

# Cancer screening and prevention in people with intellectual disabilities

Cancer and intellectual disabilities;  
*current knowledge*

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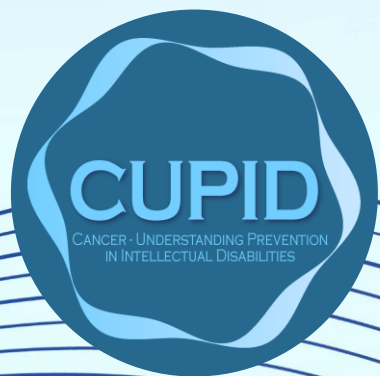
# COST Action – Cancer Understanding Prevention Intellectual Disability (CUPID)

- EU funded
- Stimulates networking, collaborations
- Meetings and researcher mobility

**Establishing active working partnerships with academics, researchers, NGOs, carers, people with intellectual disabilities and policy makers**

**Establishing a research agenda and exchanging information about cancer prevention in the intellectual disability population**

**Organizing short-term scientific exchanges, training schools, conferences and seminars**



# Introduction to the relation between intellectual disability and cancer





## ID - definition

- Significant limitation in cognitive functioning and adaptive behavior
- Originated before adulthood
- IQ below 70/75
- ID prevalence estimated at 1-3%
- Higher prevalence at lower age, and among males

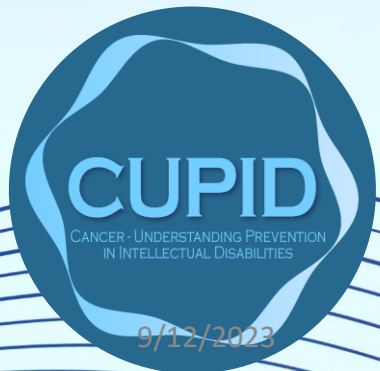


<https://www.aaid.org/intellectual-disability/definition>



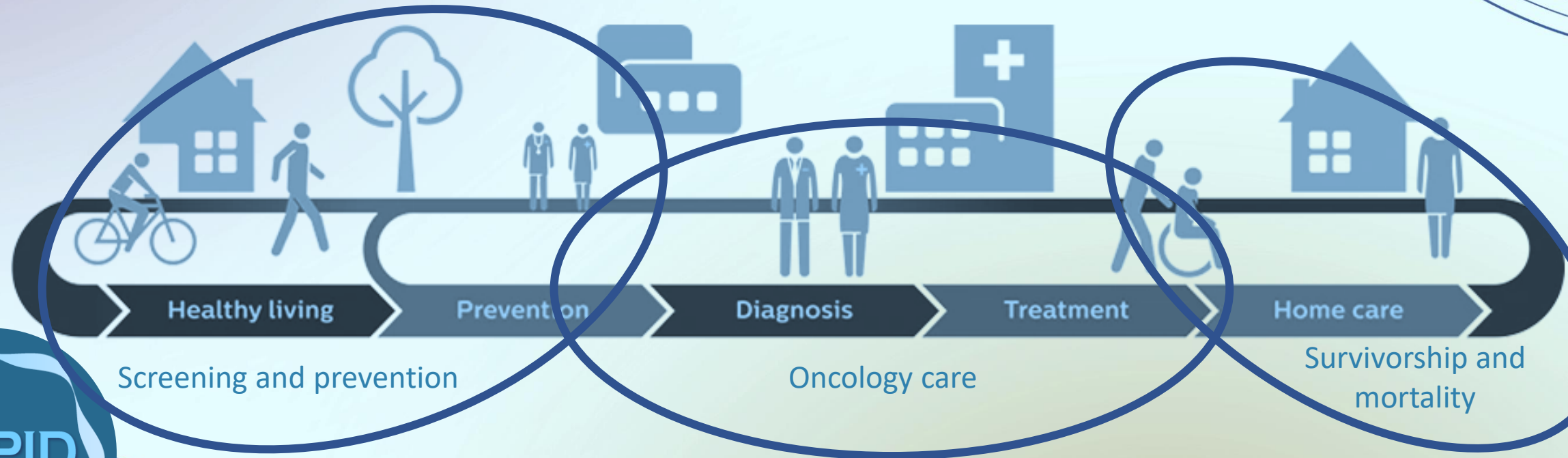
# Causes of ID

- **Genetic**
  - Down's syndrome
- **Prenatal**
  - Maternal infection, toxins
- **Perinatal**
  - Premature birth, lack of oxygen
- **Postnatal**
  - Early childhood infections, injury
- **Environmental**
  - Socioeconomic deprivation
- **Cause often unknown**





# Throughout the cancer journey



12/09/2023

# Cancer – ID related risk factors



- **Genetics**

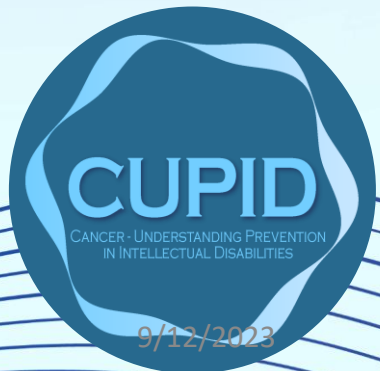
- Some causes of ID may also be involved in cancer development

- **Lifestyle**

- Obesity and lack of exercise are common
- Risk behavior; unprotected exposure to sun, smoking (in some sub groups)

- **Health(care) disparities**

- Communication
- Health skills and literacy
- Diagnostic overshadowing



# 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,<sup>\*</sup> Laura Hammond, and Anne Turner

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

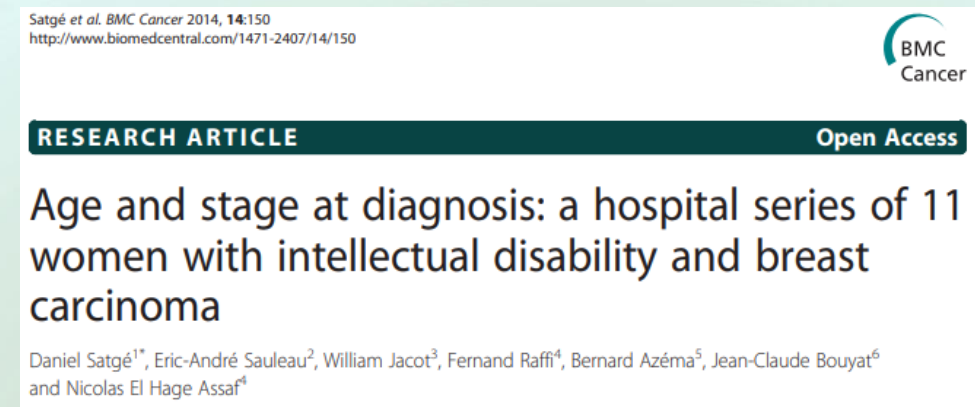
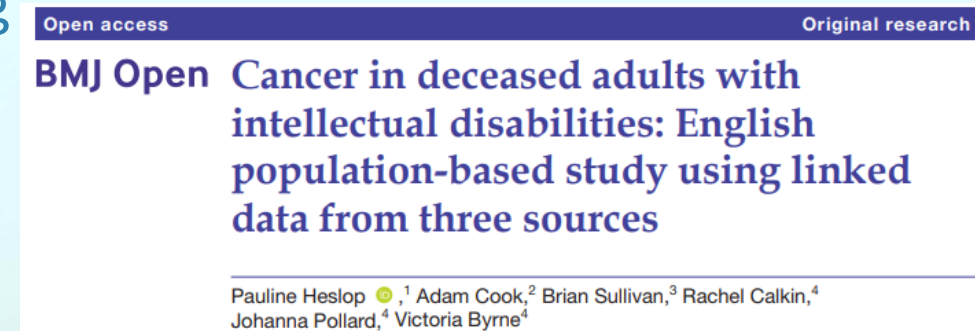
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2023

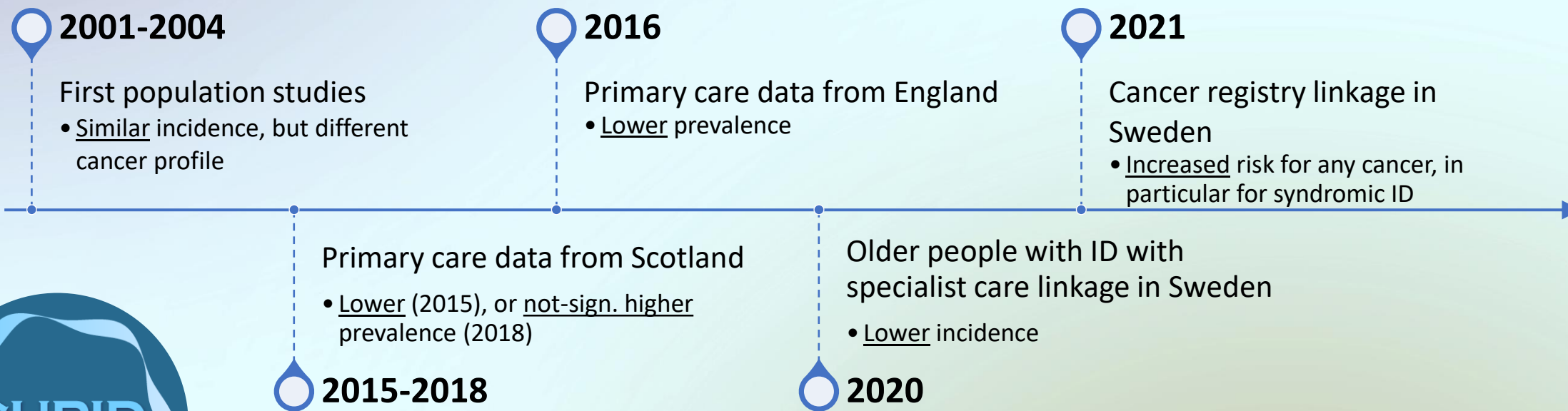


# (early) detection

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



# Cancer incidence and prevalence – Brief overview of literature



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

# Cancer incidence – some examples

- Screening cancers and skin cancer
  - lower incidence of early-stage tumors
- Lung cancer
  - in particular high in mild ID groups
- Prostate cancer
  - Age groups with high Pca incidence are often not reached by men with ID, except for healthy survivors
- Cancer of unknown primary
  - Indicative for late diagnoses and limited diagnostic procedures





# Cancer care


- Barriers in accessing care
  - Lower utilization of oncology care
- Less extensive treatment
  - Little evidence supporting choices
  - Adjustments attributed to disability



## 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<sup>1</sup>  | Hilde Tobl<sup>2</sup> | Cornelis A. A. Huijsmans<sup>3</sup> | Lieke van Gerwen<sup>3</sup> | Michiel ten Hove<sup>3</sup> | Chris van Weel<sup>1,4</sup> | Lambertus A. L. M. Kiemeny<sup>5</sup> | Jenneken Naaldenberg<sup>1</sup> | Geraline L. Leusink<sup>1</sup>

THE LANCET  
Oncology

Submit Article

Access provided by Radboud University

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

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

Anne J Boonman, MSc   • Maarten Cuypers, PhD • Prof Geraline L Leusink, MD • Jenneken Naaldenberg, PhD • Prof Haiko J Bloemendal, MD





Published: April, 2022 • DOI: [https://doi.org/10.1016/S1470-2045\(21\)00694-X](https://doi.org/10.1016/S1470-2045(21)00694-X) •  Check for updates

# Cancer-related mortality


- More often cause of death
  - Appr. 1.5 times more often (age and sex standardized)
- Different types of cancer involved
  - Cancers with screening
  - Cancer of unknown primary



## 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

First published: 17 November 2021 | <https://doi.org/10.1002/cncr.34030> | Citations: 6



# From equal health system to equitable cancer care

## Equality



The assumption is that everyone benefits from the same supports. This is equal treatment.

## Equity



Everyone gets the supports they need (this is the concept of "affirmative action"), thus producing equity.

## Justice



All 3 can see the game without supports or accommodations because **the cause(s) of the inequity was addressed.** The systemic barrier has been removed.



## In sum

- Different characteristics and specific care needs
- No complete understanding yet of;
  - Biology and genetics involved in ID and cancer
  - Role of age and aging in cancer incidence
  - How to optimize cancer care for the ID population
- At risk to be underserved throughout oncological journey
- From equal cancer care to equitable cancer care
- Better screening and prevention is crucial first step





## Questions?



## Contact

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COST Action CUPID

<http://www.cupidproject.eu>

