



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



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Introduction to the relation between intellectual disability and cancer



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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.aaidd.org/intellectual-disability/definition

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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

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Throughout the cancer journey





Cancer – ID related risk factors



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



- 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

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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

12 september





Disability and Health Journa

www.disabilityandhealthjnl.com

Original research

Disability and Health Journal 8 (2015) 9–16 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 ^aDepartment of Public Health, University of North Florida, 1 UNF Drive, Jacksonville, FL 32224, USA ^bDepartment of Behavioral Science and Community Health, University of Florida, Gainesville, FL USA

Open access

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

Pauline Heslop ³, ¹Adam Cook, ²Brian Sullivan, ³Rachel Calkin, ⁴Johanna Pollard, ⁴Victoria Byrne⁴

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 Sauleau², William Jacot³, Fernand Raffi⁴, Bernard Azéma⁵, Jean-Claude Bouyat⁶ and Nicolas El Hage Assaf⁴

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(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

	2001-2004		2016		2021	
	 First population studies Similar incidence, but different cancer profile 		Primary care data from England • <u>Lower</u> prevalence		Cancer registry linkage in Sweden • <u>Increased</u> risk for any cancer, in particular for syndromic ID	
Primary care data • <u>Lower</u> (2015), or <u>not</u> - prevalence (2018)			Older people with ID with specialist care linkage in Sweden • <u>Lower</u> incidence			
		2015-2018		2020		
Patja, 2001; Sullivan, 2004; Carey, 2016; Cooper, 2015 and 2018; Satge, 202						2021
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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

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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

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Cancer care

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



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

Maarten Cuypers¹ || Hilde Tobi² | Cornelis A. A. Huijsmans³ | Lieke van Gerwen³ | Michiel ten Hove³ | Chris van Weel^{1,4} | Lambertus A. L. M. Kiemeney⁵ | Jenneken Naaldenberg¹ | Geraline L. Leusink¹

THE LANCET Oncology

Submit Article

WILE

Cancer Medicine

Access provided by Radboud University

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

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

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

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

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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



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

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From equal health system to equitable cancer care



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

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

Equity

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

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