

# Equitable Cancer Prevention & Screening: Advancing Inclusion for People with Intellectual Disabilities

## Take-away messages

In the following slides, the take-away messages from all presentations/sessions have been collated.



# The Cancer – Understanding Prevention in Intellectual Disabilities (CUPID) Project

Organise a training school  
about organisational  
context and  
implementation of  
equitable cancer prevention  
and access to screening  
programmes.

WG2: Cancer prevention  
policies: audit and  
evaluation

WG1: The  
interdisciplinary co-  
production team

WG3: Universal EU Cancer  
prevention strategy  
methodology

Organise a training school  
about health system goals  
for targeted cancer  
prevention and screening  
programmes for people with  
intellectual disabilities.

WG4: Dissemination and  
Outreach

Monday 12<sup>th</sup> May 2025

# Session names and presenters

Presenter	Session name	Slide
Dr Bilge Güvenç Tuna	Novel Technologies in Cancer Screening: Needs Assessment of Wearables and Point-of-Care Tests for Individuals with Intellectual Disabilities	5
Dr Mairead O'Connor & Professor Cara Martin	Cancer screening and inequity	6
Dr Chris Stinton & Dr Samatha Flynn	Health outcomes of cancer screening programmes for adults who have intellectual disabilities.	7
Professor Lau Caspar Thygesen, Trine Toft Sørensen & Dr Trine Allerslev Horsbøl	Participation in breast and colorectal cancer screening among people with intellectual disability – results from Denmark	8
Dr Martin McMahon & Dr Vladimir Vuković	Cancer Prevention Policy	9

# Novel Technologies in Cancer Screening

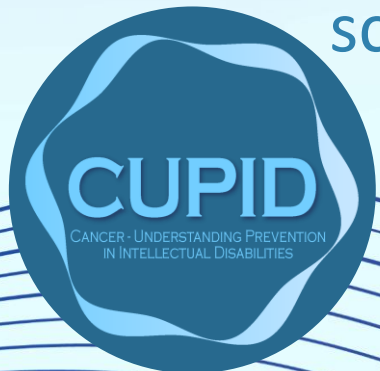
- In Türkiye healthcare services are a combination of publicly funded (79%) and privately operated (21%).
- Insights into how technological interventions can be used in relation to cancer screening access
- Wearable devices such as smartwatches, biosensors and fitness bands could make testing process faster, easier, cost-effective, and suitable for on-site measurements
- Different sub-populations might have a distinct properties
- Output and points from group discussions





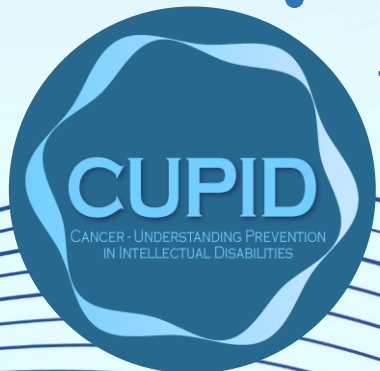
# Cancer screening and inequity

- The National Screening Service (NSS) runs 3 national population-based cancer screening programmes in Ireland
- NSS have developed an “equity in screening framework” - [Improving equity in screening: A strategic framework 2023-2027 - Corporate](#)
- There are multiple factors associated with reducing participation in screening including gender, education, employment, being fearful, finding screening painful, perception of risk, knowledges and attitudes towards screening.



# Health outcomes of cancer screening programmes for adults who have intellectual disabilities.

- No studies examining benefits or harms of organised cancer screening programmes for people who have intellectual disabilities.
- Published evidence relates to uptake and determinants of uptake of cancer screening programmes. Important, but does not address the overarching aims of screening: to reduce mortality and morbidity.
- There is a need to explore and understand what happens throughout the screening pathway for people with intellectual disabilities.



# Participation in breast and colorectal cancer screening among people with intellectual disability – results from Denmark

Use of register data can identify and quantify inequalities in cancer screening

- People with ID are more likely not to complete cancer screening
- This inequality increases with increased severity of ID

Research can inform the design of equitable screening programs and targeted policy adaptations

- Output and points from group discussions.





# Cancer Prevention Policy

Opinions on Cancer Prevention Policy of organizations from UMIC and HIC shown no statistical difference.

**Around 86%** of all participating organizations sees having tailored cancer prevention policy for people with intellectual disabilities as of the **major importance**, and the rest (13.8%) as of **medium importance**.

Cancer prevention policy for people with intellectual disabilities should be a **separate document** for 31% and **incorporated into general policy** for **69%** of participating organizations

A 93% of organizations see a **pan-European policy for cancer prevention** for people with intellectual disabilities as a useful strategy.

**Around 93%** of organizations declared that **more research is needed** in this field, and **around 90% think more funding** should be allocated for research on cancer prevention policies for people with intellectual disabilities.

Top three entities responsible for initiating policy changes at the national level according to participating organizations are **National government/ministries** (89.7%), **Organizations** for people with intellectual disabilities (82.8%), and **Research entities** (universities, research centers) (79.3%)

All agreed that more training is needed to implement cancer prevention policies for people with intellectual disabilities (100%), and in particular a 48.3% of organizations think that future cancer prevention policies should **focus on Specific training programs for healthcare providers.**

Tuesday 13<sup>th</sup> May 2025

# Session names and presenters

Presenter	Session name	Slide
Natalie Gil	Overview of – Cancer risk-factor and symptom awareness for people with intellectual disabilities.	12
Dr Kate Sykes	Inclusive and Accessible cancer screening/prevention information.	13
Dr Kate Sykes and Aysenur Dogan	Health Systems across the EU (and beyond): What does cancer screening and prevention look like?	14
Dr Margaret Denny, Dr Suzanne Denieffe, Dr Oliwia Kowalczyk, and Dr Laura Widger	Learning from WG1 – The voice of people with ID toward cancer screening and cancer prevention systems.	15
Working Group 2 and 3	Cancer screening and cancer prevention- How do these apply to people with ID and what should health systems do?	16

# Cancer risk-factor and symptom awareness for people with intellectual disabilities.

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Primary prevention is proactive measures to prevent disease occurring; Secondary prevention is identifying disease in nascent stage; Tertiary prevention aims to enhance quality of life

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Pathway to Treatment Model - Weller, D., et al., *The Aarhus statement*: Br J Cancer, 2012. **106**(7): p. 1262-7.

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Systematic review attempts to collate empirical evidence from a relatively smaller number of studies pertaining to a focused research question

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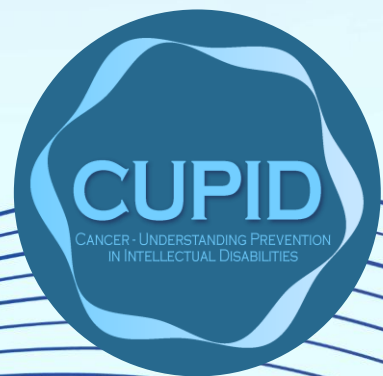
Scoping review seeks to present an overview of a potentially large and diverse body of literature pertaining to a broad topic.

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Arksey & O'Malley Framework for Scoping Review (2005) - 5 Stages to complete a scoping review

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Narrative synthesis : 1) Risk factors and symptoms awareness; 2) Interventions to improve cancer awareness





# Inclusive and Accessible cancer screening/prevention information

Accessible information is a combination of the right resource and the right support

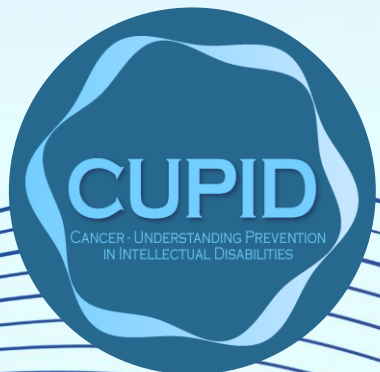
Can include easy to read material, Makaton, sign language, braille, audio recordings, bigger font, videos

There are 12 key principles of easy-to-read information

Applied principles to cancer prevention and cancer screening information

Discussed and listed of considerations to make cancer screening and prevention more accessible.

The results of the menti meter show the results of the what accessible information exists in countries and considerations.



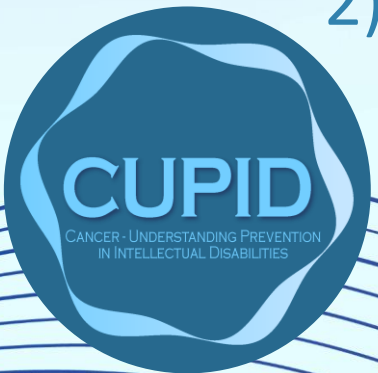
# Health Systems across the EU (and beyond): What does cancer screening and prevention look like?

- Please look at the PDF of the mentimeter to show the results highlighting 1) what health systems look like across different countries; 2) what prevention initiatives look like across different countries, and; 3) what cancer screening initiatives look like across different countries
  - Please look at the PDF of the padlet which shows the results of the groups consideration of how the mentimeter results impact people with intellectual disabilities.



# Learning from CUPID WG1: Voices of People with Intellectual Disabilities

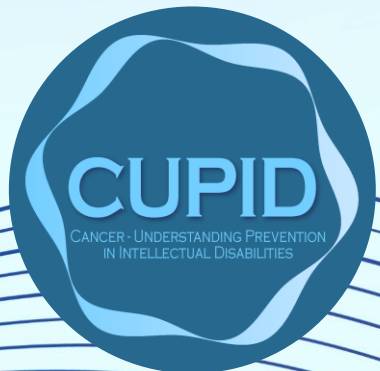
- Raymond's journey teaches us that cancer prevention, early diagnosis, empathetic communication, and proactive healthcare are essential. His resilience reminds us never to underestimate the capacities/capabilities of persons with intellectual disabilities.
- 1) Empower healthcare providers through education, co-production;  
2) Reform policies to promote inclusive cancer prevention healthcare, and 3) Drive research that centres the voices of persons with intellectual disabilities.





## A world café approach

- Following the world café approach the following key points were identified.
- 1) Need for education; 2) Involvement of carers and different organisations is important; 3) empower people with intellectual disabilities to know about cancer prevention and screening; 4) health systems need to be inclusive; 5) need for inclusive cancer screening and prevention policy.
- We will analyse the notes from the world café.







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## COST Description

COST (European Cooperation in Science and Technology) is a funding agency for research and innovation networks. Our Actions help connect research initiatives across Europe and enable scientists to grow their ideas by sharing them with their peers. This boosts their research, career and innovation.

## Weblink

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