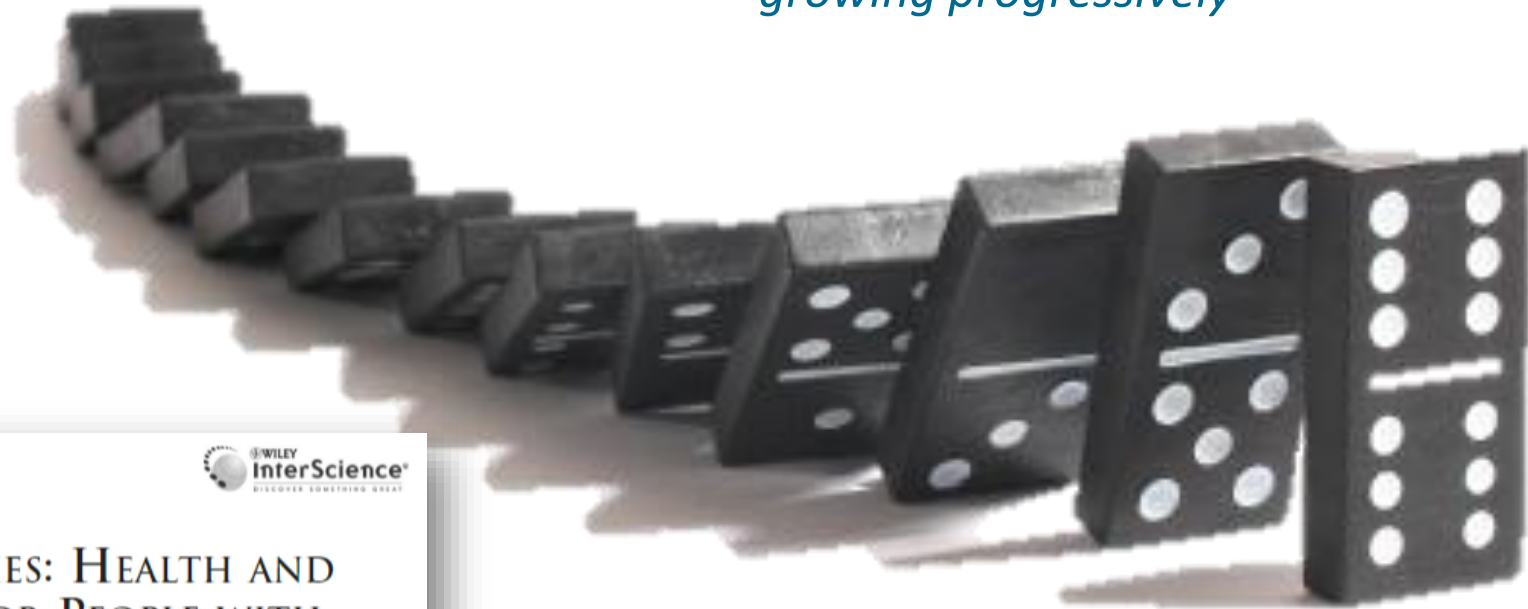
Cancer risks related to intellectual disabilities: A systematic review

Amina Banda¹ | Jenneken Naaldenberg¹ | Aura Timen¹ | Agnies van Eeghen^{2,3} |
Géraline Leusink¹ | Maarten Cuypers¹

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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

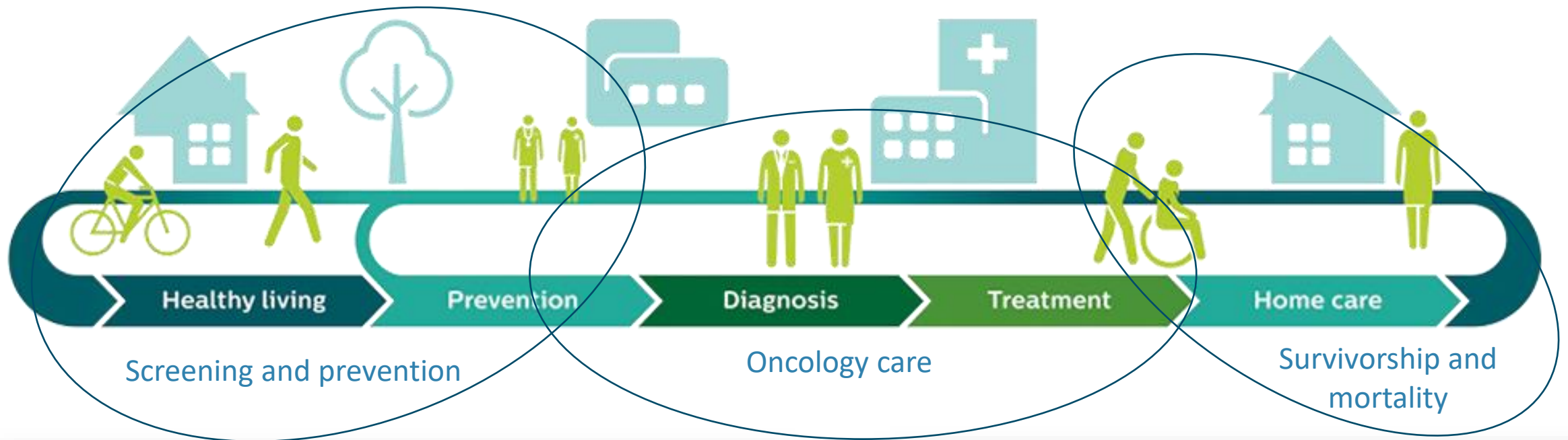
Gloria L. Krahn,* Laura Hammond, and Anne Turner

Child Development and Rehabilitation Center, Oregon Health & Science University, Portland, Oregon

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Challenges throughout cancer continuum



Open access Editorial

BMJ Oncology

Identifying the deficits in cancer care for people with intellectual disabilities

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

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

(early) detection

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



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



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 Sauleau², William Jacot³, Fernand Raffi⁴, Bernard Azéma⁵, Jean-Claude Bouyat⁶
and Nicolas El Hage Arafat⁴

Open access

Original research

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

Pauline Heslop¹, Adam Cook², Brian Sullivan³, Rachel Calkin⁴,
Johanna Pollard⁴, Victoria Byrne⁴

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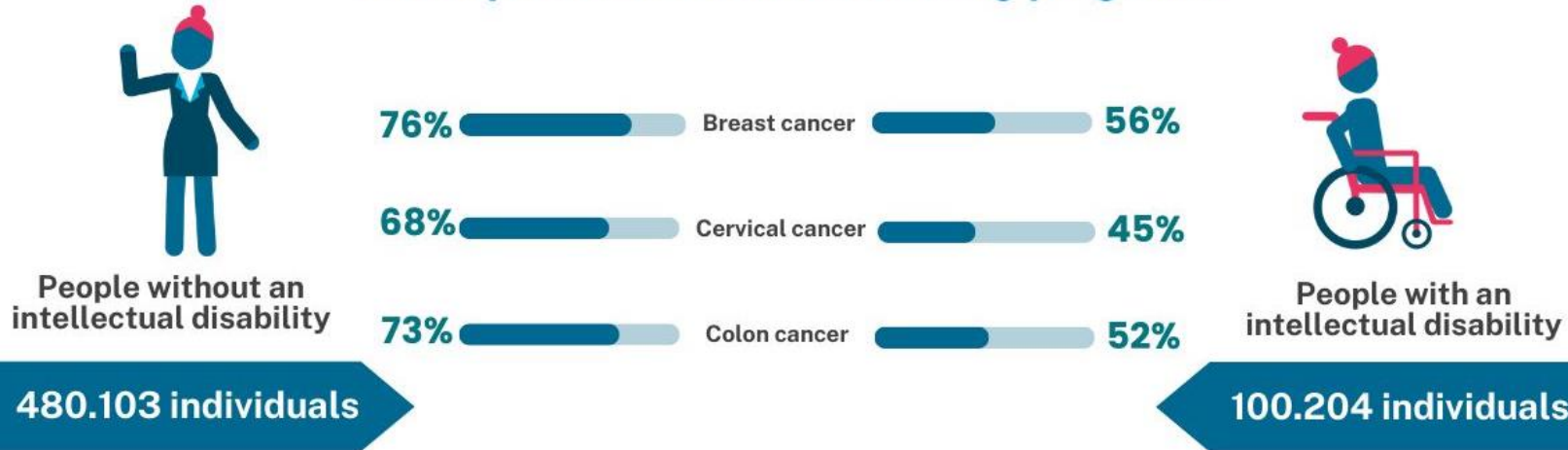
Cancer screening in The Netherlands

- Work by Amina Banda and colleagues
- Combined population data on presence of ID with cancer screening outcomes
- Three programmes:
 - Breast
 - Colon
 - Cervix
- 5-6 years of follow-up



Cancer screening in The Netherlands

Participation in cancer screening programs



Screening outcomes



Unfavorable result occurs just as often in people with and without an intellectual disability.



There are more invalid results because testing is more difficult in people with an intellectual disability.



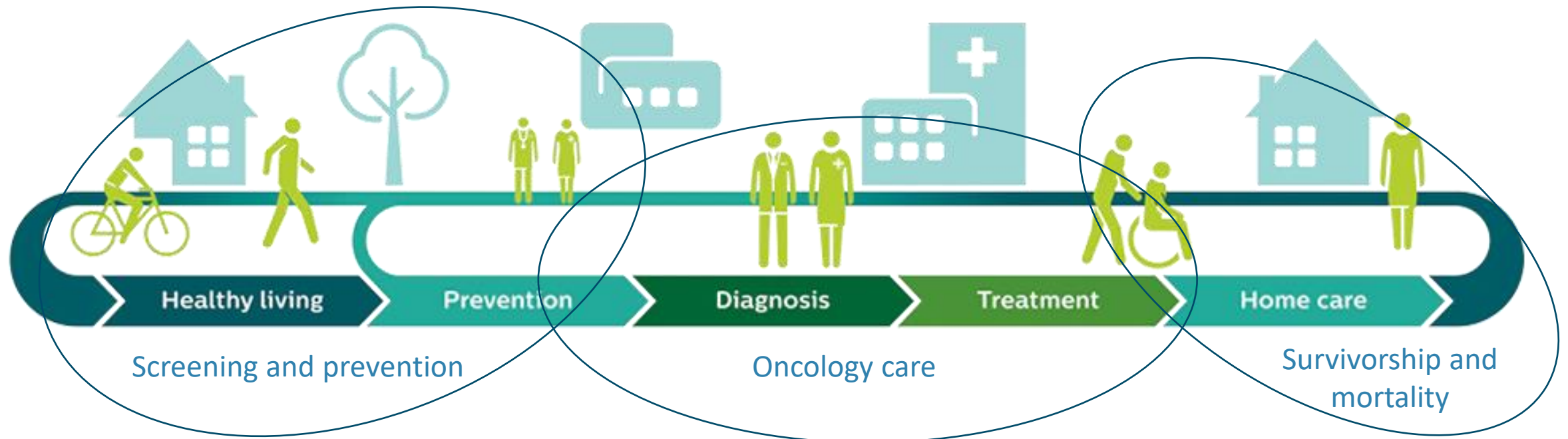
People with an intellectual disability are less likely to participate in follow-up examinations for colorectal cancer.

- Different programmes
- Different age and sex groups
- Comparable findings
- Consistent with other literature

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STERKER
OP EIGEN BENEN

Oncology care journeys



Oncology care journeys

- 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

Cancer Medicine

Open Access

ORIGINAL RESEARCH | [Open Access](#)

Disparities in cancer-related intellectual disabilities: A health insurance claims study

Maarten Cuypers , Hilde Tobi, Cornelis A. M. Kiemer, Chris van Weel, Lambertus A. L. M. Kiemer

First published: 25 July 2020 | <https://doi.org/10.1016/j.cmed.2020.07.001>

SERIES | DISABILITIES AND CANCER | VOLUME 23, ISSUE 4, E174-E183, APRIL 2022

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Cancer treatment and decision making in people with intellectual disabilities: a scoping literature review

Anne J Boonman, MSc   • Maarten Cuypers, PhD  
Prof Haiko J Bloemendal, MD

Published: April, 2022 • DOI: [https://doi.org/10.1016/S1473-2101\(22\)00041-1](https://doi.org/10.1016/S1473-2101(22)00041-1)

Cancer

An International Interdisciplinary Journal of the American Cancer Society

Original Article | [Open Access](#) |    

Cancer-related mortality among people with intellectual disabilities: A nationwide population-based cohort study

Maarten Cuypers PhD , Bianca W. M. Schalk PhD, Anne J. N. Boonman MSc, Jenneken Naaldenberg PhD, Geraline L. Leusink MD, PhD

First published: 17 November 2021 | <https://doi.org/10.1002/cncr.34030> | Citations: 11

Experiences of ID patients in cancer care



Interviews with 9 ID patients who are post cancer-treatment and reflect on trajectory



Detection: mostly by others, during routine check-ups



Diagnosis: logistic challenges, distress



Difficult to distinguish type of hospital encounters (diagnostics, decision-making, treatment) or phase in process



Coordination in informing, decision-making, recognizing key decision moments

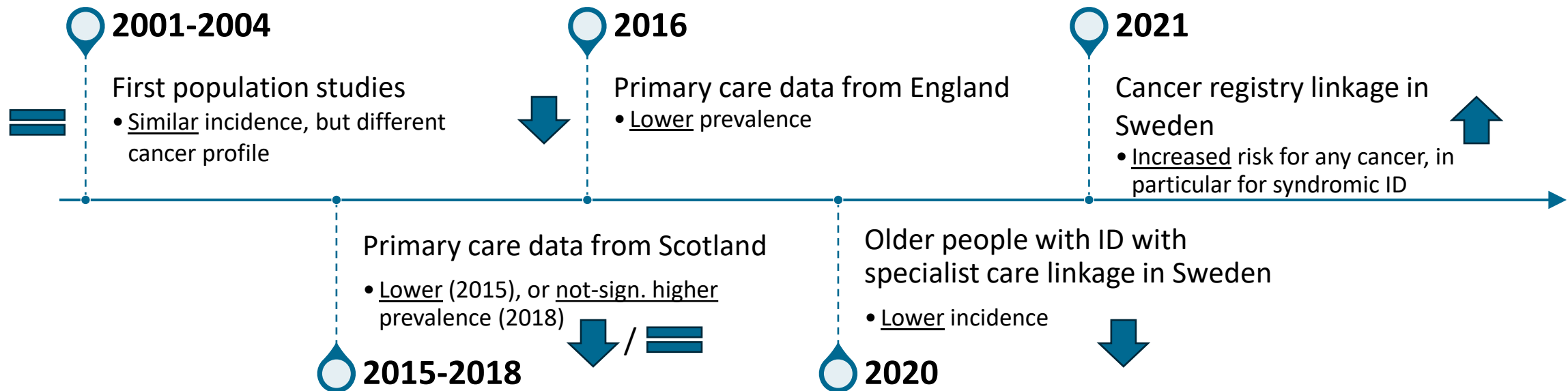
What about the incidence of cancer?



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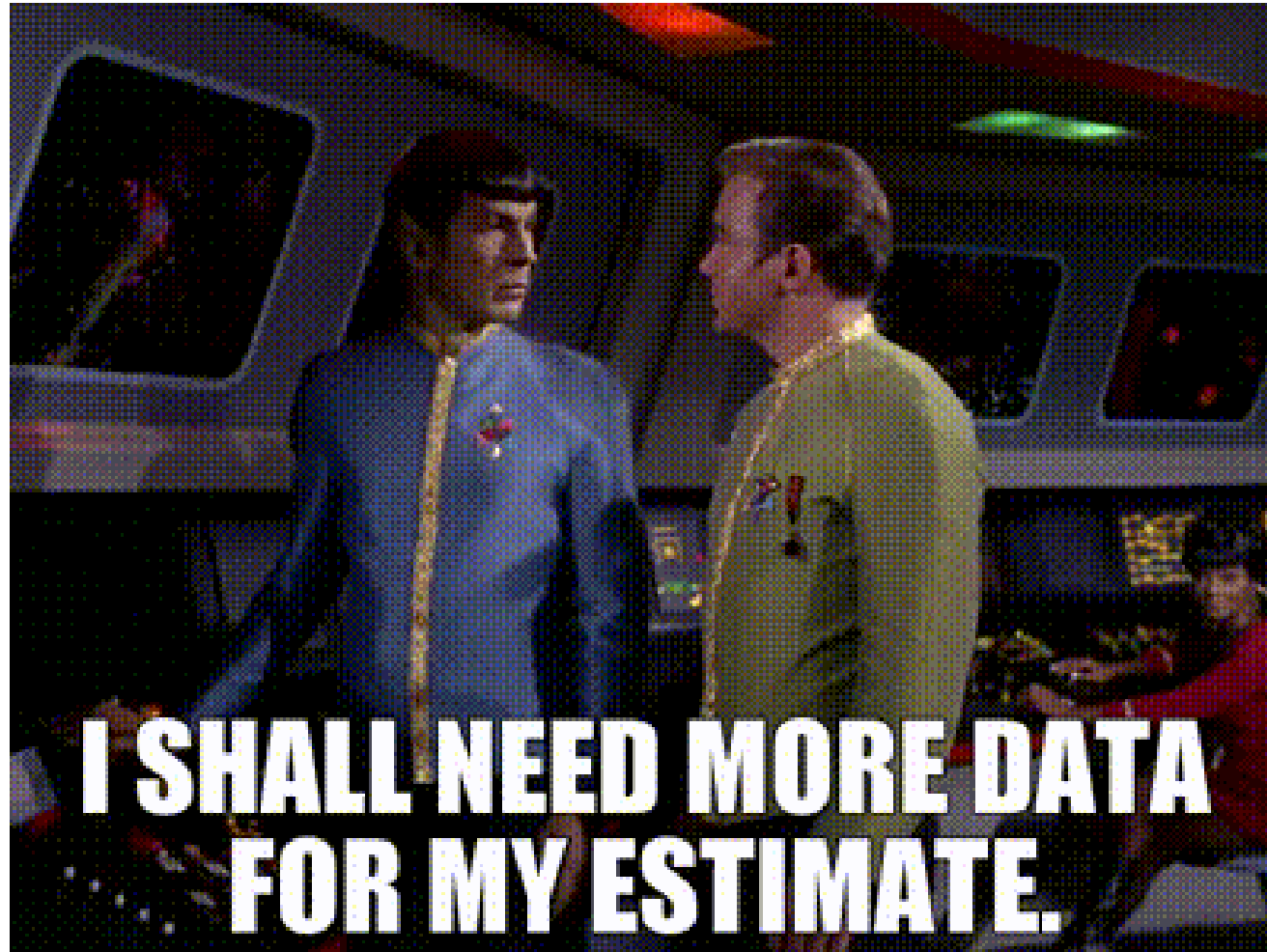
Methodological issues related to measuring cancer incidence

- Literature since 2000:



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

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Data sources



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

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

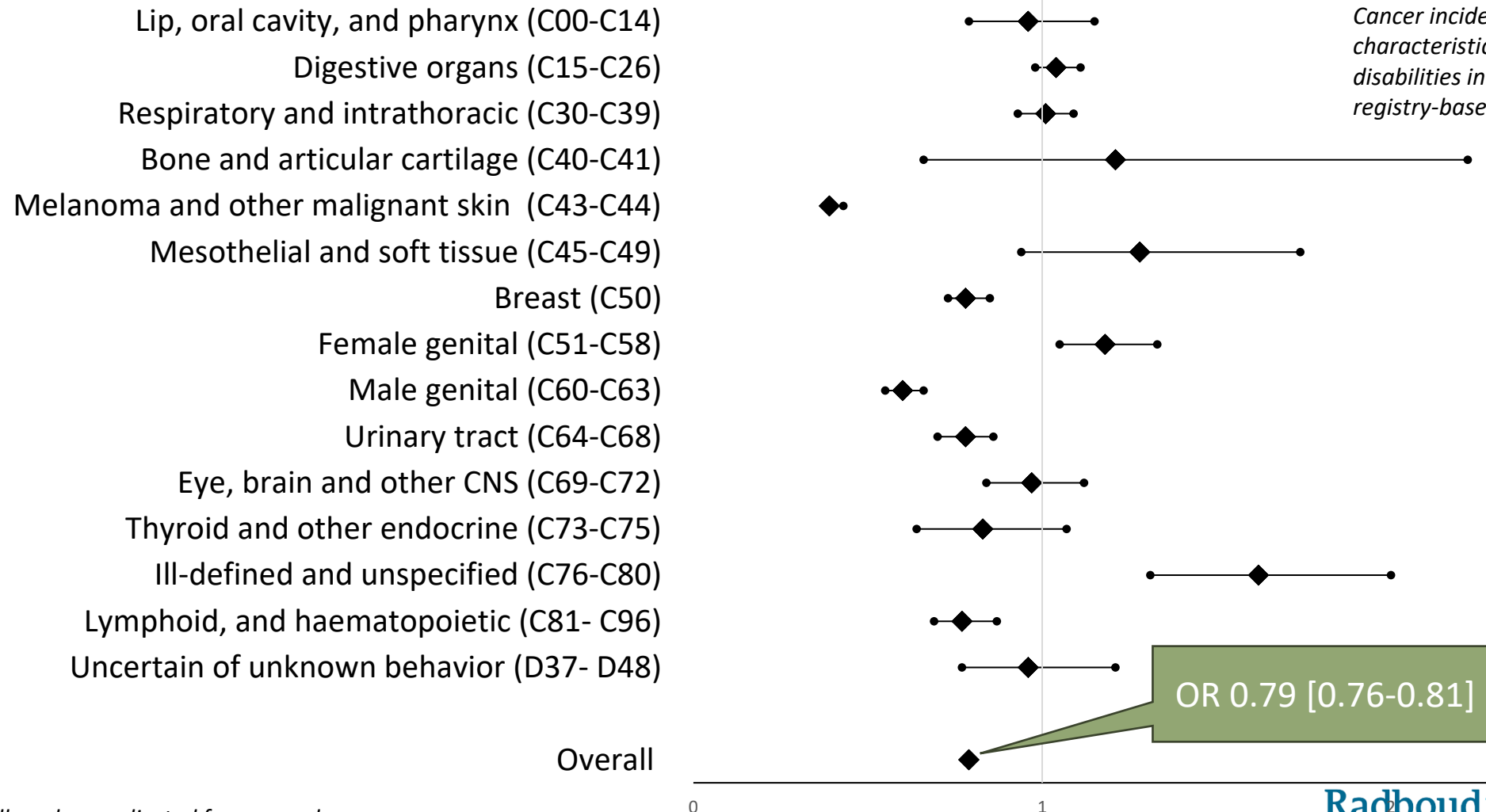
New cancer diagnoses in national cancer registry (2015-2020) (N=50,257)

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Cancer incidence in The Netherlands

Publication pending in **BMJ Oncology**:
Cancer incidence and diagnostic characteristics in people with intellectual disabilities in the Netherlands: A national registry-based cohort study

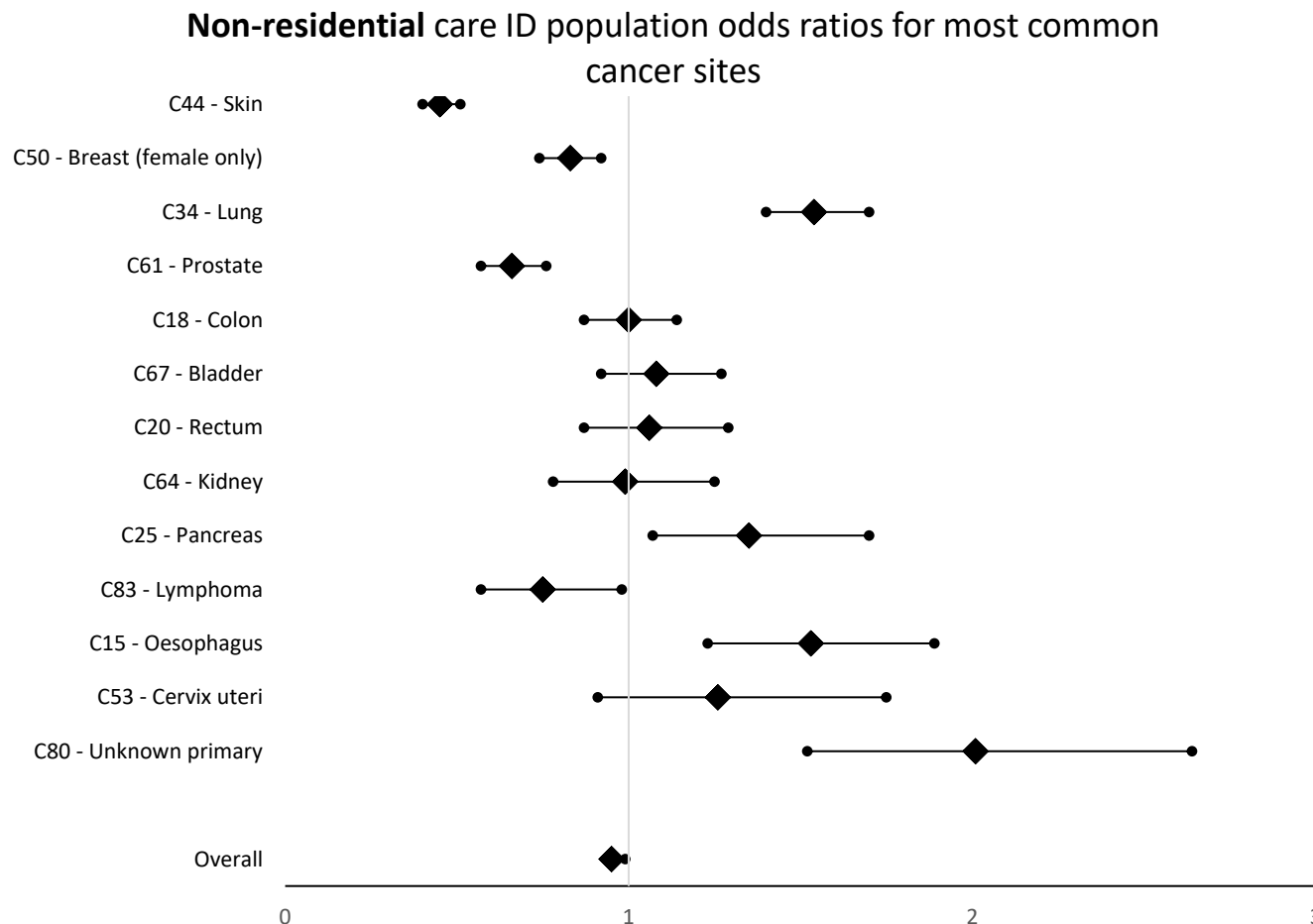


All analyses adjusted for age and sex

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Findings – Most common sites

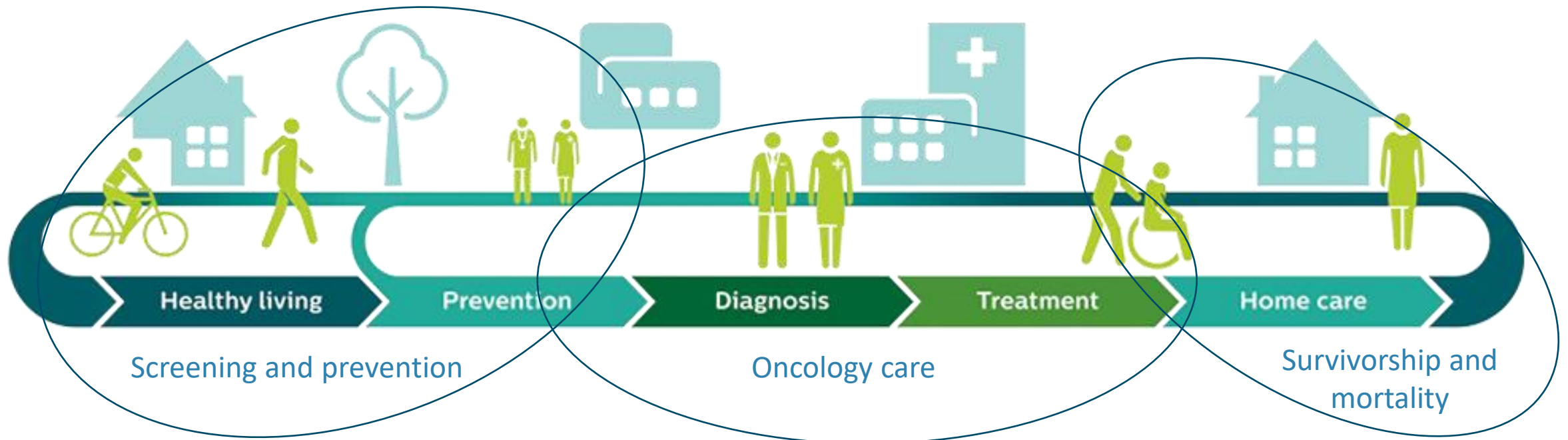
- Stratified by access to residential care (i.e. proxy for ID severity)



Research challenges related to cancer incidence

- Literature is inconclusive
 - Depends on which groups are studied and compared
- Aetiology
 - Genetic subgroups can have specific risks
 - Down's syndrome lower risk for solid tumors, increased leukemia risk
 - Challenging to identify ID population
 - Impossible to compare ID groups across countries by ID definition
- Demographical differences
 - Different age profiles
 - Between 5 and 12 years younger at diagnosis
 - Lower life expectancy (i.e. affects prostate cancer incidence)
 - Length of follow-up
- Different cancer types and stage at diagnosis

Palliative care



Palliative care

- And cancer survivorship

Palliative Medicine
Volume 34, Issue 8, September 2020, Pages 1006-1018
© The Author(s) 2020, Article Reuse Guidelines
<https://doi.org/10.1177/0269216320932774>



Review Article



The palliative care needs of adults with intellectual disabilities and their access to palliative care services: A systematic review

Emily Adam ¹, Katherine E Sleeman ¹, Sarah Brearley², Katherine Hunt ³, and Irene Tuffrey-Wijne⁴

samenvatting richtlijn

Palliatieve zorg
voor mensen met
een verstandelijke
beperking

PERSPECTIVE | APRIL 01 2021

Are Researchers Addressing Cancer Treatment and Survivorship Among People With Intellectual and Developmental Disabilities in the U.S.? A Scoping Review

Grace Samtani ; Tamsen L. Bassford; Heather J. Williamson; Julie S. Armin

Intellect Dev Disabil (2021) 59 (2): 141–154.

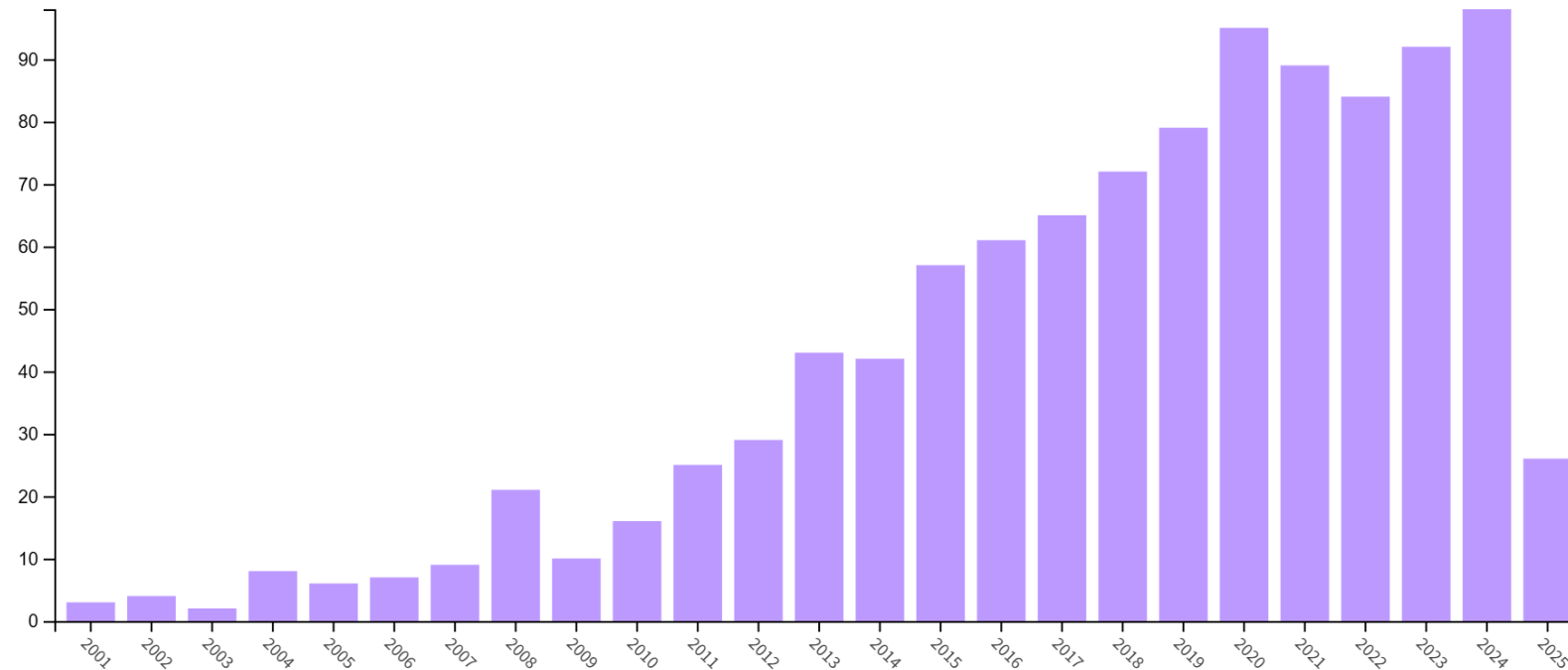
<https://doi.org/10.1352/1934-9556-59.2.141> [Article history](#)

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Bridging research gaps

- Publications on (Cancer) AND (Intellectual disability)



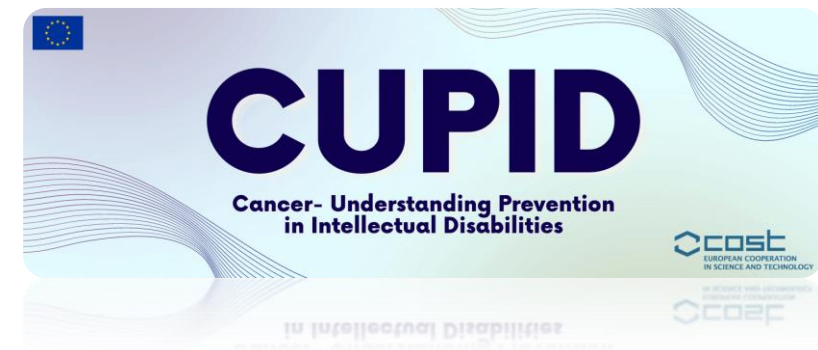
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Bridging research gaps

- Attention by government and policy makers
 - UN Convention on the Rights of Persons with Disabilities
 - EU Beat Cancer Plan
- Engagement and inclusion of people with ID in research and implementation
- Broader dissemination and implementation of interventions that work:
 - Decision-support
 - Reasonable adjustments

European network: COST Action

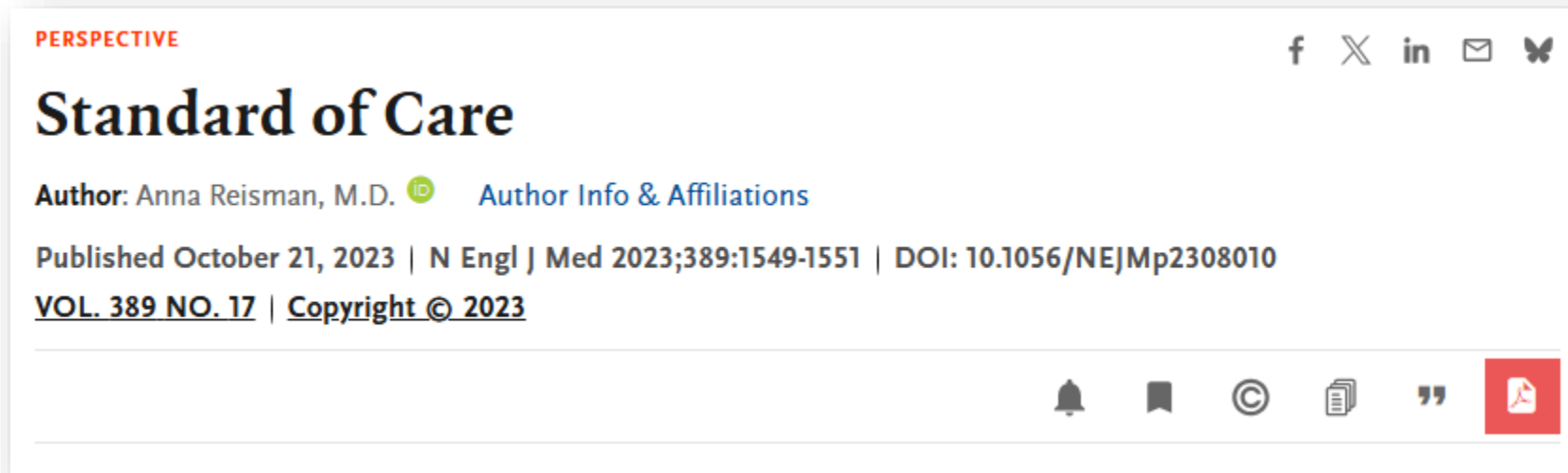
- CUPID: Cancer – Understanding Prevention in Intellectual Disabilities
- >200 associated members
- Review in which countries there is policy or guidance



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Standard of care



'I don't know whether Deborah would still be alive had there been more information and guidance available.

...

Not so much to suggest that the health care system was functioning for people with intellectual disabilities, but simply to have someone there. Someone who could have offered a slate of workarounds to make these onerous treatments feasible..'

Thank you for your attention

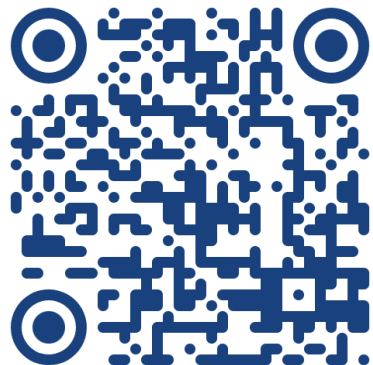
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