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Cancer screening and intellectual disability

Roundtable Tackling avoidable cancer deaths and associated health inequalities

IASSIDD Europe 2026 - Munich

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COI

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ZonMw

Maarten van der Weijden foundation

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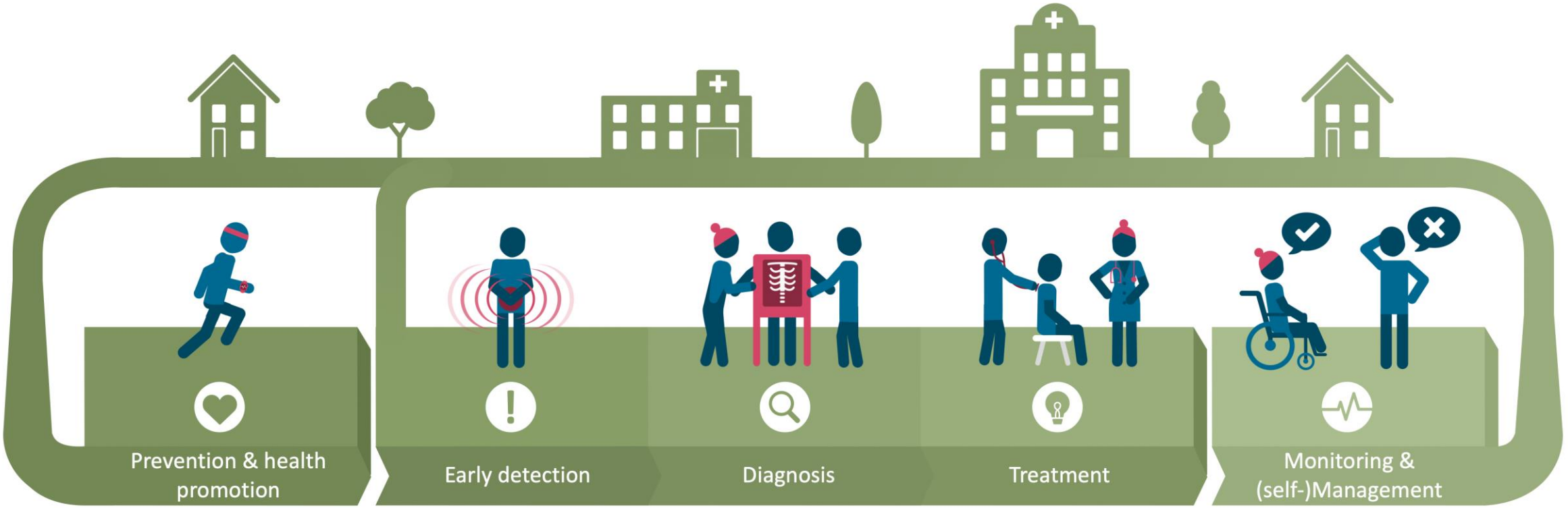
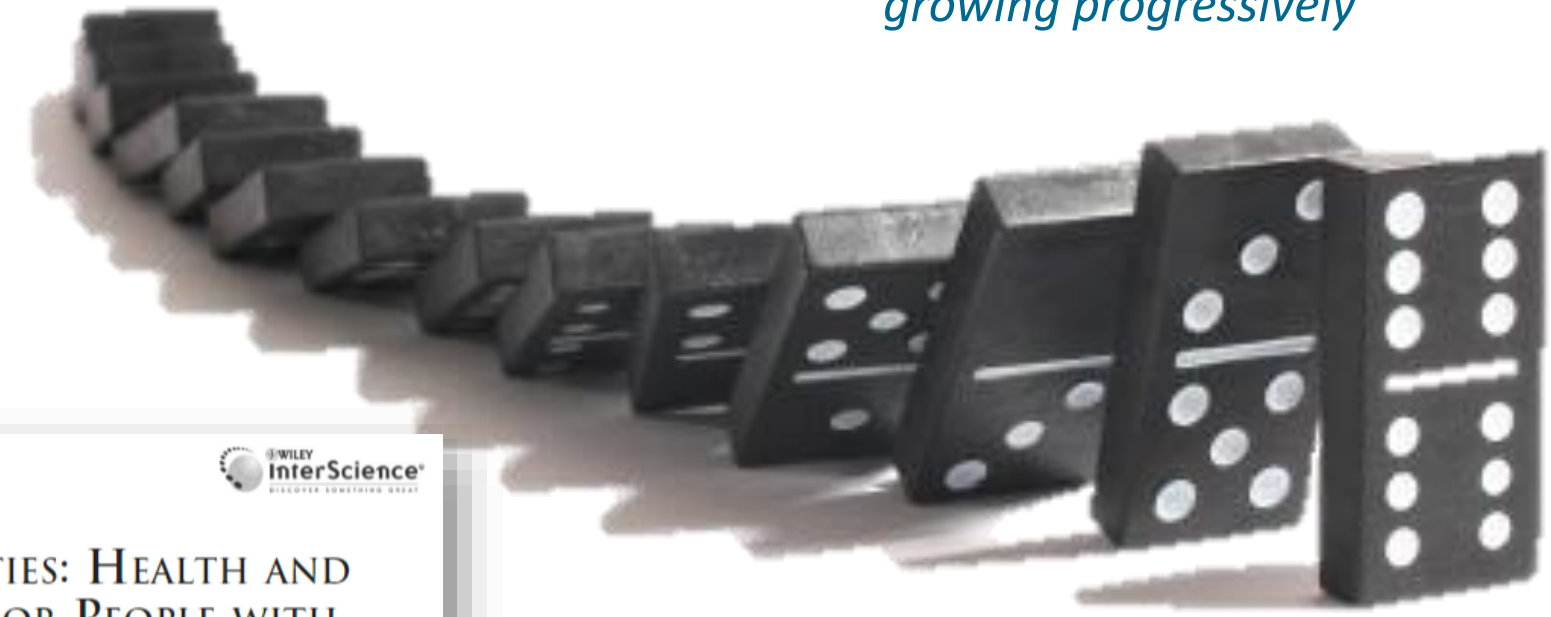
Figure 1. **Navigating people with ID through healthcare**



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)

WILEY InterScience

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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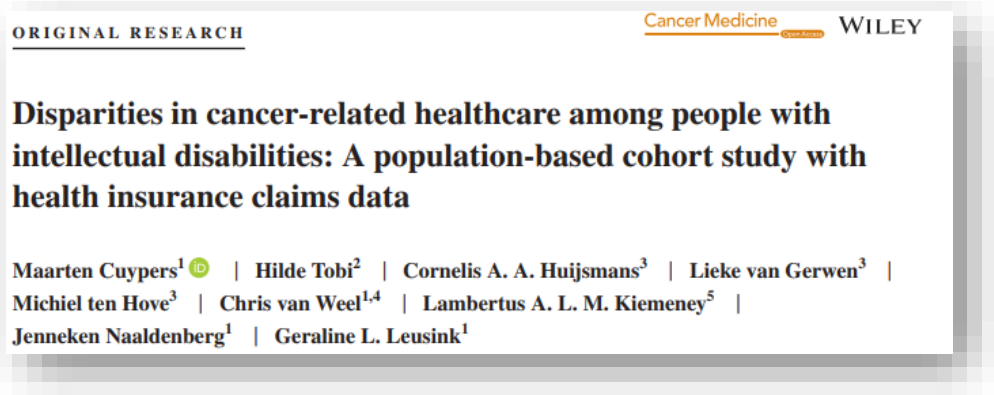
Earlier work in The Netherlands

- Oncology care

*"The lowest IRRs were found for lung cancer and for **cancer types with national screening programs**: cervical, colon, and female breast (IRRs 0.42-0.60)"*


ORIGINAL RESEARCH

Cancer Medicine WILEY

Disparities in cancer-related healthcare among people with intellectual disabilities: A population-based cohort study with health insurance claims data

Maarten Cuypers[1] | Hilde Tobi[2] | Cornelis A. A. Huijsmans[3] | Lieke van Gerwen[3] | Michiel ten Hove[3] | Chris van Weel[1,4] | Lambertus A. L. M. Kiemeney[5] | Jenneken Naaldenberg[1] | Geraline L. Leusink[1]

- Cancer-mortality

*"High-mortality cancers included **cancers within the national screening program** (SMRs, 1.43-1.94)"*


Cancer

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

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Leading to next question…

- What about cancer screening access and uptake?

Screening literature

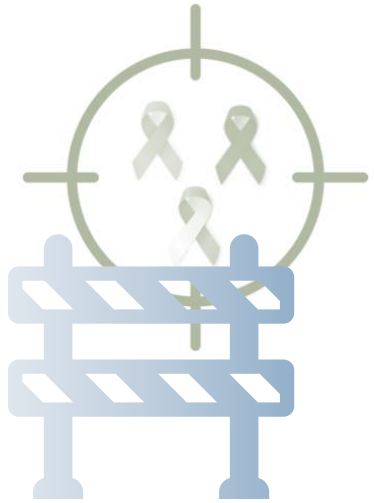
ELSEVIER

Cancer Epidemiology

Volume 76, February 2022, 102084

A systematic review of the barriers and facilitators influencing the cancer screening behaviour among people with intellectual disabilities

Dorothy N.S. Chan [a], Bernard M.H. Law [a], Doreen W.H. Au [a], Winnie K.W. So [a], Ning Fan [b]



ELSEVIER

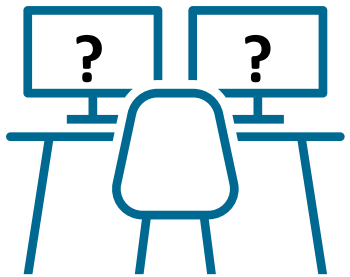
Contents lists available at ScienceDirect

Journal of Cancer Policy

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

The benefits and harms of cancer screening programmes for adults with intellectual disabilities: A systematic review

Martin McMahon [a], Samantha Flynn [b], Samantha A. Johnson [c,d], Chris Stinton [d,*]



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Dutch context

- Single national system for long-term (disability) care
- GP or ID physician have central role in coordination and referrals
- Single healthcare system with statutory health insurance
- Access to hospital care same for everyone
- Three nationally coordinated cancer screening programmes
- National statistics office serves as hub for population-based linkage

Cancer screening in The Netherlands

- Work by Amina Banda and colleagues
- Three programmes:
  - Breast
  - Colon
  - Cervix
- 2015 population-based cohort
  - All persons with ID indicators
  - 1:4 general population comparator group
- Linked with cancer screening databases
- 5-6 years of follow-up
  - Uptake
  - Initial results
  - Follow-up results, if available

Participation in cancer screening programs

People without an intellectual disability

480.103 individuals

76%	Breast cancer	56%
68%	Cervical cancer	45%
73%	Colon cancer	52%

People with an intellectual disability

100.204 individuals

Screening outcomes

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

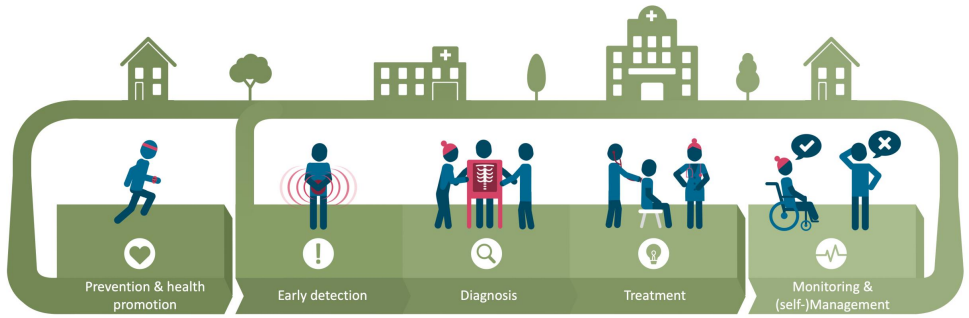
There are more invalid results because testing is more difficult in people with an intellectual disability.

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

Back to the oncology care trajectory

- Poorer overall health and lower health skills
- Lower screening uptake
- Higher dropout during screening follow-up
- Less oncology care
- Higher cancer-related mortality

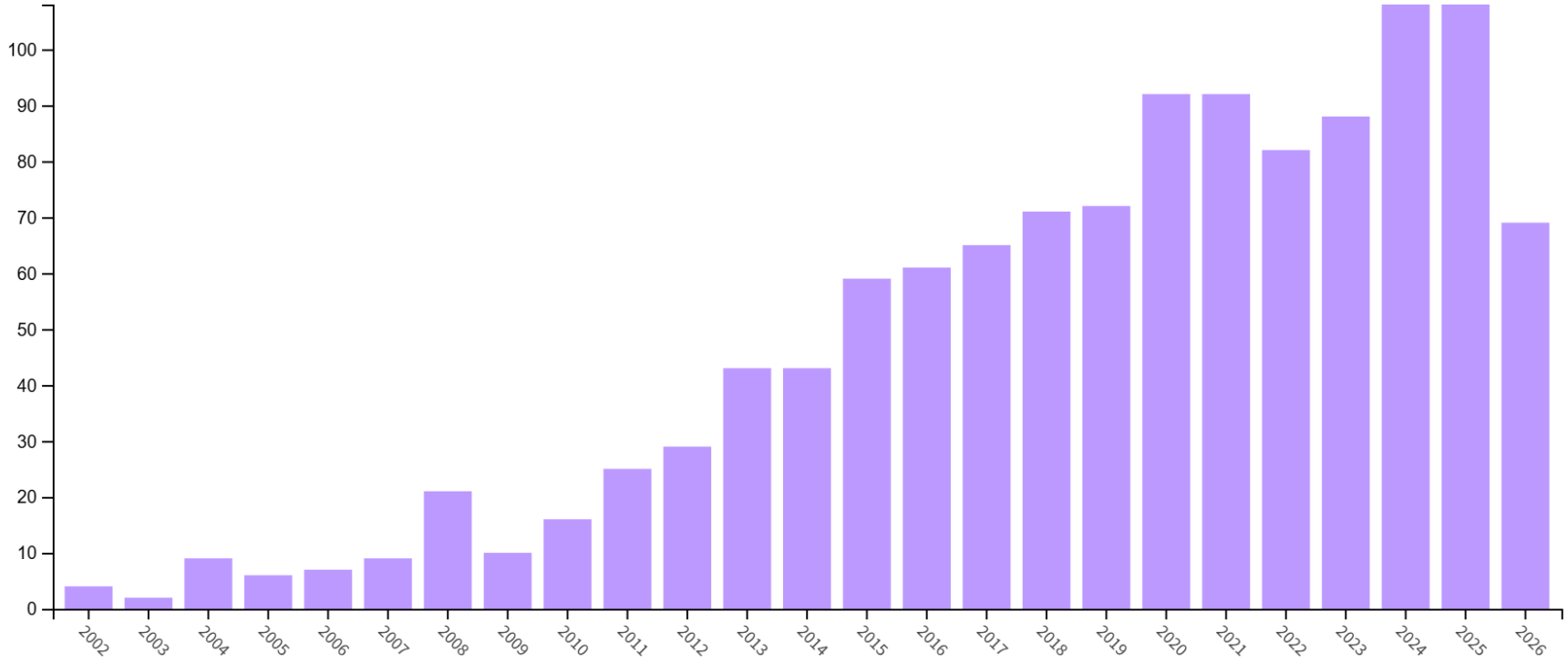
Figure 1. **Navigating people with ID through healthcare**



- Our next research steps: in-depth understanding of cancer-screening routines in the ID-setting
- **A system dynamics approach to cancer screening for people with intellectual disabilities (429)**
- Poster presentation by Amina Banda today at 13:00

Bridging research gaps

- Publications on (Cancer) AND (Intellectual disability) since 2002



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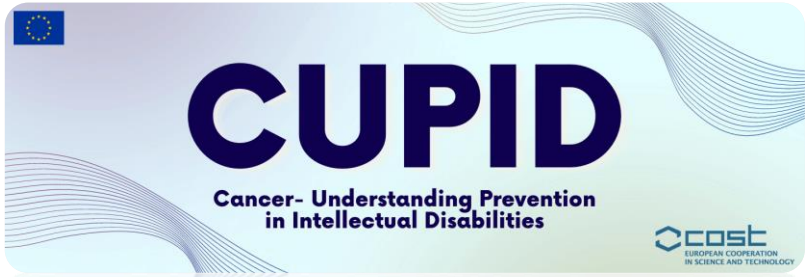
Bridging research gaps

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



Radboud University

University of Glasgow


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]

Contact

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