EUROPEAN COOPERATION IN SCIENCE AND TECHNOLOGY

Overview of CUPID & Training School, Welcome and Icebreakers

09:30 – 10:00AM

CUPID
CANCER - UNDERSTANDING PREVENTION IN INTELLECTUAL DISABILITIES

By the end of this session, you will have;

1) Have gained an understanding of the aims of the CUPID project
2) Be aware of the what the training school will cover
3) Taken part in icebreaker activities

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

CUPID will establish a research agenda and knowledge base to improve this in the European Union and beyond.

WG1: The interdisciplinary co-production team

WG2: Cancer prevention policies: audit and evaluation

WG3: Universal EU Cancer prevention strategy methodology

WG4: Dissemination and Outreach

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

CUPID will establish a research agenda and knowledge base to improve this in the European Union and beyond.

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

WG2: Cancer prevention policies: audit and evaluation

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.

WG1: The interdisciplinary co-production team

WG4: Dissemination and Outreach

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

Training school organising committee: Dr Martin McMahon; Dr Vladimir Vukovic; Dr Bilge Tuna; Prof Peter Knapp; Prof Soner Dogan; Dr Kate Sykes; Ayşenur Doğan; Francoise Hickey; Dr Maarten Cuypers

Objectives

- To bring people together from different working groups within the CUPID COST action, to gain practical skills, and awareness of methods, and frameworks that they can use or apply in their work.
- Equip participants with knowledge on the organisational context and strategies for implementing equitable cancer prevention and screening programmes.
- Examine how different health systems approach cancer prevention and screening, including policy that can impact on access and equity for people with Intellectual Disabilities.
- Develop recommendation from discussions to improve accessibility and participation in cancer screening programmes and cancer prevention initiatives for individuals with Intellectual Disabilities.

Timetable

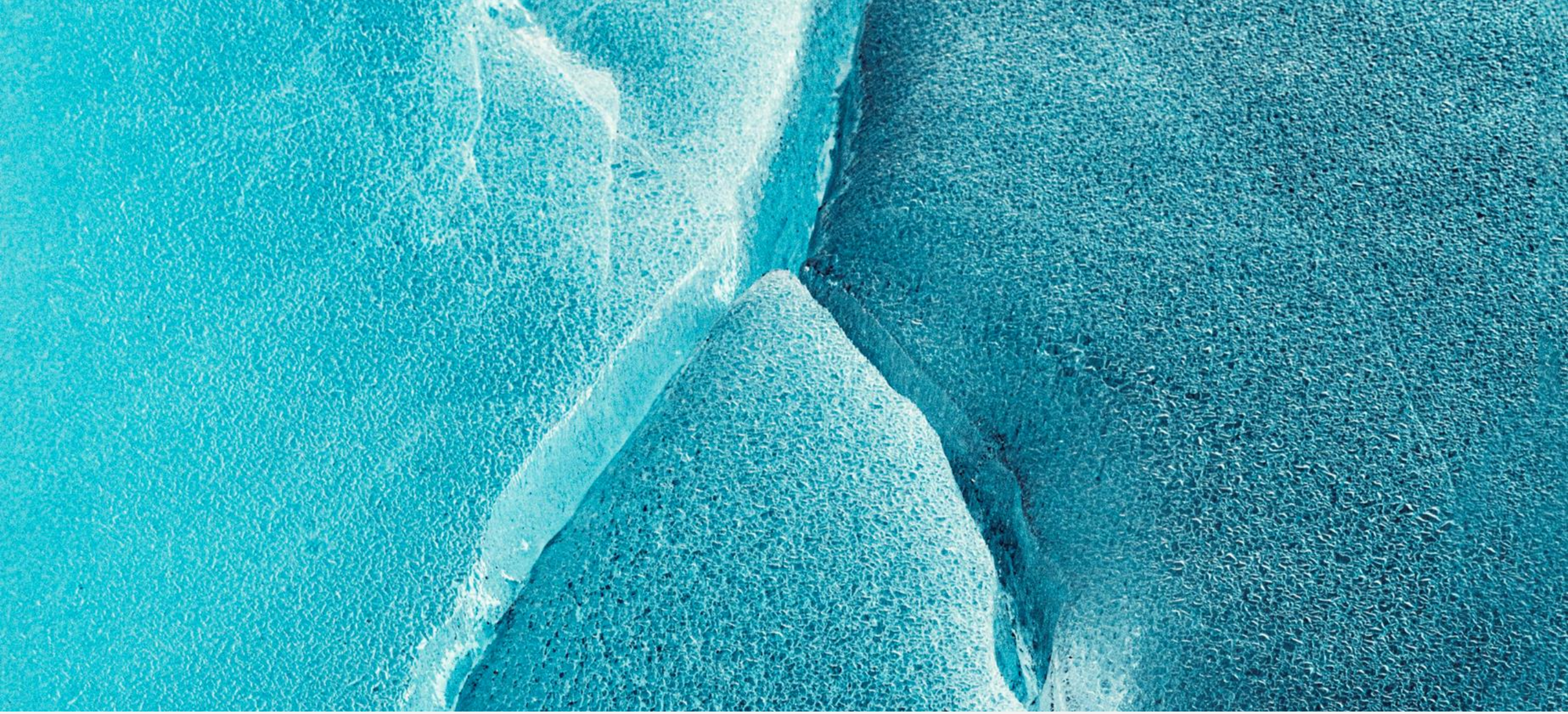
Date	Information
Monday 12th May	9am – 1pm = Morning sessions and break 1pm-2pm = Lunch 2pm-4:45pm = Afternoon sessions and break 5pm = Wine reception - Senior Common Room
Tuesday 13th May	9am – 1pm = Morning sessions and break 1pm-2pm = Lunch 2pm-4:45pm = Afternoon sessions and break 5pm = Tour and Book of Kells experience - Main Square 8pm = Celtic Nights - The Arlington Hotel
Wednesday 14th May	Conference Make sure you have registered!

Supporting your learning

- Talks and interactive activities.
- Each session has take-away messages.
- Each session has a designated slide sharing the key take-away messages.
- Some sessions utilise interactive activities. The results from these session can be shared at the end of the training school.

Evaluation of training school

- Survey 1 – About day 1. Shared at the end of Monday.
- Survey 2 – About day 2. Shared at the end of Tuesday.
- Survey 2 – About entire training school. Shared at the end of Tuesday.



Icebreakers

Why Are You Here?

- **Before we start…**
- **We'd love to understand what brought you here.**
- **What are you hoping to learn, share, or take away from this training school?**

- **Write down**
- **Post it**
- **Share it**

Coming next…

- Novel Technologies in Cancer Screening: Needs Assessment of Wearables and Point-of-Care Tests for Individuals with Intellectual Disabilities. Dr Bilge Tuna

- Break at 11am

Are there any questions?

Novel Technologies in Cancer Screening: Needs Assessment of Wearables and Point-of-Care Tests for Individuals with Intellectual Disabilities

10 am – 10:45 am

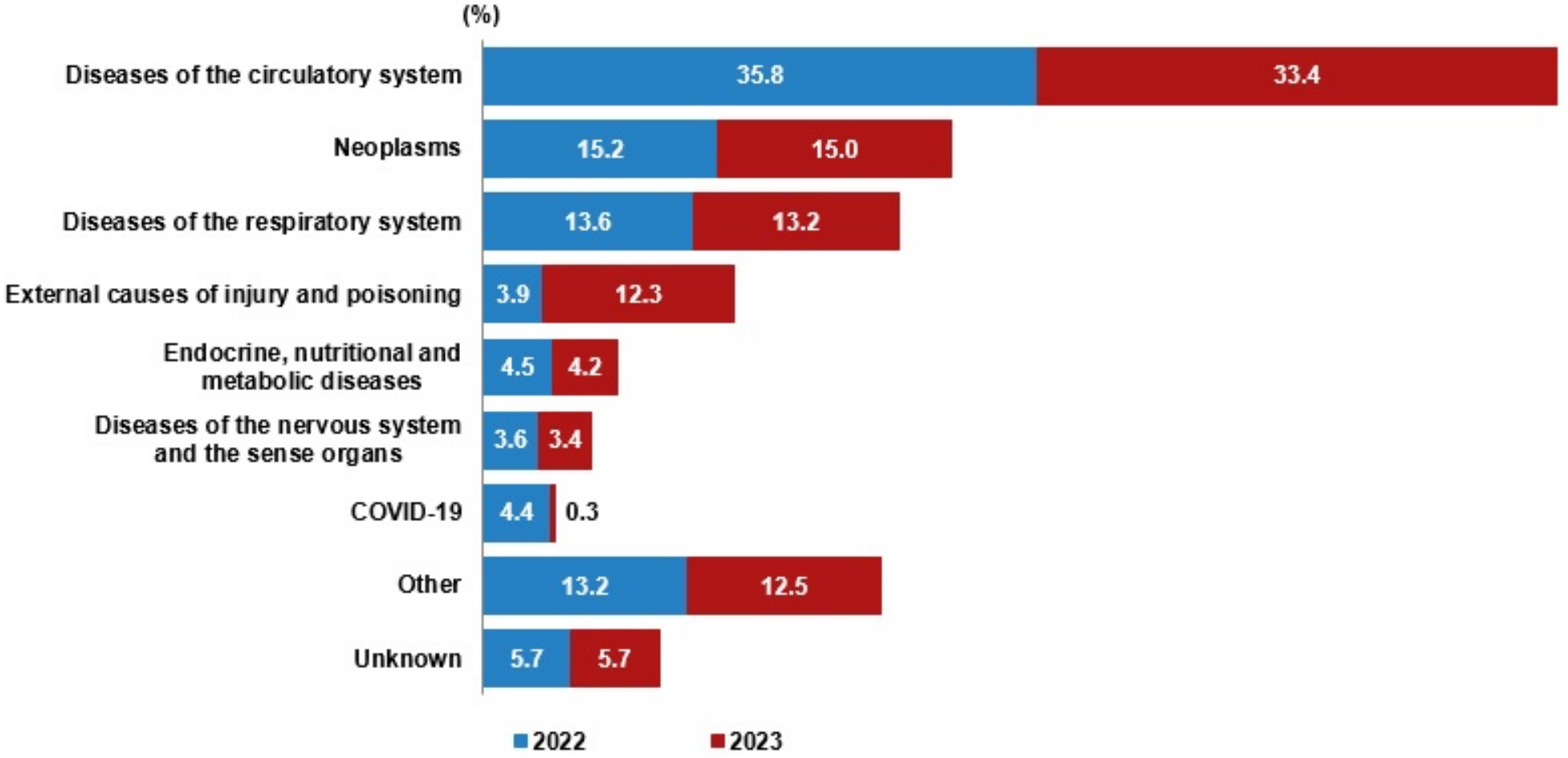
Dr. Bilge Güvenç Tuna

Yeditepe University, School of Medicine, Department of Biophysics

By the end of this session, you will

1. Explain the potential applications of wearable devices (e.g., biomarker detection, continuous monitoring) and point-of-care tests (e.g., rapid, non-invasive diagnostics) in cancer screening.
2. Have an understanding of how novel technologies in screening technology can support equity in cancer screening for people with intellectual disability.
3. Explore and evaluate how barriers and potential facilitators of novel technologies can be used.

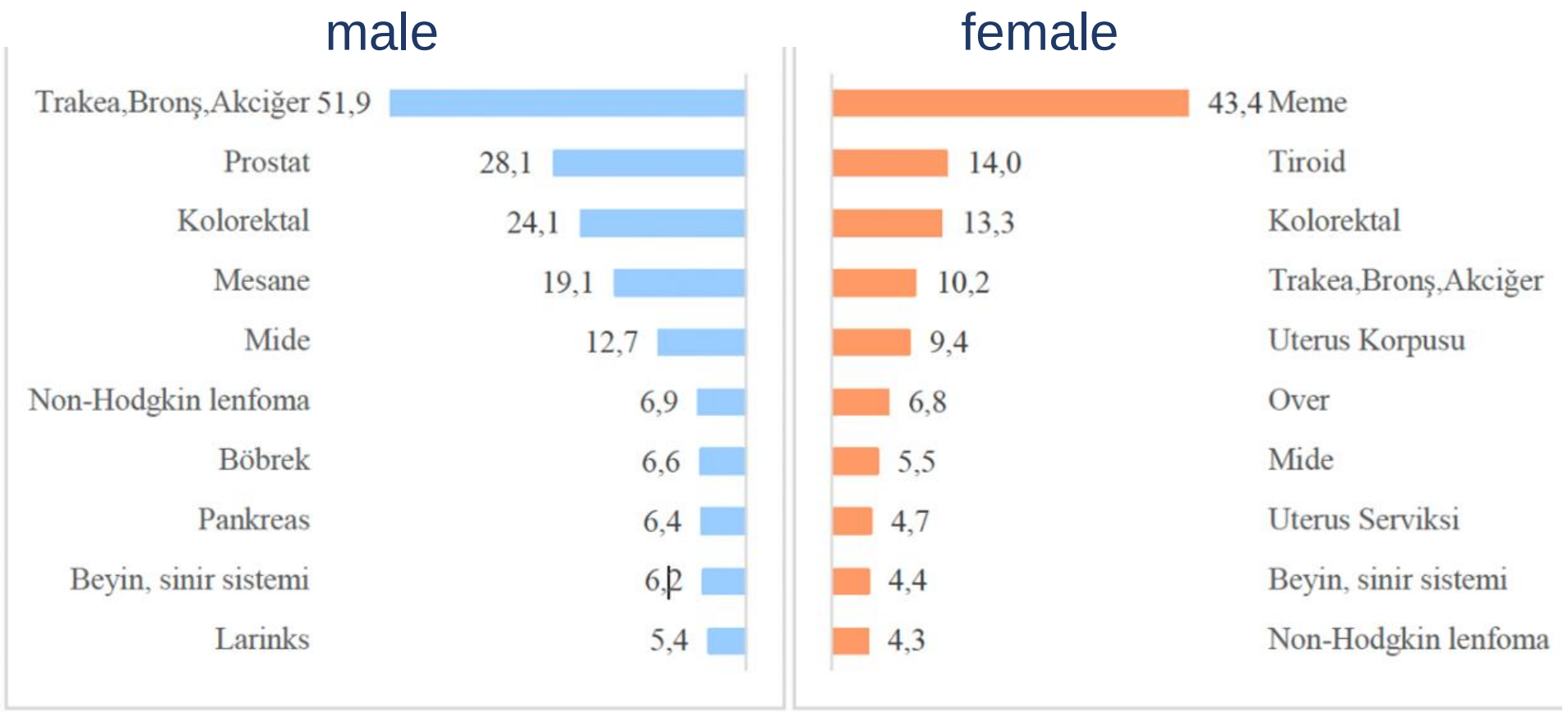
Proportion of Cuses of Death in Türkiye



Turkish Statistical Institute, 2023

Cancer Screening: Why important?

The most common cancer types normalised to age

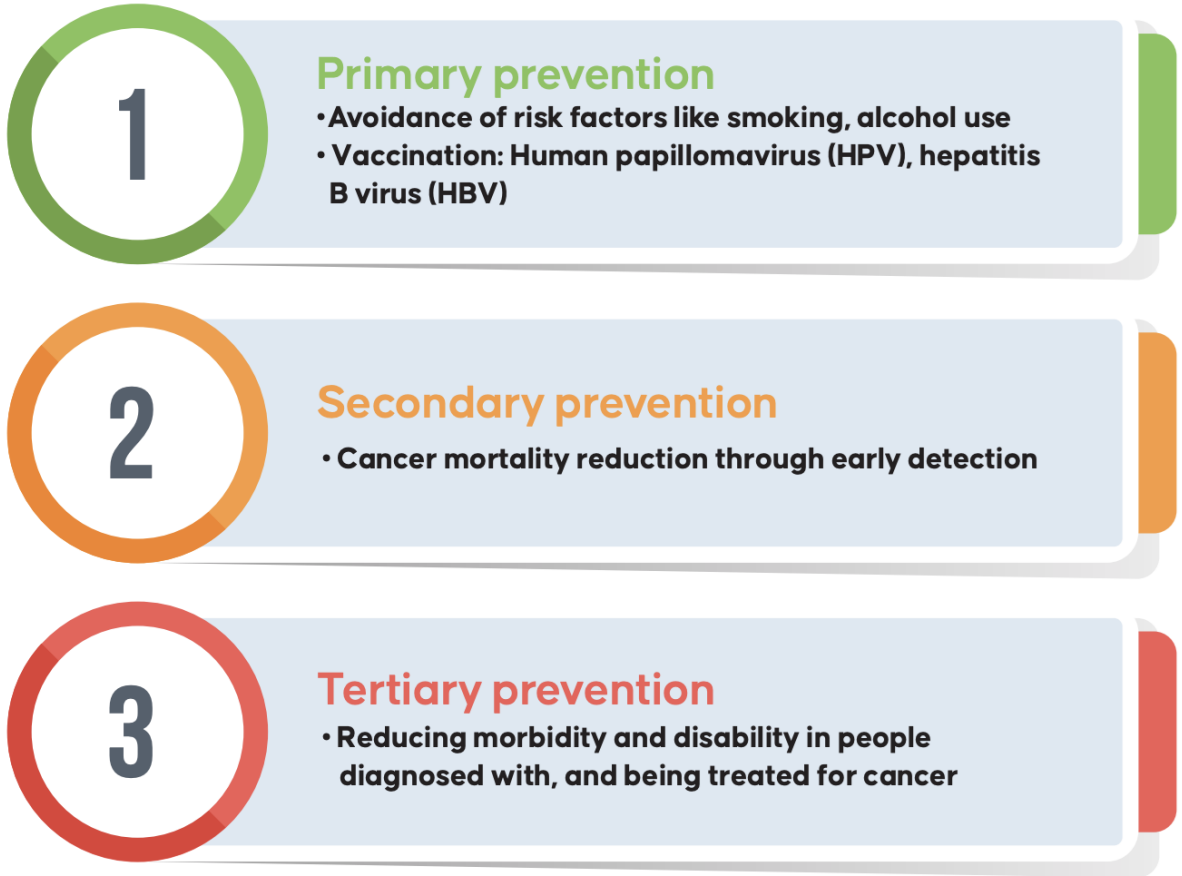


Screening of cancer before symptoms appear, involving various methods such as blood tests, urine tests, DNA tests, and medical imaging

Turkish Statistical Institute 2020

Screening: Secondary Prevention

Approximately 30-50% of cancers can currently be prevented by avoiding risk factors and implementing existing evidence-based prevention strategies



people living with ID:

- 2.3 times more likely to die of breast cancer,
- 2.6 times more likely to die of colorectal cancer,
- 1.4 times more likely to die of lung cancer

study period (2009–17)

compared to people without ID

Cancer Screening in Türkiye

	Screening Types	Screening Method	Age/Gender	Statistics (2024)
	Mammography Ultrasounds MRI	Mammography in every 2 years Clinical breast examination once a year	40-69	3.300.000 screening
	Fecal Occult Blood Test (FOBT) Colonoscopy CT Colonography	FOBT in every 2 years Colonoscopy in every 10 years	50-70	2.700.000 screening
	Pap Smear HPV Test	HPV-DNA Test In every 5 years	30-65	3.500.000 screening
				9.500.000 screening 223.000 diagnosis

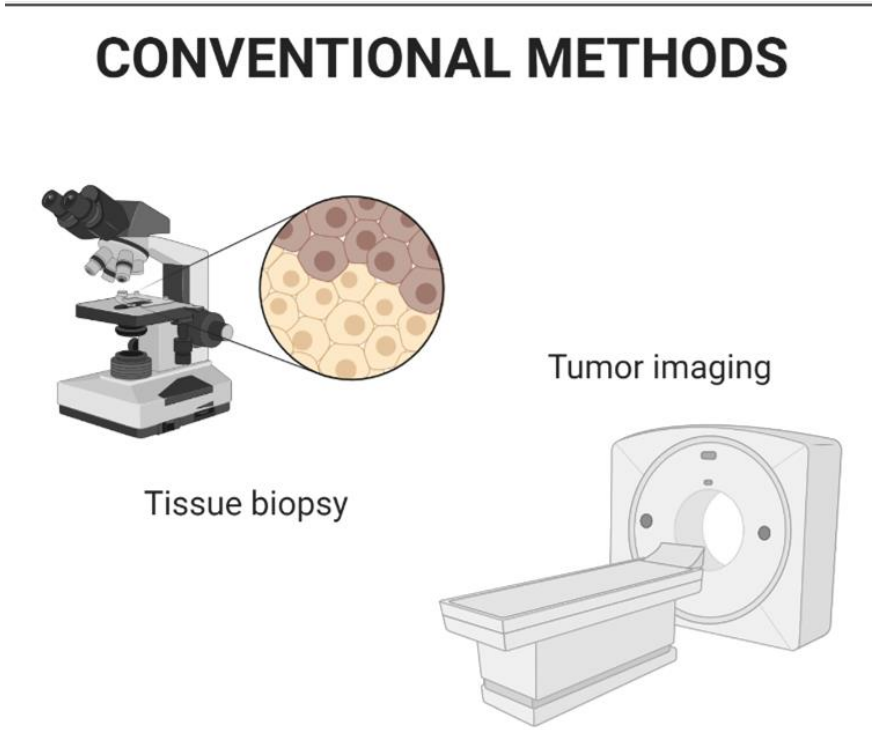
Where?

- Cancer Early Diagnosis, Screening, and Training Centers (KETEM)
- Family health centers
- Public hospitals

No specific screening program for people with ID

Cancer Screening Challenges

- **Lack of awareness**
- **Socioeconomic barriers**
- **Healthcare infrastructure issues**
- **Psychological factors like fear or anxiety**

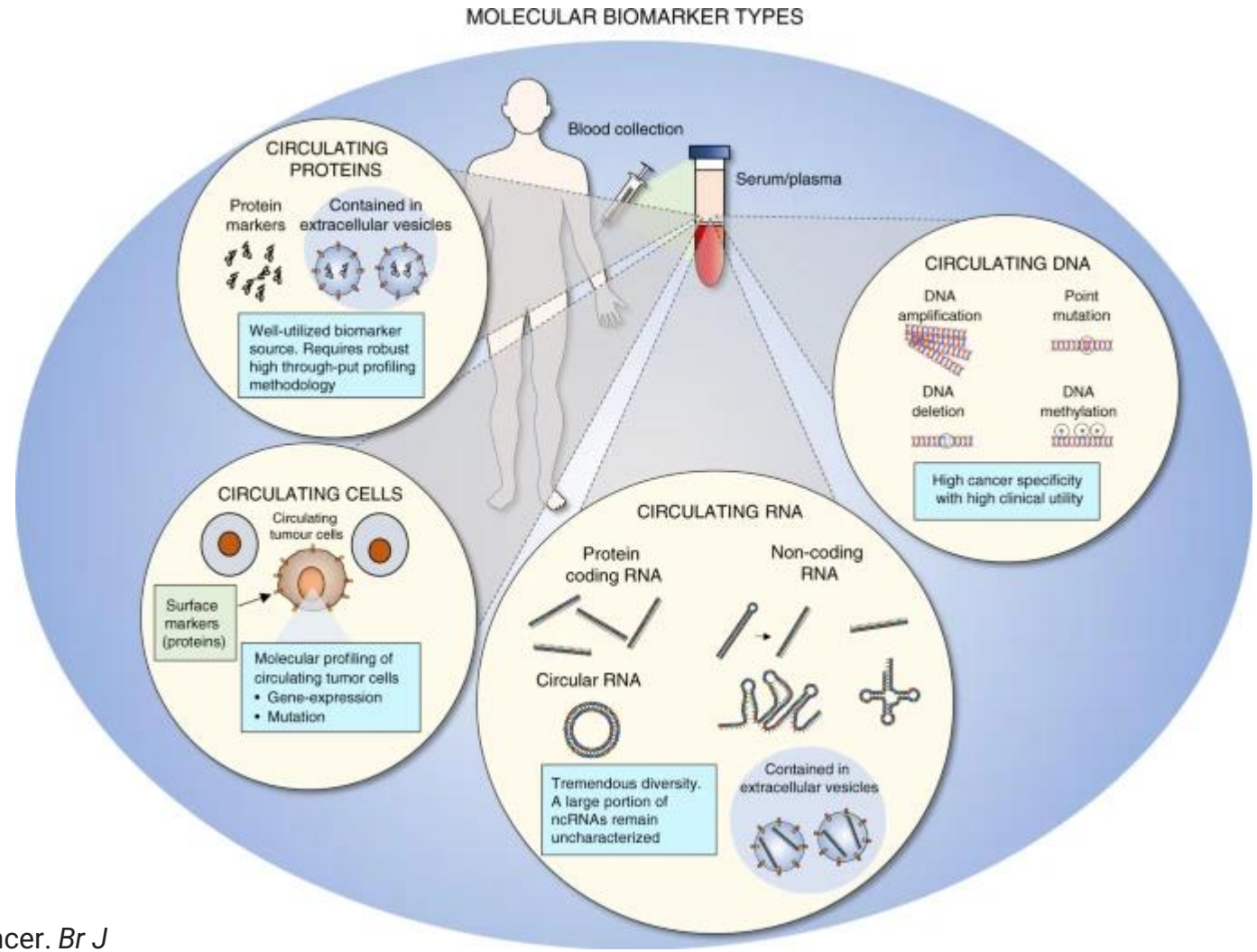


Cancer Screening Challenges in ID Populations

- Lower participation rates in screening.
- Communication barriers and cognitive limitations.
- Dependency on caregivers and service accessibility.
- Stigma or diagnostic overshadowing in healthcare settings.

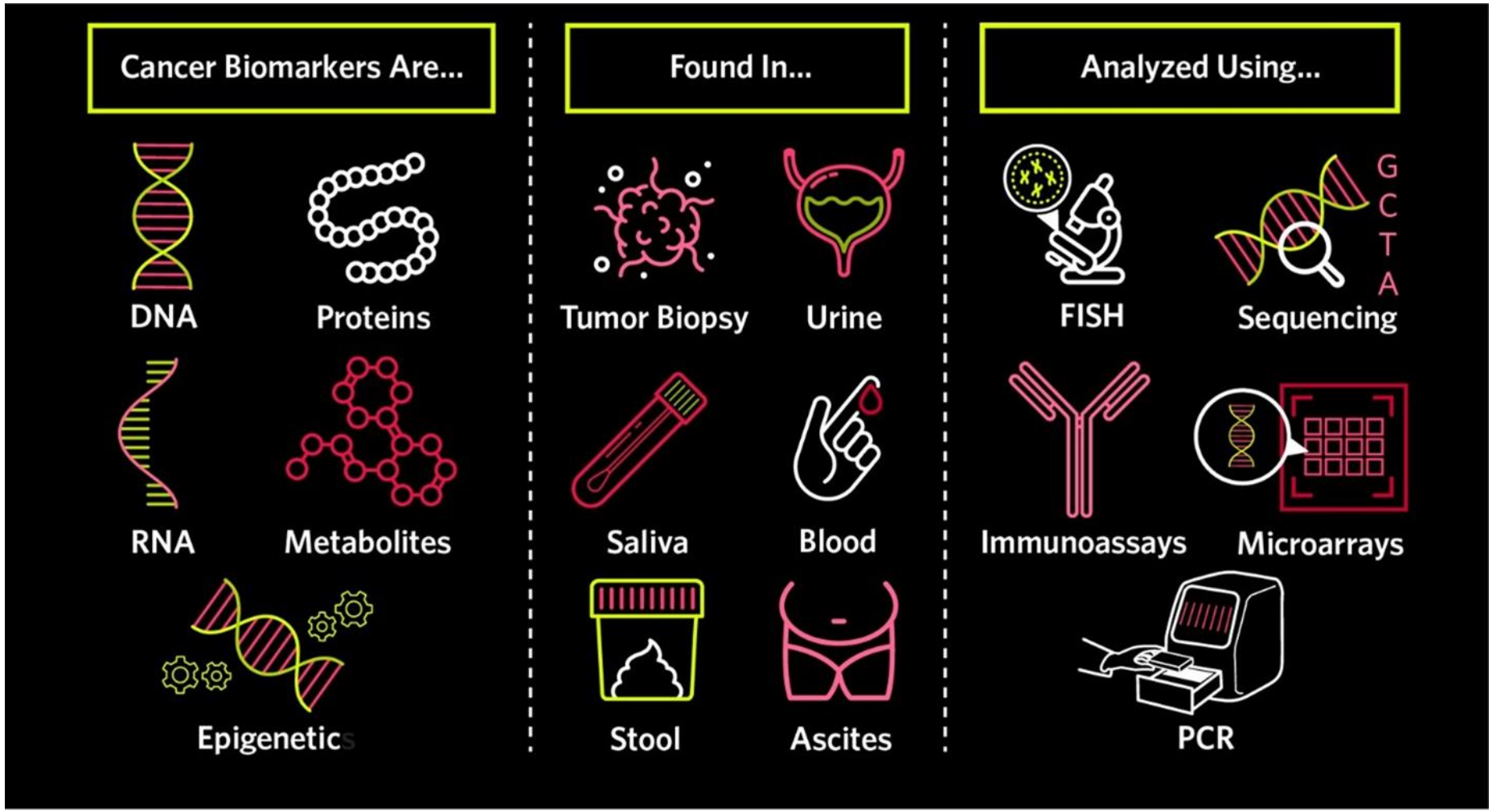
Biomarkers for cancer detection

- Nucleic Acid biomarkers
- Protein biomarkers
- Circulating tumor cells
- Exosomal nucleic acid biomarkers
- Exosomal protein biomarkers



Toden S, Goel A. Non-coding RNAs as liquid biopsy biomarkers in cancer. *Br J Cancer*. 2022;126(3):351-360. doi:10.1038/s41416-021-01672-8

Methods for biomolecular detection



- Time consuming
- Expensive
- Complex

https://www.the-scientist.com/decoding-cancer-how-cancer-biomarkers-aid-diagnosis-and-treatment-72506

Novel Technologies in Cancer Screening

Wearable Devices

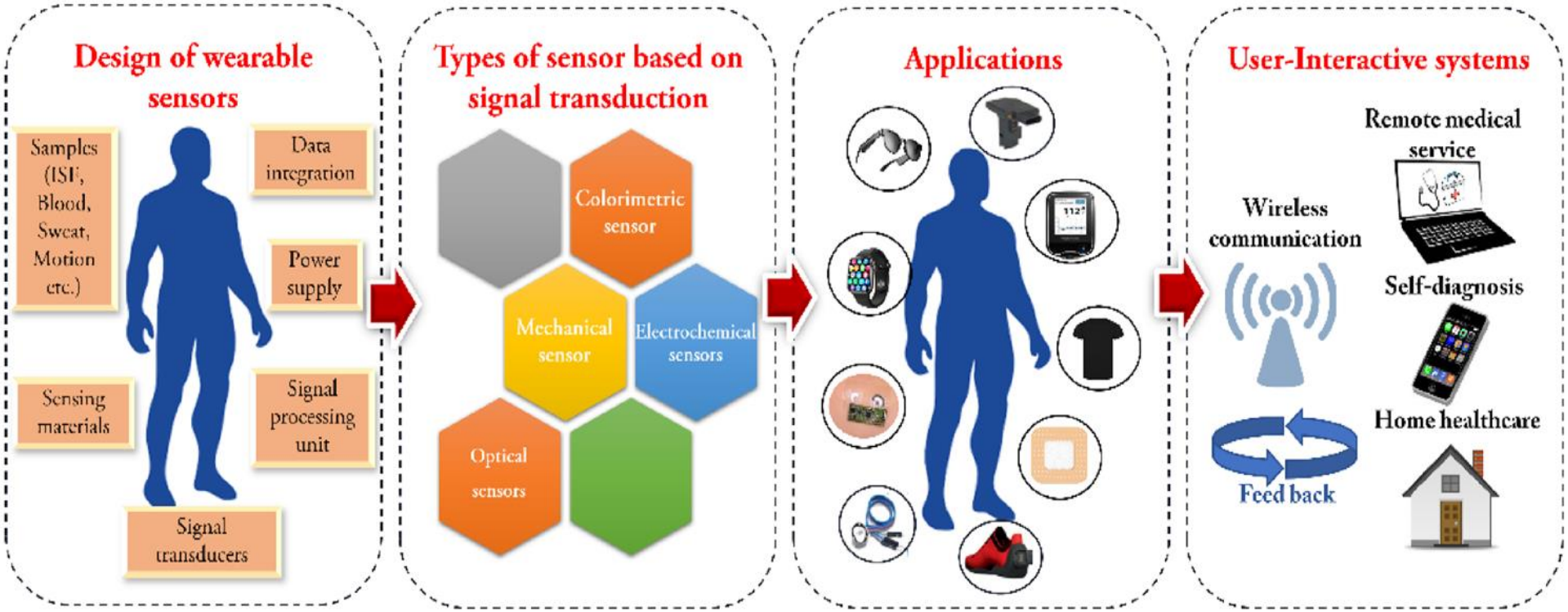
- Smartwatches, biosensors, fitness bands.
- Potential for continuous monitoring (e.g., HRV, skin temp, activity).
- Relevance for early symptom detection or risk stratification.

Point-of-Care Tests (POC)

- Rapid tests for HPV, FIT for colorectal cancer.
- Portable, easy-to-use, minimal infrastructure.
- Potential for home use or supported community settings.

making the testing process faster, easier, cost-effective, and suitable for on-site measurements

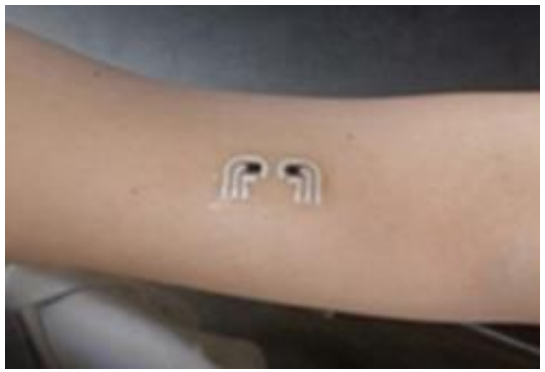
Novel Technologies in Cancer Screening



An overview of design, types, and applications of wearable sensors

Wearable device worn on various body parts and vital signs can be monitored

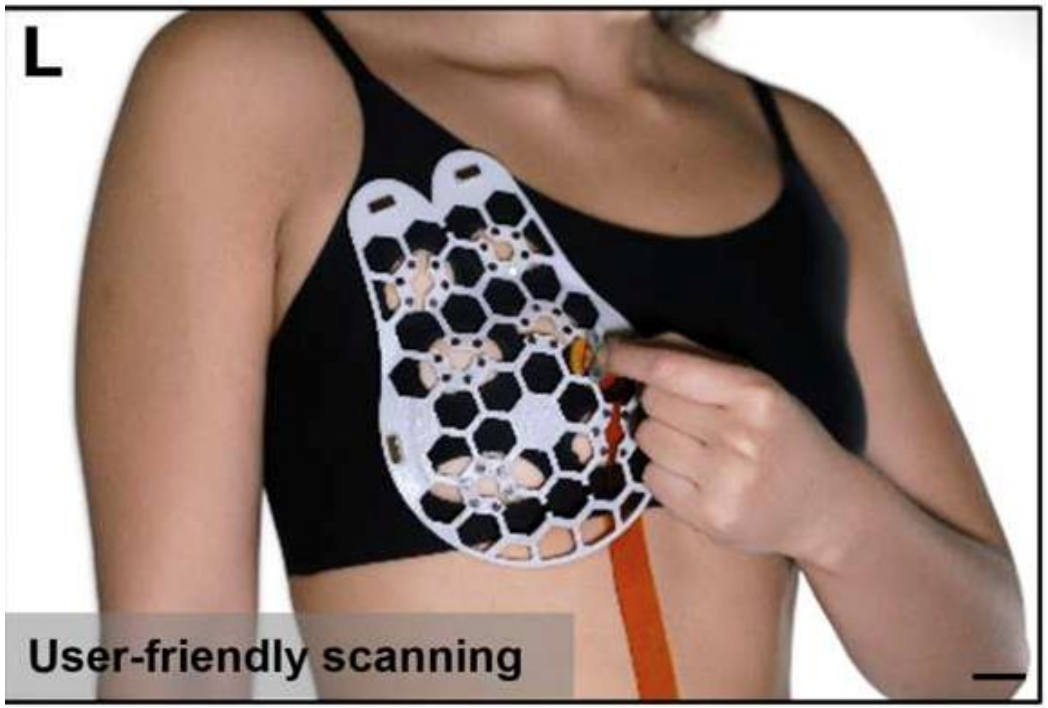
Breaking Down Barriers with Technology



Memory Aids: Wearable Reminder Devices
Learning Enhancement: Smartwatches and Apps
Emotional Support: Wearable Sensors
Physical Activity: Smart Clothing

Example: A wearable ultrasound scanner to detect breast cancer

Allows the observation of small cysts (~0.3 cm) in the breast

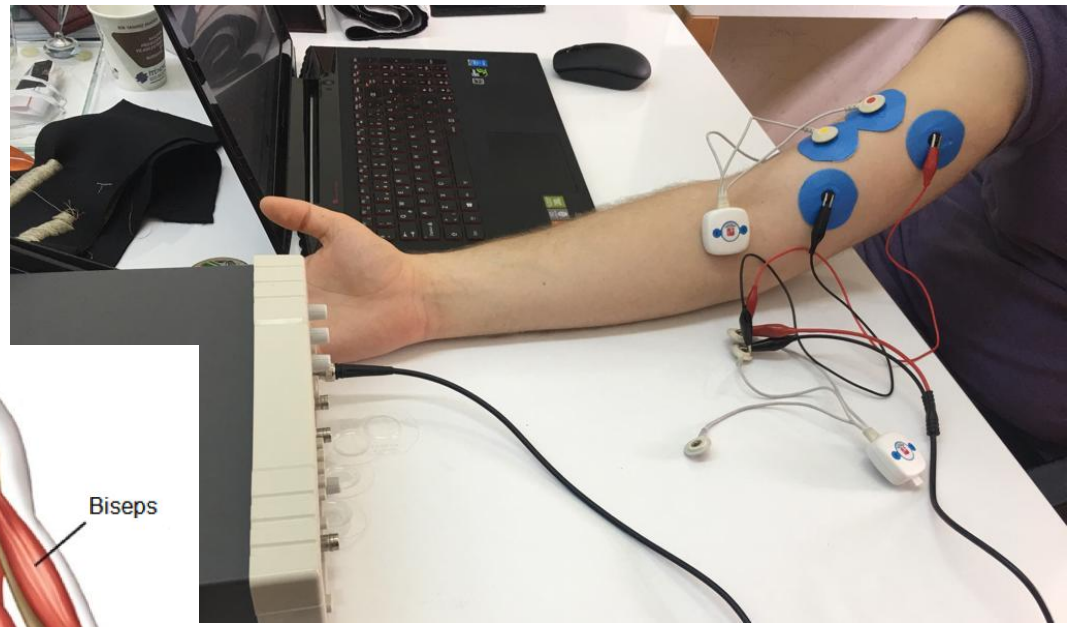


Du W, Zhang L, Suh E, et al. Conformable ultrasound breast patch for deep tissue scanning and imaging. *Sci Adv*. 2023;9(30):eadh5325.

Example: Wearable e-textile Electromyography electrodes

EMG widely used to track **sports performance** in addition to diagnosis of neural and muscular diseases in medical sciences.

silver/silver chloride electrodes (Ag/AgCl)

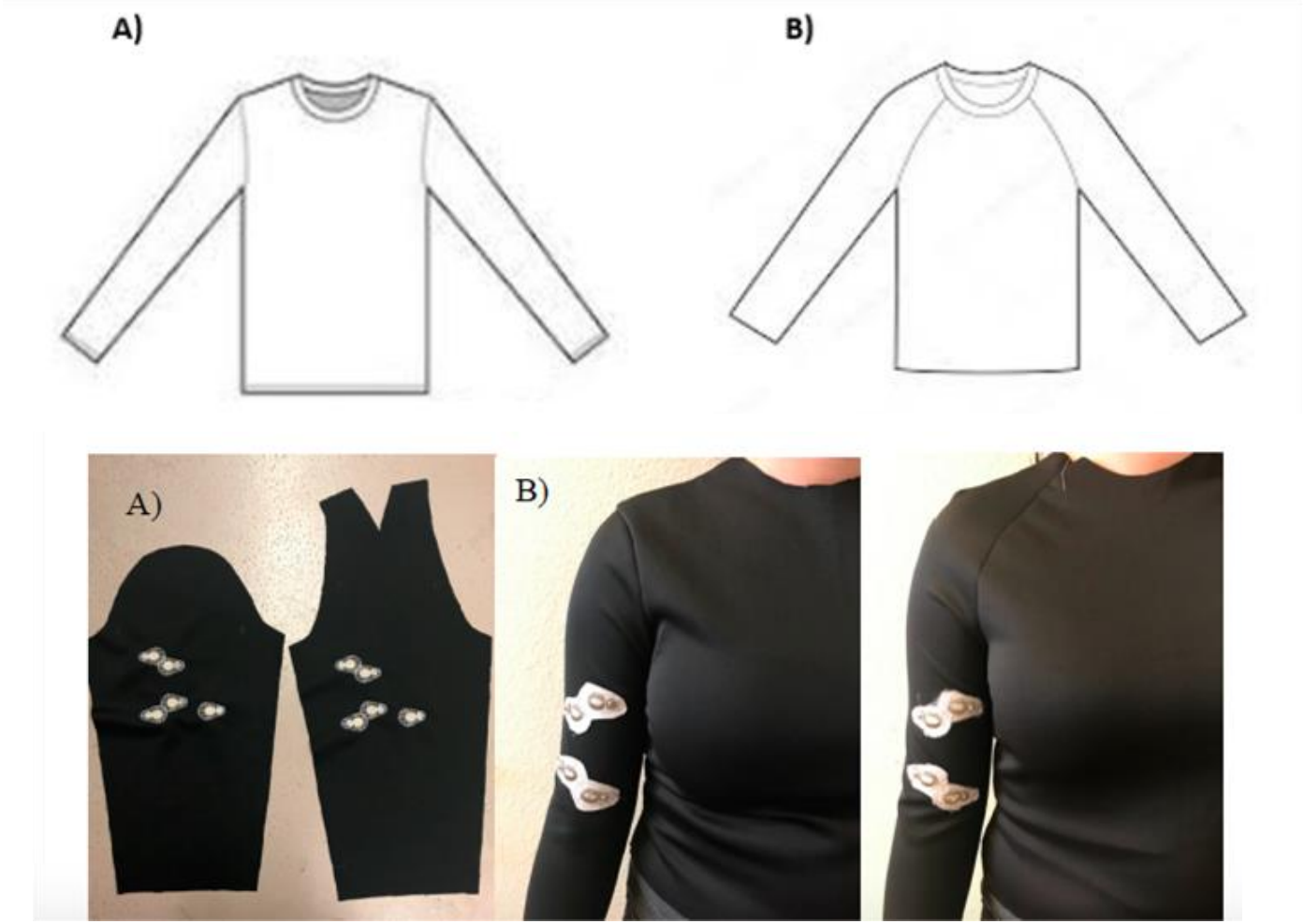


Electronic textile based electrodes

- Dry
- Free from gel
- Do not need skin preparation
- Flexible
- Higher performance over time
- Reusable and washable

Goncu-Berk and Tuna., 2021. Sensors

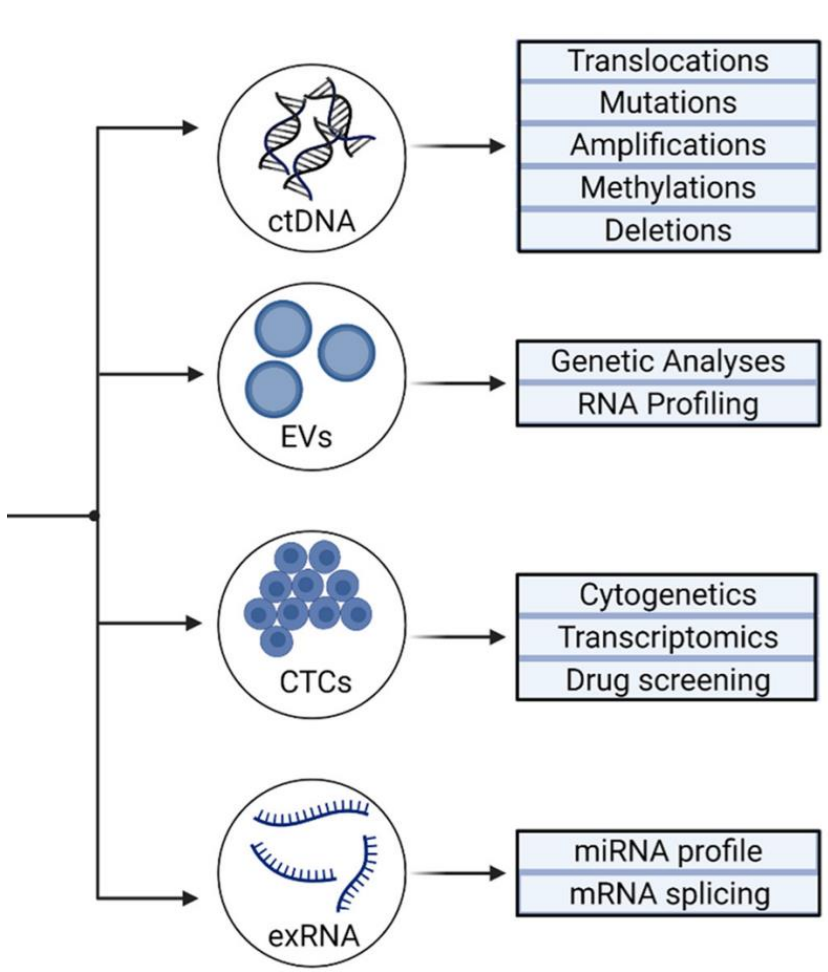
Example: Wearable e-textile Electromyography electrodes

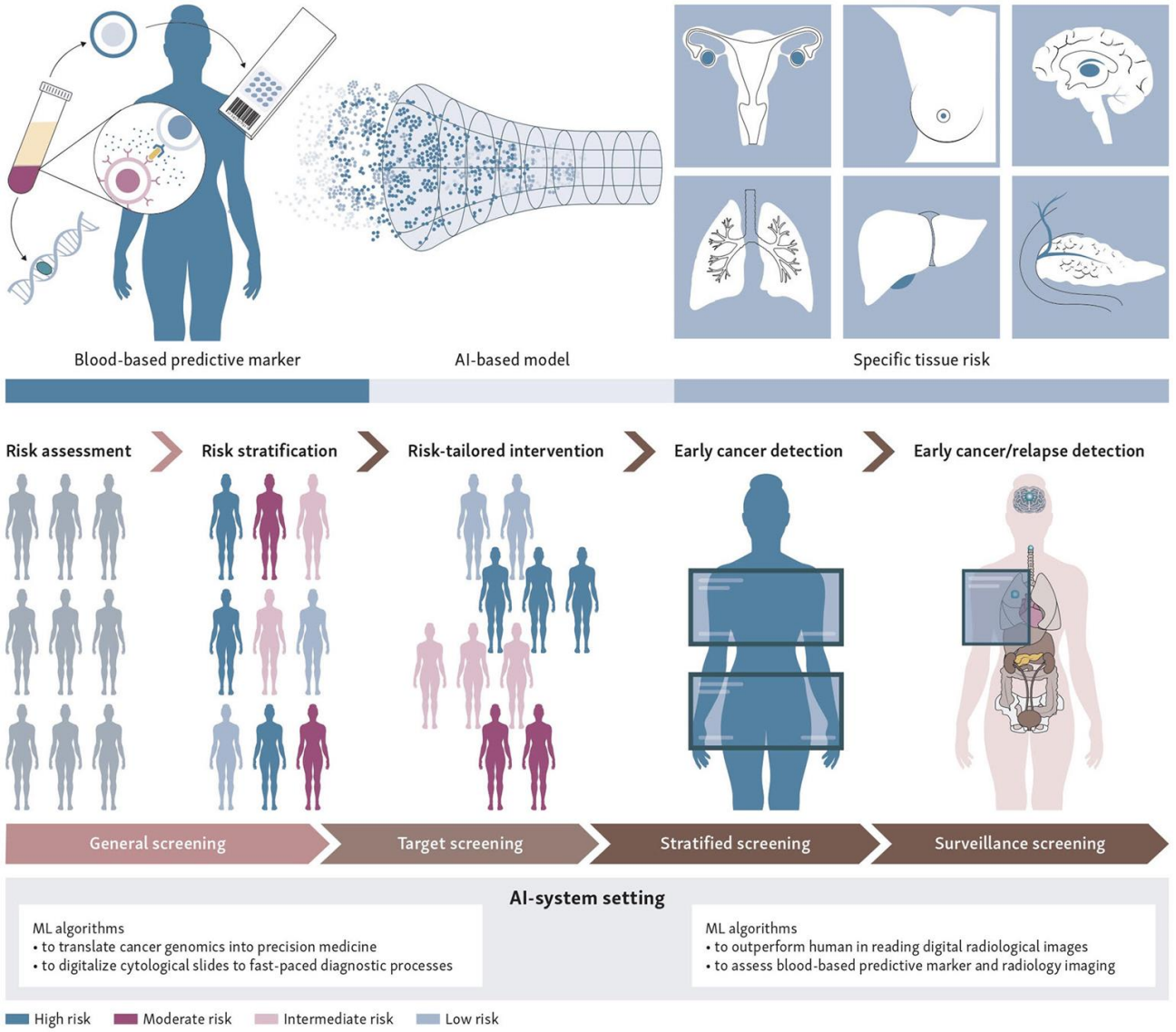


- 6 custom-fitted t-shirt prototypes
- 3 participants (one male and two female)
- body measurements were retrieved using a **Size Stream 3D body scanner**

Satin Stitch Type
Silver-plated Madeira
HC 12 (<100 W /m)

Circulating Signatures

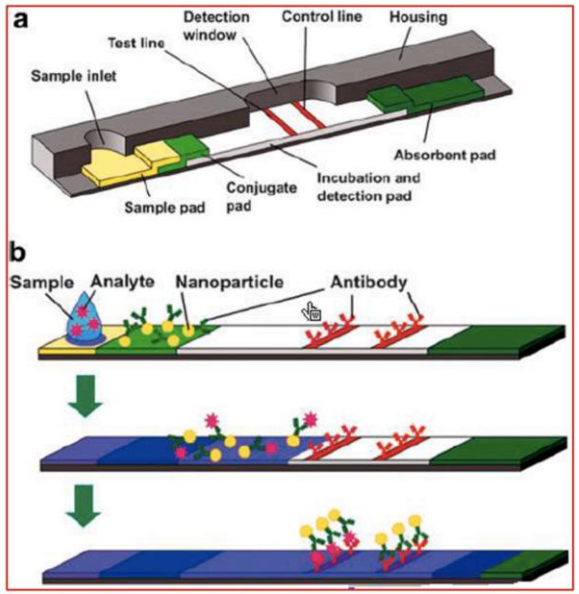




Saha et al., 2022. *Journal of the Egyptian National Cancer Institute*
Gentile & Malara 2024. *ESMO Real World Data and Digital Oncology*

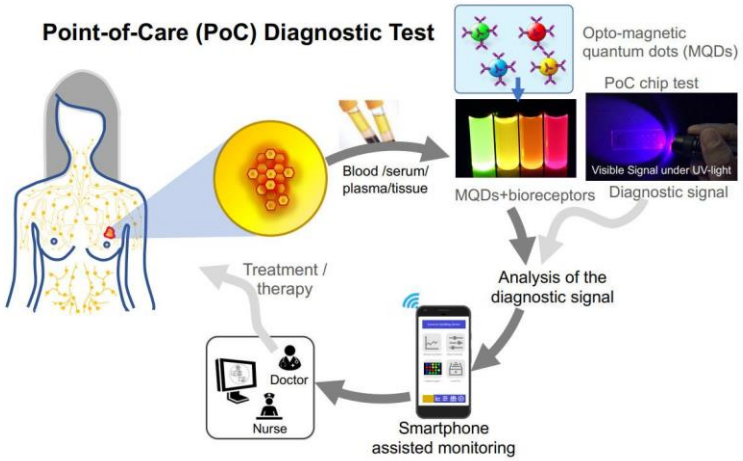
Point of Care Tests (POC)

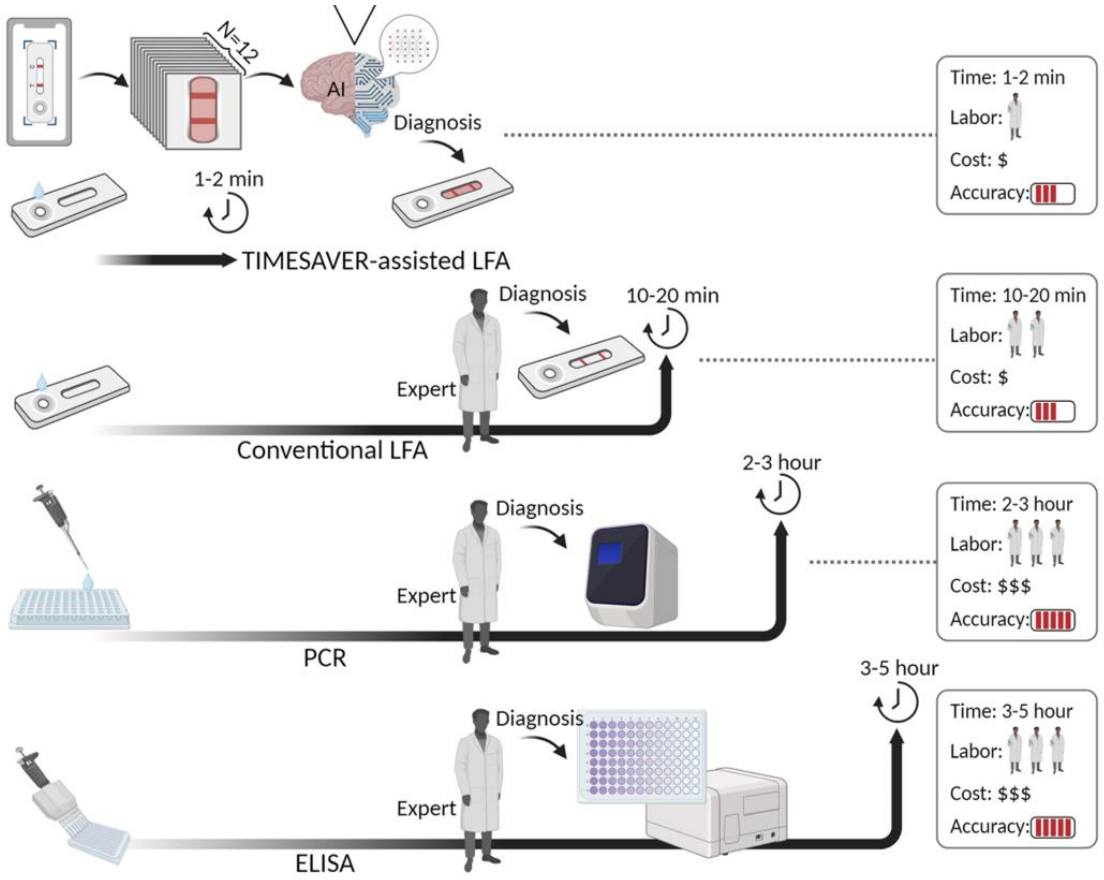
Lateral Flow Kits



provide a rapid initial diagnosis

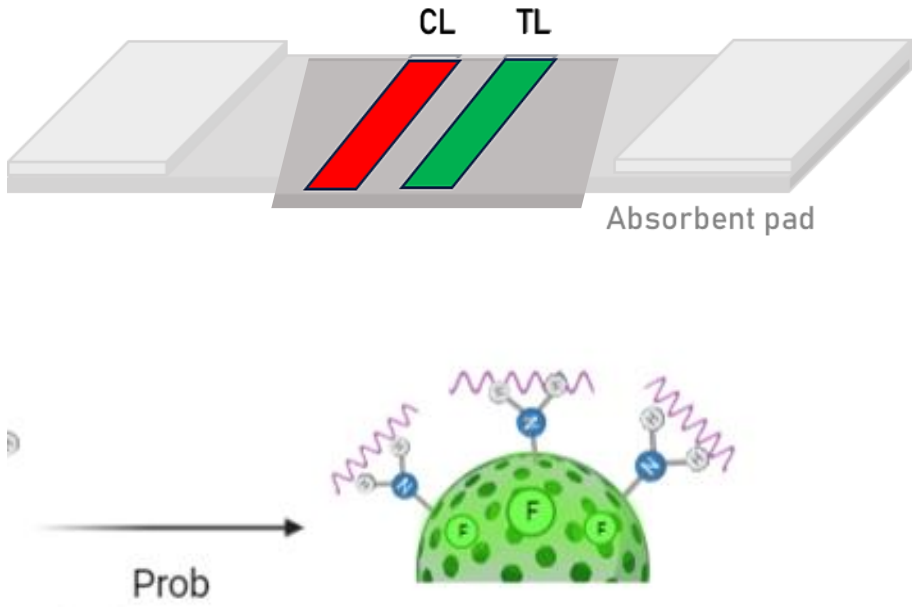
enabling prompt, early, and proper management due to its shorter turnaround time

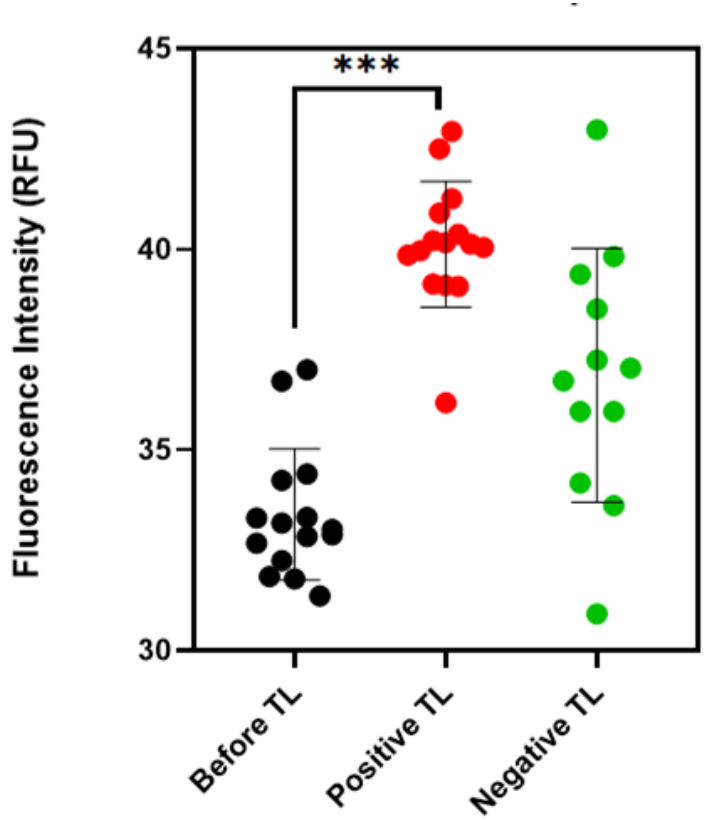


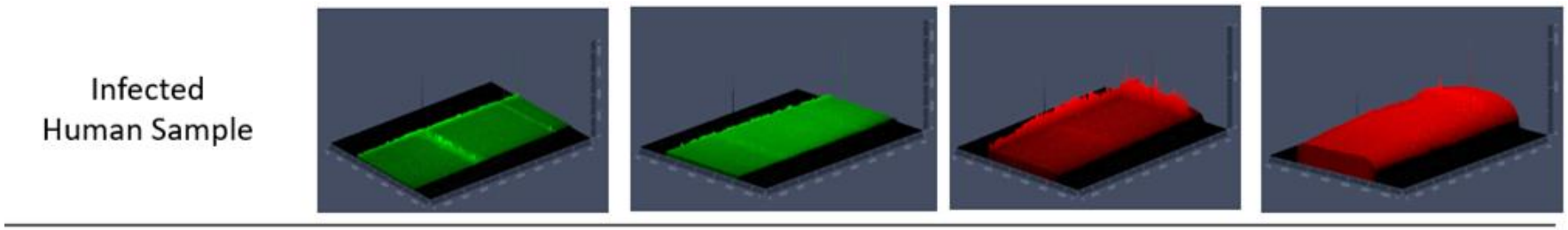


Example: Nucleic acid based POC

Swap samples



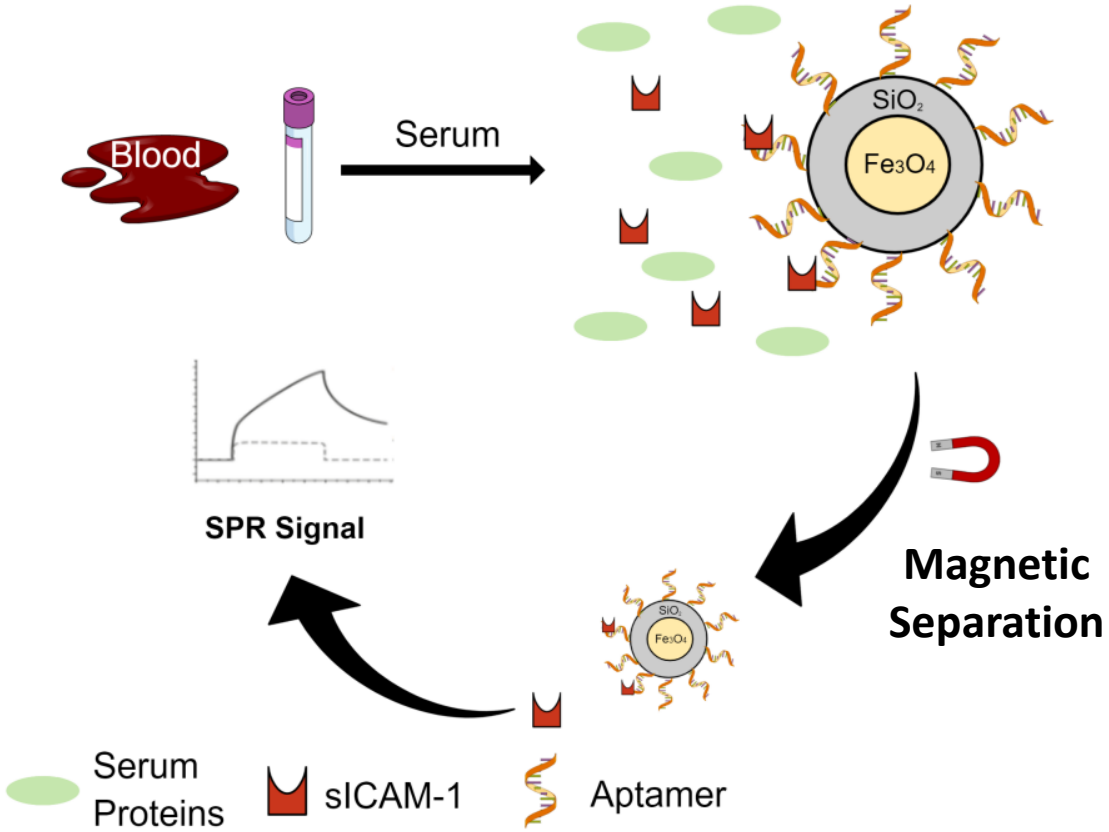


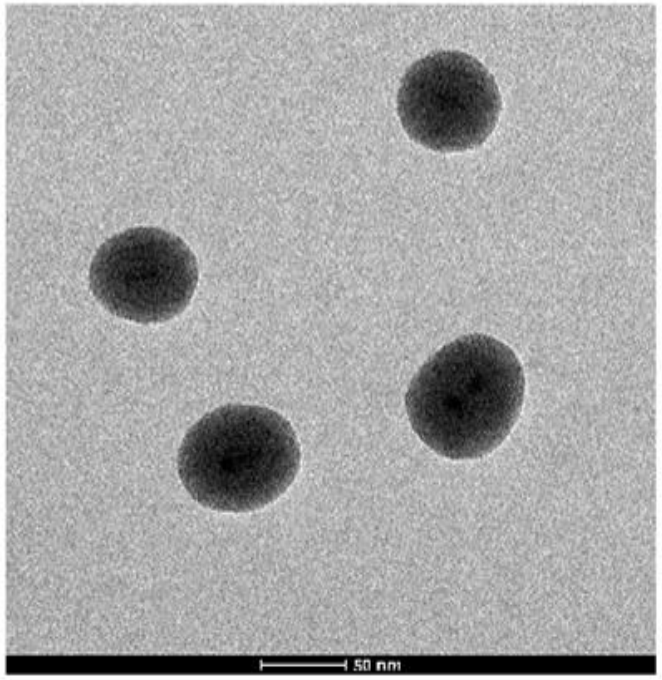


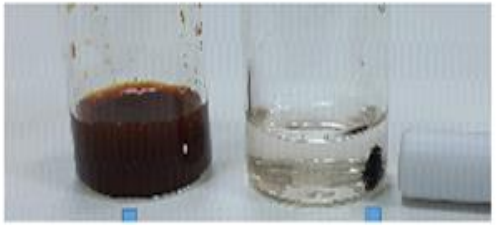
(Tuna et al., Talanta 2022, Durdabak et al., ChemistryOpen 2023)

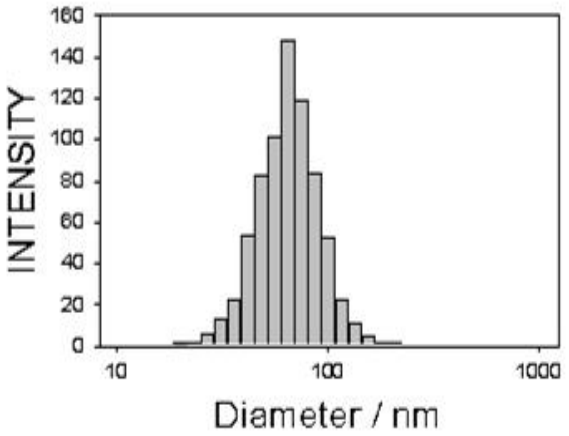
Example: Soluble ICAM-1 protein with aptasensor

Soluble ICAM-1 (sICAM-1): a biomarker for cancer metastases









TEM Fe_3O_4@SiO_2 nanoparticles

Aptasensor limit of detection (LOD) 1.4 ÷ 0.2 ng ml^{-1}

Based on knowledge from today:

Group 1-2:

- Designing for Sensory Needs: What Would a ‘Perfect’ Wearable Look Like? (List 3 features a cancer-screening wearable must have)

Group 3-4:

- Which type of biological sample would be better for screening? (saliva, blood, stool ..?)

Group 5-6:

- How Can Clinicians and Tech Developers Collaborate Better? (practical step to bridge communication gaps between disability advocates and engineers creating point-of-care tests)

Key Learning Takeaways from this Session

- Insights into how technological interventions can be used in relation to cancer screening access
- Different sub-populations might have a distinct properties
- Output and points from group discussions

Thank you for listening

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Dr. Bilge G. Tuna and Dr. Soner Doğan Groups

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TÜBA
TÜRKİYE BİLİMLER AKADEMİSİ
TURKISH ACADEMY OF SCIENCES

PANDORA IG17104

Nano2Clinic
Cancer Nanomedicine - from the bench to the bedside

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Cancer screening and inequity

Dr Mairead O'Connor, The National Screening Service

and

Professor Cara Martin, Trinity College Dublin and Trinity St James Cancer Institute

CUPID
Cancer - Understanding Prevention in Intellectual Disabilities

Institiúid Ailse Choláiste na Tríonóide/San Séamas
Trinity St James's Cancer Institute

Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

An tSeirbhís Náisiúnta Scagthástála
National Screening Service

COST Action CA21123
Cancer- Understanding Prevention in Intellectual Disabilities (CUPID)

30/05/2025

Outcomes from today's session

By the end of this session, you will:

1) Have an understanding of why inequities exist in cancer screening programmes through exploring the equity in screening framework

2) Understand the elements that cancer screening programmes need to consider to help facilitate participation among people with intellectual disabilities

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Background

- **Objective of screening the population:**
  - ✓ Reduce morbidity and mortality in the population through early detection of disease and treatment.
  - ✓ Identify those people amongst an apparently healthy population (asymptomatic) who may have an increased chance of cancer.
- **Screening test:**
  - ✓ A screening test is designed for populations of individuals who have no symptoms of disease and aims to identify those with a risk marker for a disease and ensure early treatment.
- **Screening programmes:**
  - ✓ Screening programmes are operated on a call /re-call system.

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Background

- The National Screening Service (NSS) runs 3 national population-based cancer screening programmes in Ireland:

BreastCheck
An Clár Náisiúnta Scagthástála Cioch
The National Breast Screening Programme

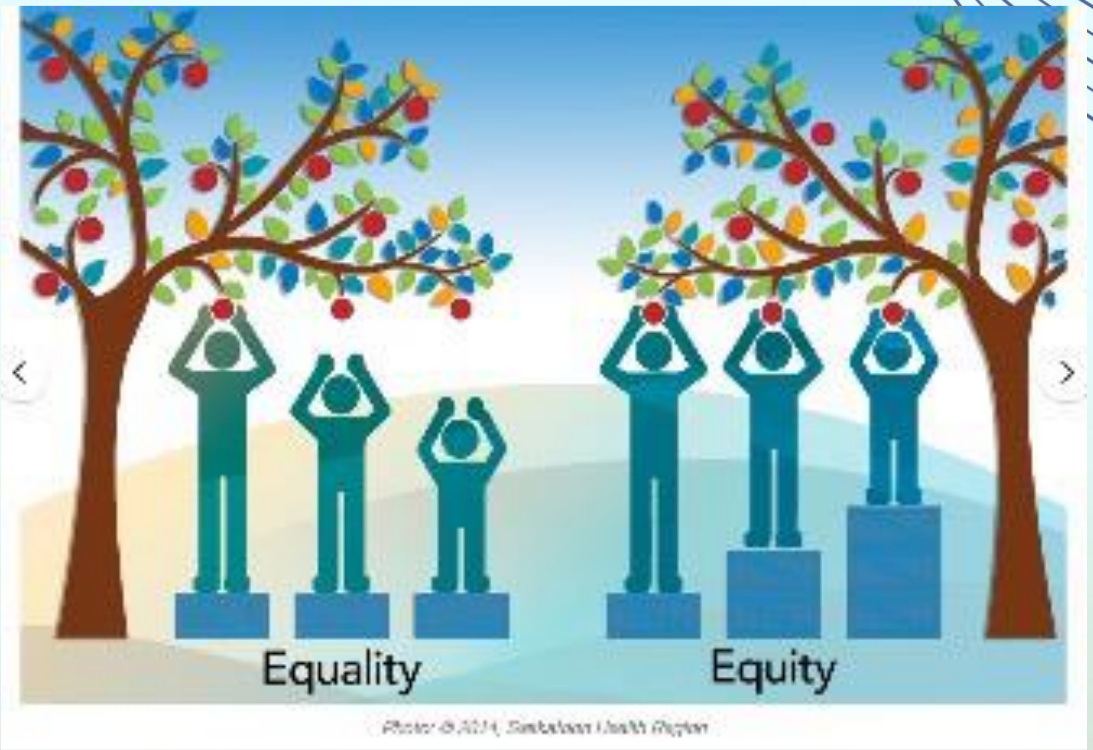
CervicalCheck
AN CLÁR NÁISIÚNTA SCAGTHÁSTÁLA CEIRBHEACS
IRELAND'S NATIONAL CERVICAL SCREENING PROGRAMME

BowelScreen
An Clár Náisiúnta Scagthástála Putóige
The National Bowel Screening Programme

Health Equity

What is (health) equity?

*"**Health equity** is when everyone has the opportunity to be as healthy as possible. Health inequities are differences in health status between population groups that are socially produced, systematic in their unequal distribution across the population, avoidable and unfair."*



The equity in screening framework

- ✓ Sets out how we can better understand and improve equity in cancer screening
- ✓ Developed with a wide range of stakeholders including screening participants, representatives from the community, voluntary and statutory sectors, and our staff.
- ✓ Aims to better understand and address the barriers people experience across the screening pathway

National Screening Service Improving equity in screening A STRATEGIC FRAMEWORK 2023-2027. Improving equity in screening: A strategic framework 2023-2027 - Corporate

Inequity in cancer screening:
Factors associated with reduced participation in screening

Type of screening	Bowel Screening	Breast Screening	Cervical Screening
Characteristic			
Gender (male)	● 20, 21	NA	NA
Older age			●
Urban			
Deprivation *Pobal HP Index*	● 20		
Medical card			
Low education		● 23	
Unemployed		● 23	
Health status*		● 23	
Travellers *Co. Clare study*	● 22	● 22	● 22
Intellectual disability		● 25	
LGBTQI+			● 27

Other factors associated with reduced participation:

- Having a physical disability
- Being from a minority background/ethnic minority
- Age (e.g. in Ireland women over 50 are less likely to participate in cervical screening)

National Screening Service Improving equity in screening A STRATEGIC FRAMEWORK 2023-2027. Improving equity in screening: A strategic framework 2023-2027 - Corporate

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Barriers to participation in screening programmes

BreastCheck BowelScreen DiabeticRetina Screen CervicalCheck

Psychological Barriers				
Barrier	Programme			
Trust and confidence in the service	●	●	●	
Attitudes & behaviours (shame, guilt, embarrassment, violation & disgust)	●	●	●	●
Fear & anxiety of the test or results	●	●	●	●
Fatalism		●		●
Fear of burdening family		●		●
Lack of coping skills	●			●
Painful procedure	●	●	●	●
Not a priority			●	●
Self-esteem/self-confidence	●			
Forgetting appointments/lack of reminders		●		
Privacy		●		●
Belief that screening test is not accurate		●	●	●
Cognitive Barriers				
Not knowing how to conduct the test		●		
Knowledge, awareness and understanding	●	●	●	●
Perception of risk	●	●	●	●
Health/cancer literacy	●	●	●	●
Language			●	●

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Barriers to participation in screening programmes

Structural Barriers				
Transport		●	●	●
Availability of appointments/opening hours			●	●
Waiting times/lists			●	●
Locations		●	●	●
Availability/consistent Healthcare Professional (HCP)		●	●	●
Lack of pathology services				●
Male physicians/HCP	●		●	●
Insufficient medical advice/lack of physian recommendation		●	●	●
Social/cultural Barriers				
Age		●		●
Relationships – spousal, family, friends, mother, HCP		●	●	●
Social acceptability				●
Discrimination/stigma			●	●
Religious beliefs	●	●		●
Education level	●	●		●
Employment status	●			●
Low income	●	●		●
Financial Barriers				
Transport			●	●
Loss of income			●	
Cost of childcare			●	●

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The equity in screening framework

- ✓ Framework consists of 5 priority areas
- ✓ These are broad areas that the NSS needs to work on to address the inequities being experienced.

National Screening Service Improving equity in screening A STRATEGIC FRAMEWORK 2023-2027. Improving equity in screening: A strategic framework 2023-2027 - Corporate

The equity in screening framework

- Building evidence – conducting research
- Educating screening providers
- Improving accessibility to screening for those who face barriers
- Methods and channels of communicating about screening

National Screening Service Improving equity in screening A STRATEGIC FRAMEWORK 2023-2027. Improving equity in screening: A strategic framework 2023-2027 - Corporate

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Instructions

- 10-11 people per table.
- Each table are allocated one of 4 priority areas from the equity framework:
  1. Research & Data
  2. Education, training & development
  3. Accessibility & inclusivity
  4. Communications

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What do you think should be a priority (or priorities) for people with intellectual disabilities?

Instructions

- 15 minutes for discussion in your group.
- Contribute your ideas and thinking.
- Listen to others at your table.
- Use the whiteboard, pens and post it notes.
- Nominate one person to report back (3 minutes max).

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

Martin McMahon, Samantha Flynn, Samantha A Johnson, Chris Stinton

Learning objectives

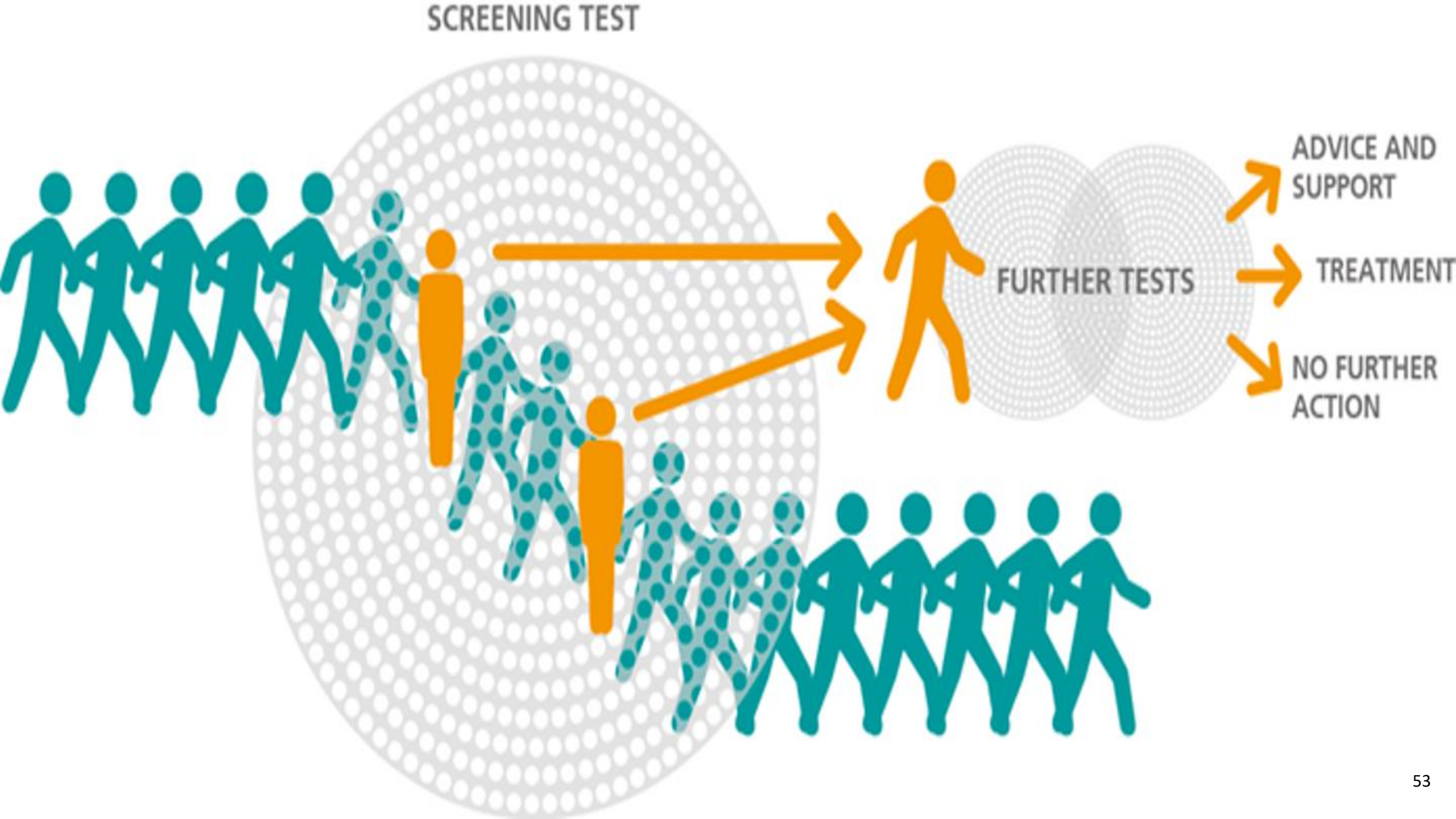
- Know about the evidence on health outcomes of cancer screening programmes for adults with intellectual disability.
- Know how to conduct a systematic review.
- Have critiqued a systematic review.

Cancer among adults who have intellectual disabilities

- People with intellectual disabilities have a unique cancer profile.
- Cancer is a common cause of death for people who have intellectual disabilities.
- Late-stage cancer diagnosis is common, when it is less amenable to treatment.

Screening for cancers

- Screening is “an organized programme of identifying **apparently healthy** people in a **defined population** who may be at increased risk of a disease or condition in order to offer information, further tests or appropriate treatment **to reduce risk** or complications arising from the disease or condition.”

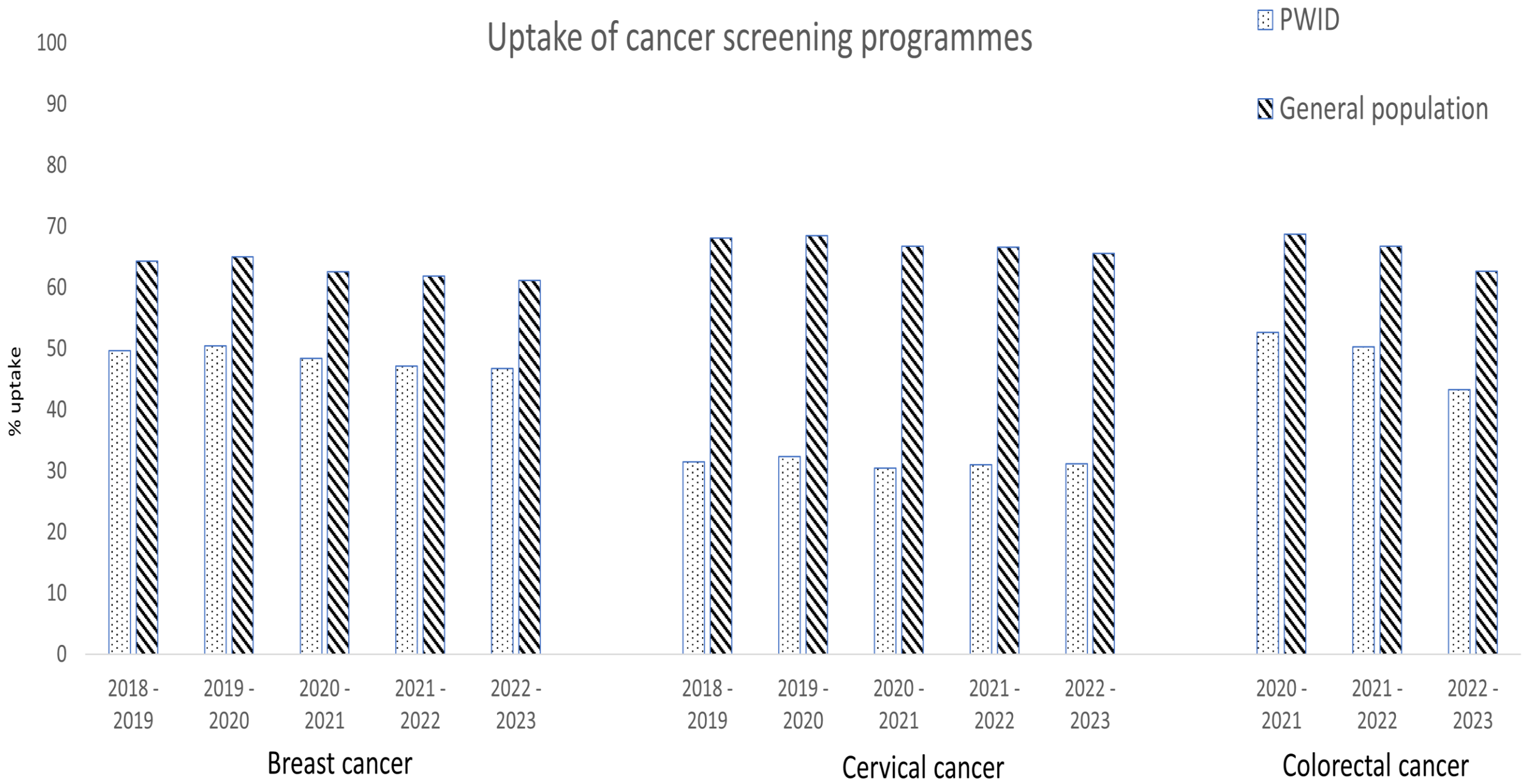

SCREENING TEST
FURTHER TESTS
ADVICE AND SUPPORT
TREATMENT
NO FURTHER ACTION

Screening for cancers

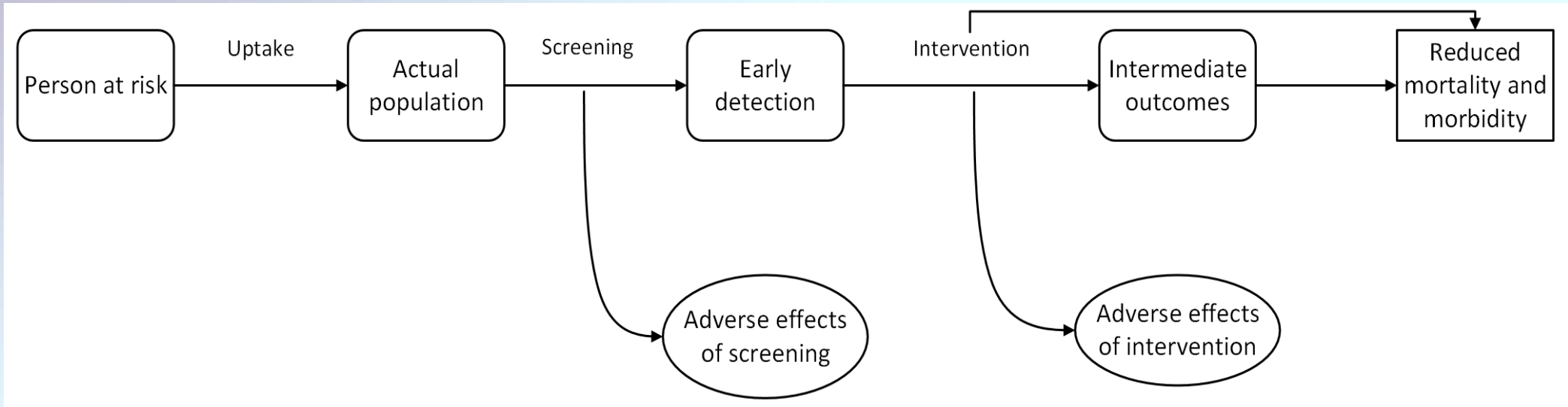
- Current UK cancer screening programmes:
  - Breast cancer
  - Cervical cancer
  - Colorectal cancer
  - (Targeted) lung cancers

Screening for cancers among adults who have intellectual disabilities

- Access to and outcomes of screening are not equal among the different groups of people who are invited.


Uptake of cancer screening programmes
PWID
General population
% uptake
100
90
80
70
60
50
40
30
20
10
0
2018 - 2019
2019 - 2020
2020 - 2021
2021 - 2022
2022 - 2023
Breast cancer
2018 - 2019
2019 - 2020
2020 - 2021
2021 - 2022
2022 - 2023
Cervical cancer
2020 - 2021
2021 - 2022
2022 - 2023
Colorectal cancer

(Rough) screening pathway



Screening

"All screening programmes do harm; some do good as well, and, of these, some do more good than harm at reasonable cost"

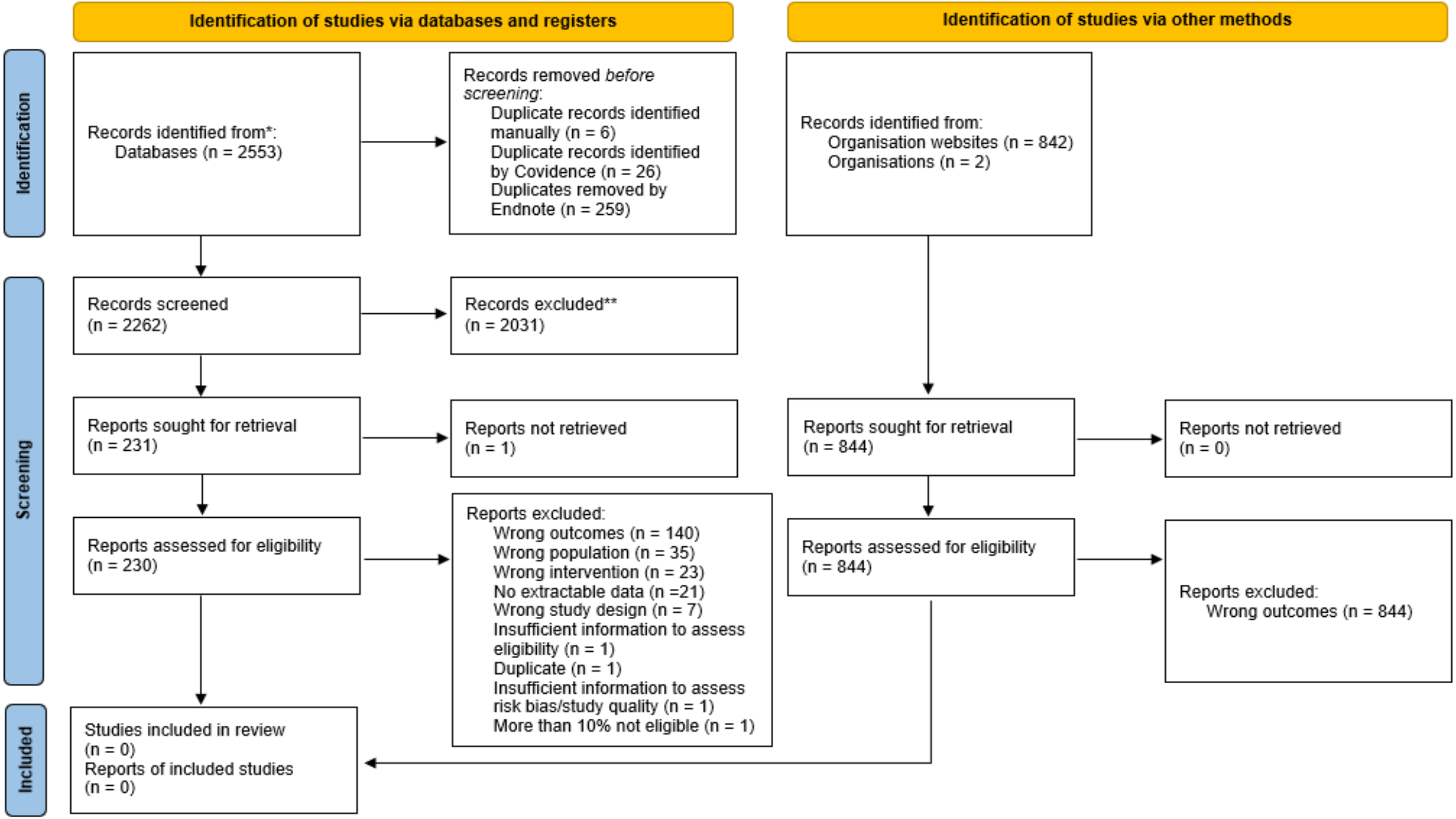
Gray et al. Maximising benefit and minimising harm of screening. BMJ. 2008 336(7642):480-3

A systematic review of health outcomes of cancer screening programmes for people who have intellectual disabilities

Research questions

1. What are the health outcomes of cancer screening programmes for adults who have intellectual disabilities?
2. What are the harms of cancer screening programmes for adults who have intellectual disabilities

Element of review	Our process
Review registration	Open Science Framework (https://osf.io/8vmkb)
Sources of evidence	Electronic databases Intellectual disabilities + cancer organisation websites Asking experts Reference lists of included studies and relevant reviews
Eligibility criteria	**Population**: adults who have an intellectual disabilities and do not have bowel, breast or cervical cancer **Target conditions**: bowel, breast, cervical cancer **Intervention**: population or targeted screening for the above cancers **Comparator**: alternative screening strategy, no screening **Outcomes**: mortality, morbidity, harms of screening **Study design**: any **Language**: English **Exclusions**: children and young people (17 years and younger); opportunistic screening, case-finding, one-off testing, routine examinations, insufficient reporting of methods or results, no quantitative results, non-English languages, reviews
Review strategy	Two reviewers independently assessing titles and abstract, then full texts of *potentially* relevant documents
Data extraction	Two reviewers independently extracting into piloted extraction form
Assessing risk of bias	Two reviewers independently, using tools that are appropriate to the study design


Identification of studies via databases and registers
Identification of studies via other methods
Identification
Screening
Included
Records identified from*:
Databases (n = 2553)
Records removed *before screening*:
Duplicate records identified manually (n = 6)
Duplicate records identified by Covidence (n = 26)
Duplicates removed by Endnote (n = 259)
Records identified from:
Organisation websites (n = 842)
Organisations (n = 2)
Records screened
(n = 2262)
Records excluded**
(n = 2031)
Reports sought for retrieval
(n = 231)
Reports not retrieved
(n = 1)
Reports sought for retrieval
(n = 844)
Reports not retrieved
(n = 0)
Reports assessed for eligibility
(n = 230)
Reports excluded:
Wrong outcomes (n = 140)
Wrong population (n = 35)
Wrong intervention (n = 23)
No extractable data (n =21)
Wrong study design (n = 7)
Insufficient information to assess eligibility (n = 1)
Duplicate (n = 1)
Insufficient information to assess risk bias/study quality (n = 1)
More than 10% not eligible (n = 1)
Reports assessed for eligibility
(n = 844)
Reports excluded:
Wrong outcomes (n = 844)
Studies included in review
(n = 0)
Reports of included studies
(n = 0)

A systematic review of health outcomes of cancer screening programmes for people who have intellectual disabilities

- We found 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.

Critiquing a systematic review – what have we missed or could have done differently?

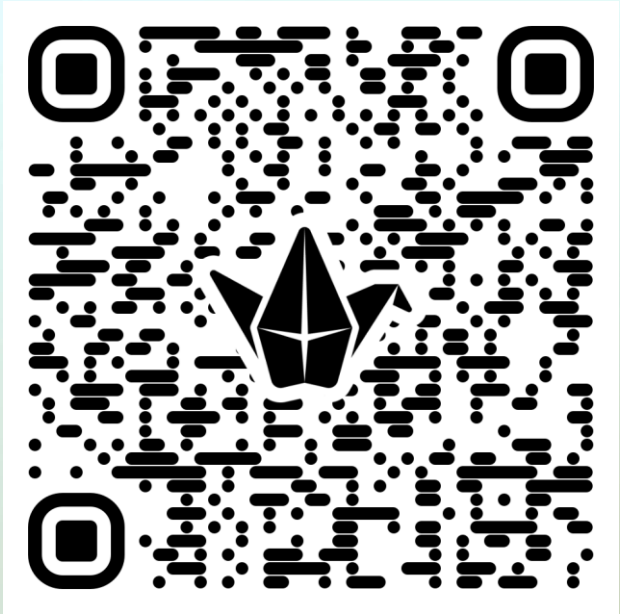
Intellectual disabilities?

Screening?

Systematic review methodology?

Anything else?

Please access our Padlet to post your critiques (anonymously!):



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

14.00 pm – 14.45pm

Professor Lau Caspar Thygesen, Research Assistant Trine Toft Sørensen, and Associate Professor Trine Allerslev Horsbøl

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By the end of this session, you will:

1. Have a greater understanding of the inequalities in cancer screening across groups of individuals with different levels of intellectual disability severity.
2. Have discussed the implications of national screening policies / guidelines on the needs of people with intellectual disability.

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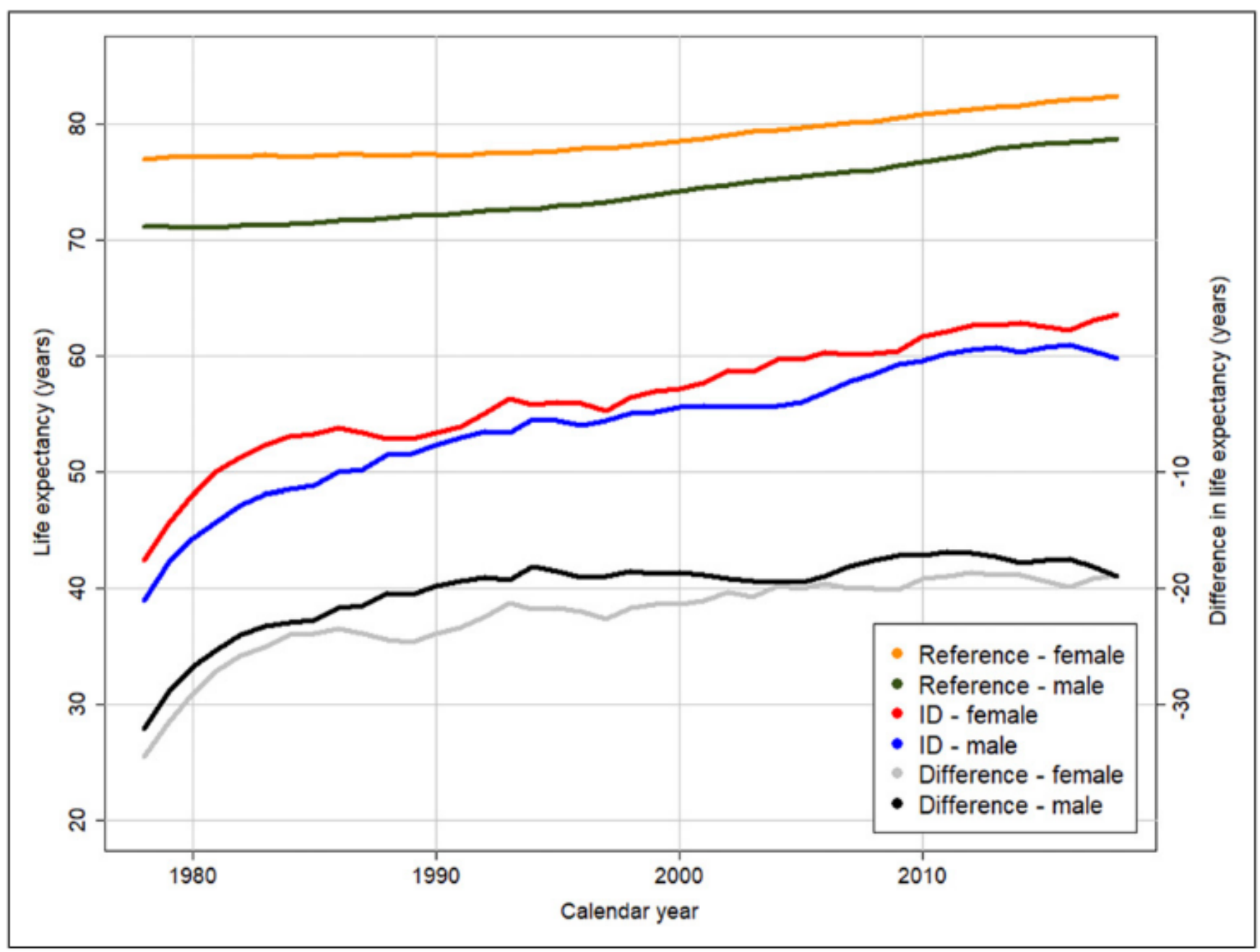
Life expectancy



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Thygesen et al. J Intellect Disabil 2024;28:359-371

Nationwide cohort study

Utilized several nationwide Danish registers to establish the cohort

- Somatic and psychiatric hospital diagnoses
- Diagnoses from the Danish Cerebral Palsy Registry
- Register of disability pensions
- Danish Register of Causes of Death
- Residential addresses of persons with ID

Matched with 10 persons without ID on sex and date of birth

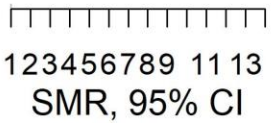
European Journal of Public Health, Vol. 34, No. 6, 1225–1231

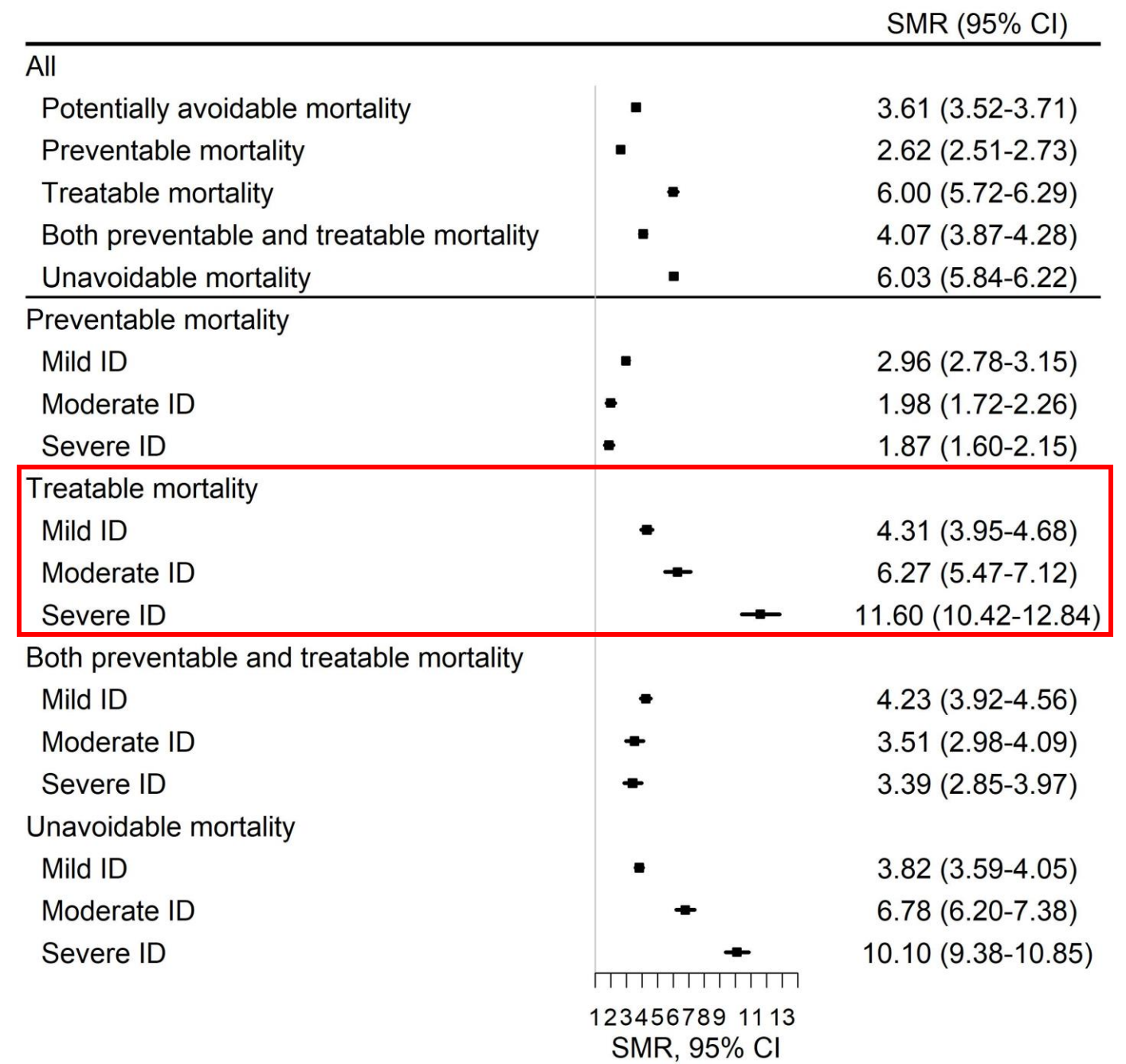
https://doi.org/10.1093/eurpub/ckae118 Advance Access published on 6 August 2024

Potentially avoidable mortality among adults with intellectual disability

Lau Caspar Thygesen [1,*], Marie Borring Klitgaard [1], Anne Sabers [2], Jakob Kjellberg [3], Jens Søndergaard [4], Jeppe Sørensen [5], Marie Sonne [6], Knud Juel [1], Susan Ishøy Michelsen [1]

	SMR (95% CI)
All	
Potentially avoidable mortality	3.61 (3.52-3.71)
Preventable mortality	2.62 (2.51-2.73)
Treatable mortality	6.00 (5.72-6.29)
Both preventable and treatable mortality	4.07 (3.87-4.28)
Unavoidable mortality	6.03 (5.84-6.22)




SMR (95% CI)
All
Potentially avoidable mortality
3.61 (3.52-3.71)
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Treatable mortality
6.00 (5.72-6.29)
Both preventable and treatable mortality
4.07 (3.87-4.28)
Unavoidable mortality
6.03 (5.84-6.22)
Preventable mortality
Mild ID
2.96 (2.78-3.15)
Moderate ID
1.98 (1.72-2.26)
Severe ID
1.87 (1.60-2.15)
Treatable mortality
Mild ID
4.31 (3.95-4.68)
Moderate ID
6.27 (5.47-7.12)
Severe ID
11.60 (10.42-12.84)
Both preventable and treatable mortality
Mild ID
4.23 (3.92-4.56)
Moderate ID
3.51 (2.98-4.09)
Severe ID
3.39 (2.85-3.97)
Unavoidable mortality
Mild ID
3.82 (3.59-4.05)
Moderate ID
6.78 (6.20-7.38)
Severe ID
10.10 (9.38-10.85)
1 2 3 4 5 6 7 8 9 11 13
SMR, 95% CI

Cancer incidence (breast cancer)

Standardized incidence ratios (SIRs) for breast cancer for the entire ID cohort and stratified by ID level, 1978-2021

Cohort	Observed	Expected	SIR (95% CI)
Entire ID cohort	777	854	0.91 (0.85-0.97)
Mild	333	370	0.91 (0.81-1.00)
Moderate to profound	165	162.2	1.02 (0.86-1.18)
Unknown/other	279	337.5	0.83 (0.73-0.92)

Cancer incidence (colon cancer and rectal cancer)

Standardized incidence ratios (SIRs) for colon cancer and rectal cancer for the entire ID cohort and stratified by ID level, 1978-2021

Colon cancer

Cohort	Observed	Expected	SIR (95% CI)
Entire ID cohort	432	434.9	0.99 (0.90-1.09)
Mild	192	196.2	0.98 (0.84-1.12)
Moderate to profound	80	80.6	0.99 (0.78-1.22)
Unknown /other	160	170.6	0.94 (0.80-1.08)

Rectal cancer

Cohort	Observed	Expected	SIR (95% CI)
Entire ID cohort	194	237.3	0.82 (0.70-0.94)
Mild	86	107.4	0.80 (0.63-0.98)
Moderate to profound	31	45.3	0.68 (0.46-0.93)
Unknown /other	77	94.4	0.82 (0.64-1.01)

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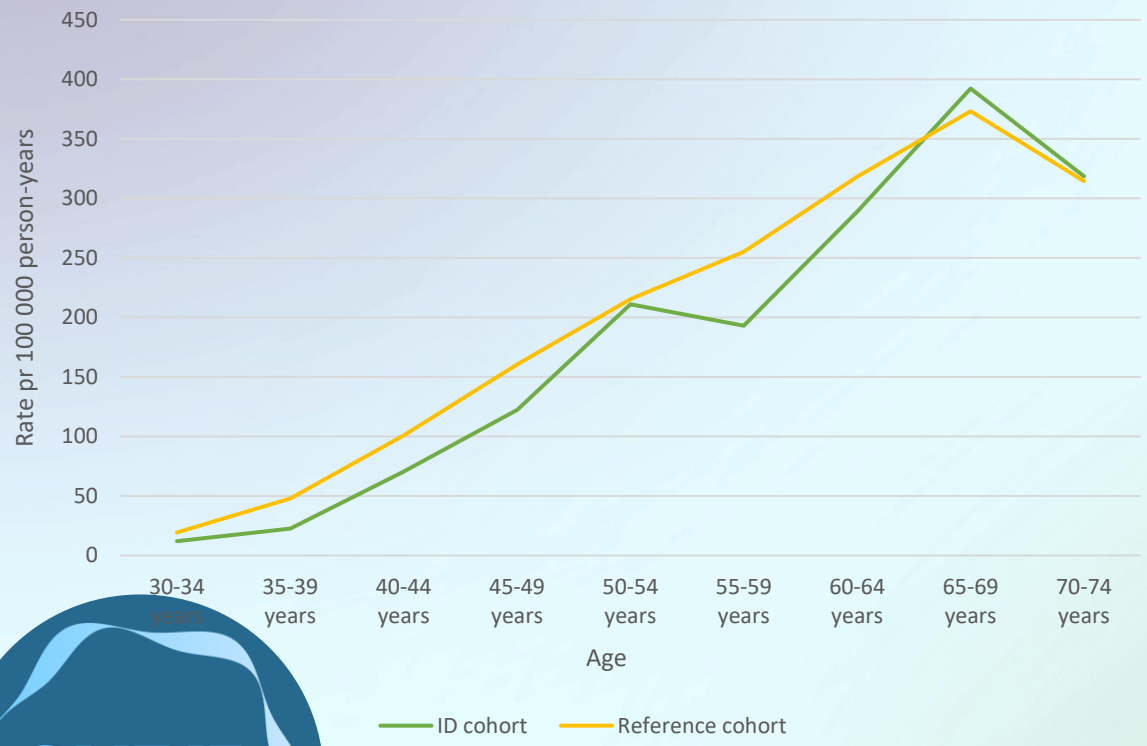
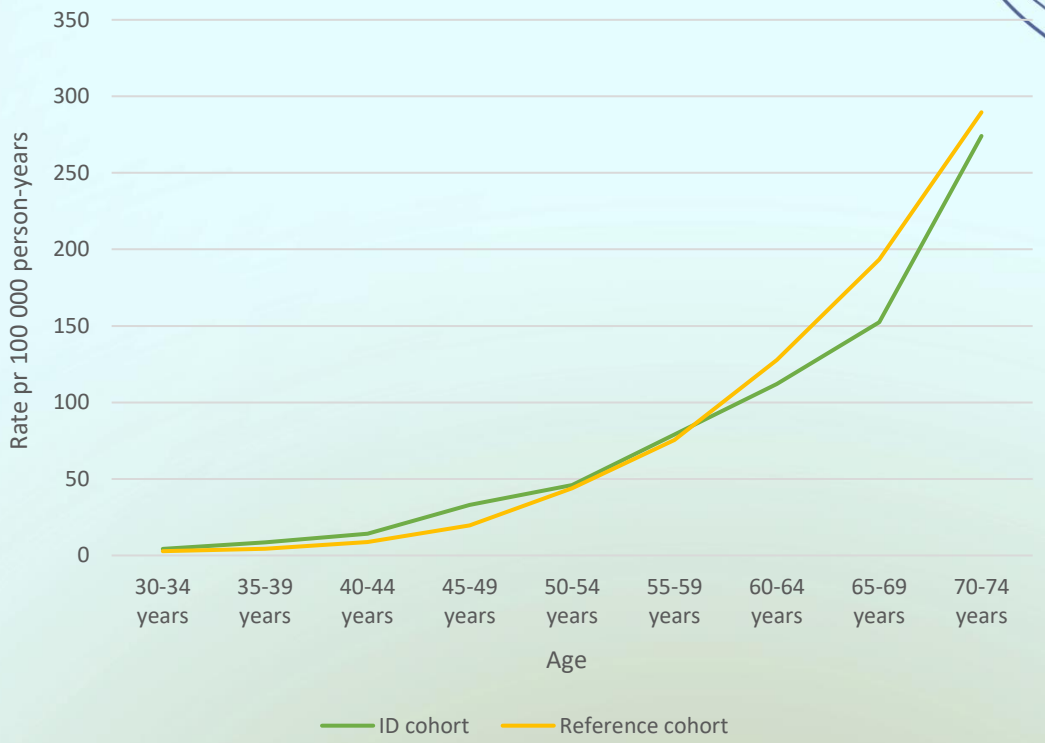
Age-specific incidence rates, 1978-2021

Colorectal cancer



Breast cancer



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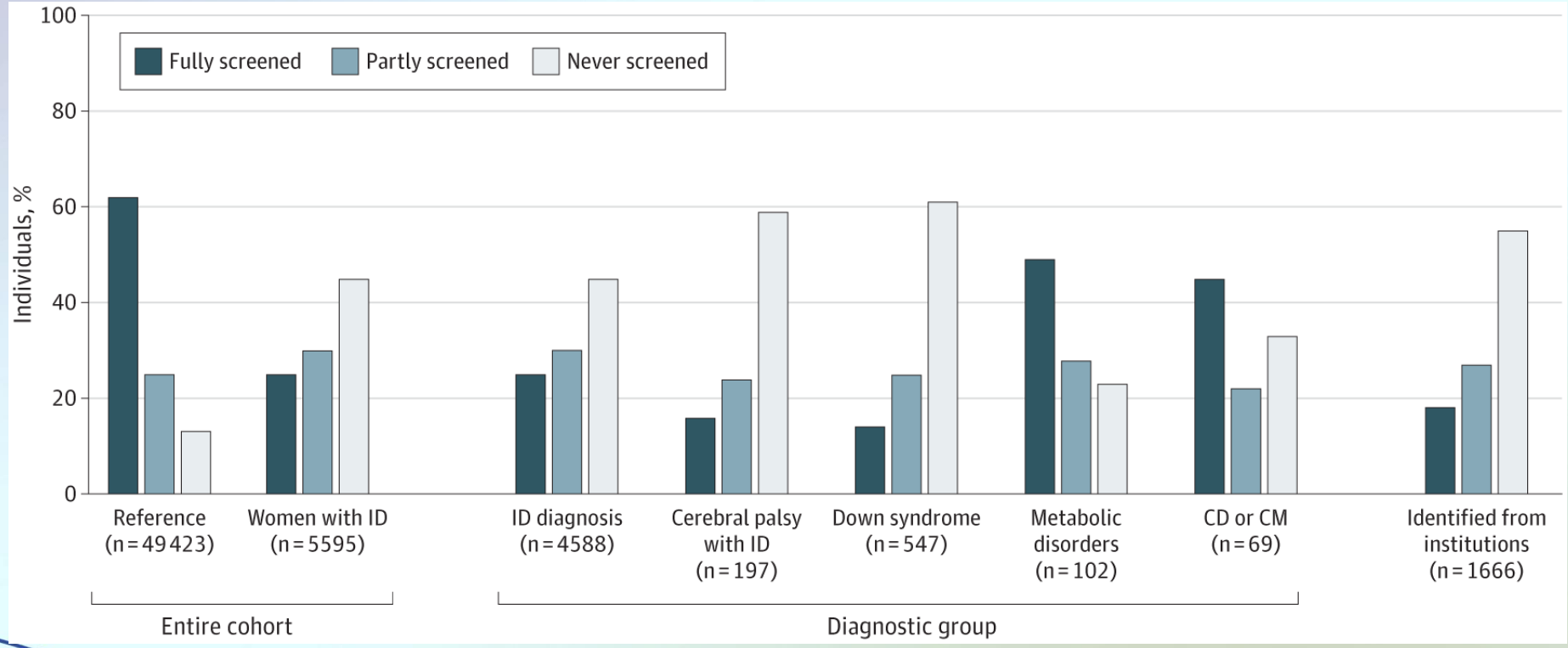
Unpublished results!

Breast cancer screening in Denmark

Information about the Danish breast cancer screening programme

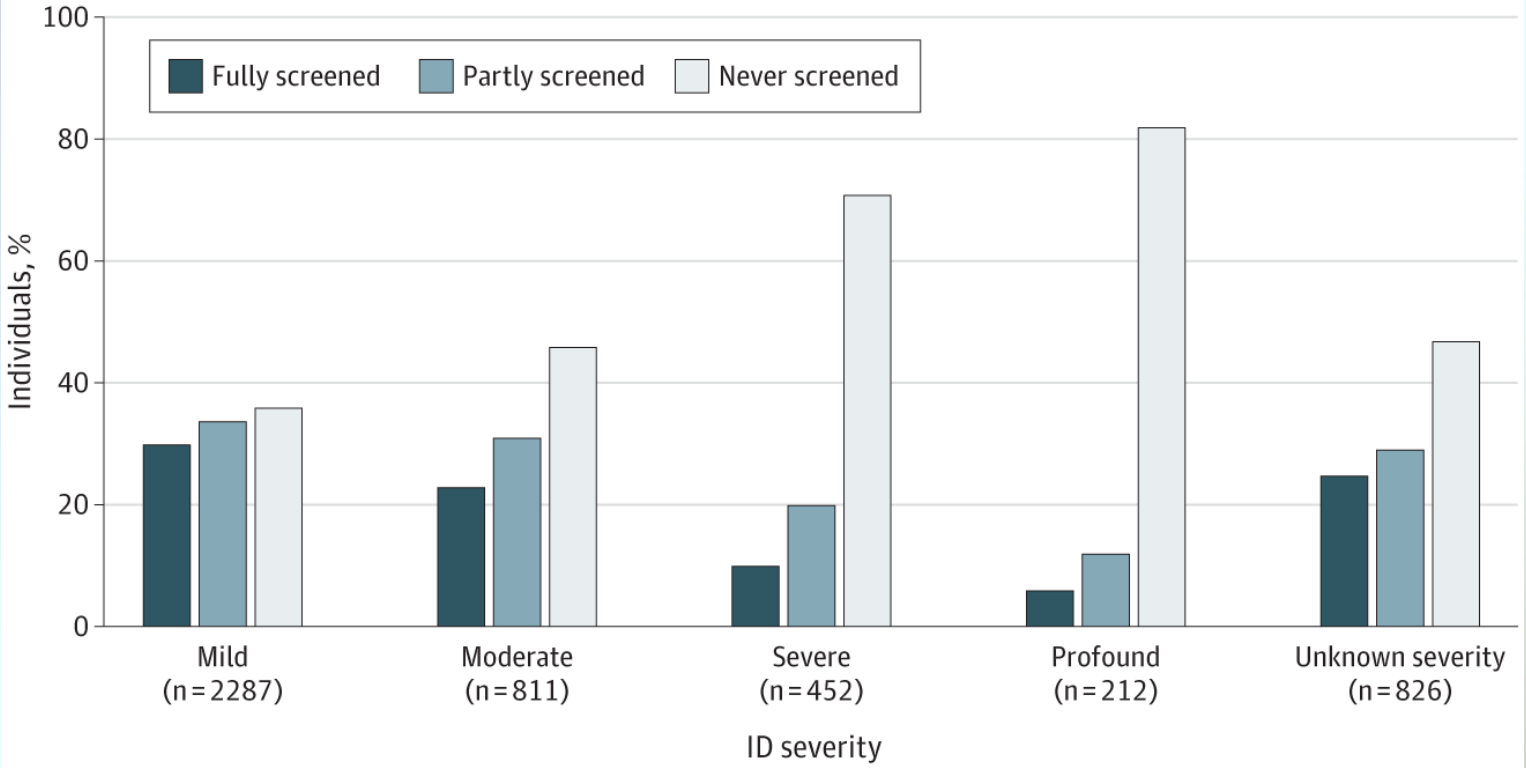
- Initiated in 2007 and fully implemented at the end of 2010
- All women aged 50-69 years are offered screening for breast cancer every second year
- The screening includes a mammography of both breasts
- Women are invited electronically unless they actively unregister from the program

Breast cancer screening participation



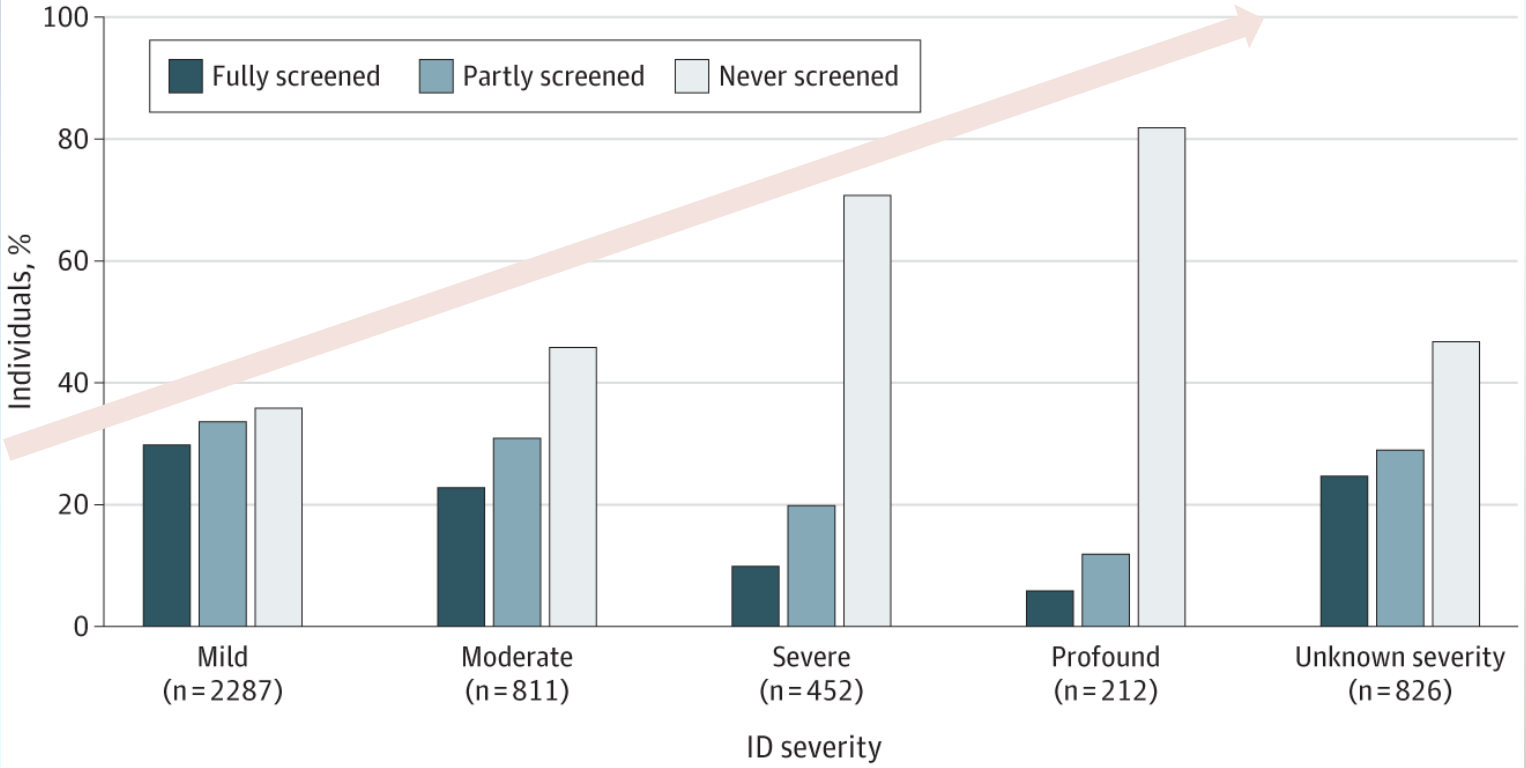
Horsbøl TA et al. Breast Cancer Screening Among Women With Intellectual Disability in Denmark. JAMA Netw Open. 2023;6(1):e2248980. doi:10.1001/jamanetworkopen.2022.48980

Screening participation by ID Severity



Horsbøl TA et al. Breast Cancer Screening Among Women With Intellectual Disability in Denmark. JAMA Netw Open. 2023;6(1):e2248980. doi:10.1001/jamanetworkopen.2022.48980

Screening participation by ID Severity



Horsbøl TA et al. Breast Cancer Screening Among Women With Intellectual Disability in Denmark. JAMA Netw Open. 2023;6(1):e2248980. doi:10.1001/jamanetworkopen.2022.48980

Bowel cancer screening in Denmark

Information about the Danish bowel cancer screening programme

- Initiated in 2014 and fully implemented at the end of 2018
- All people aged 50-74 years are offered screening for bowel cancer every second year
- The screening includes:
  - A home-based stool sample that is returned by mail and analyzed using a fecal immunochemical test (FIT-test) to detect invisible amounts of blood
  - People with a positive FIT-test are invited to a colonoscopy by mail

Bowel sample and result

Received first invitation	
ID	Non-ID
17 117	149 162

Unpublished results!

Bowel sample and result

Received first invitation

ID	Non-ID
17 117	149 162

Bowel sample within 90 days

ID	Non-ID	Difference	95% CI
30·2 %	56·1 %	-23·2 %	-24·0 %; -22·4 %

Bowel sample and result

Received first invitation	
ID	Non-ID
17 117	149 162

Bowel sample	
ID	Non-ID
5 894	91 046

Bowel sample within 90 days			
ID	Non-ID	Difference	95% CI
30·2 %	56·1 %	-23·2 %	-24·0 %; -22·4 %

Unpublished results!

Bowel sample and result

Received first invitation

ID	Non-ID
17 117	149 162

Bowel sample

ID	Non-ID
5 894	91 046

Bowel sample within 90 days

ID	Non-ID	Difference	95% CI
30·2 %	56·1 %	-23·2 %	-24·0 %; -22·4 %

Result first FIT-test

ID	Non-ID
Positive	
8·2 %	5·7 %
Negative	
90·0 %	93·9 %
Not analyzable	
1·8 %	0·4 %

Unpublished results!

Completion of colonoscopy

Positive FIT-test	
ID	Non-ID
492	5 237

Unpublished results!

Completion of colonoscopy

Positive FIT-test	
ID	Non-ID
492	5 237

Colonoscopy within 60 days			
ID	Non-ID	Difference	95% CI
70·5 %	90·2 %	-17·9 %	-22·1 %; -17·7 %

Unpublished results!

Completion of colonoscopy

Positive FIT-test	
ID	Non-ID
492	5 237

Colonoscopy	
ID	Non-ID
387	4878

Colonoscopy within 60 days			
ID	Non-ID	Difference	95% CI
70·5 %	90·2 %	-17·9 %	-22·1 %; -17·7 %

Unpublished results!

Completion of colonoscopy

Positive FIT-test

ID	Non-ID
492	5 237

Colonoscopy

ID	Non-ID
387	4878

Colonoscopy within 60 days

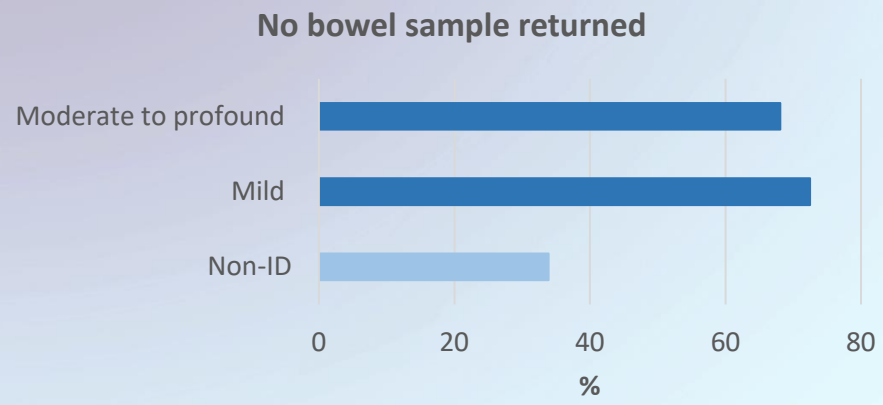
ID	Non-ID	Difference	95% CI
70·5 %	90·2 %	-17·9 %	-22·1 %; -17·7 %

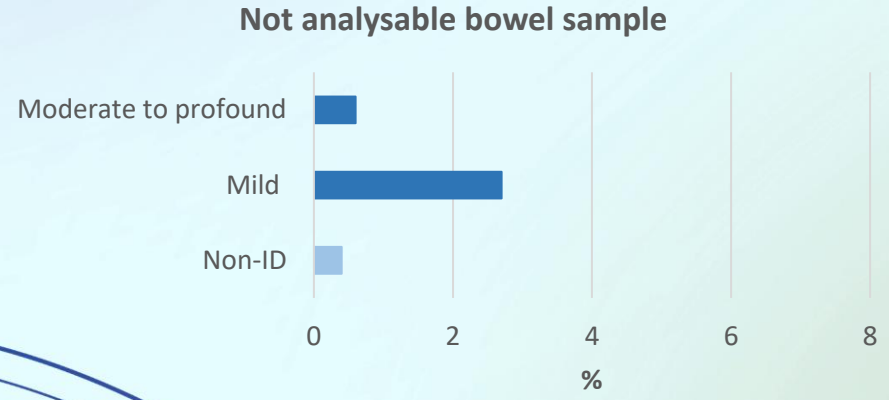
Complete colonoscopy

ID	Non-ID
71·8 %	86·2 %

Unpublished results!

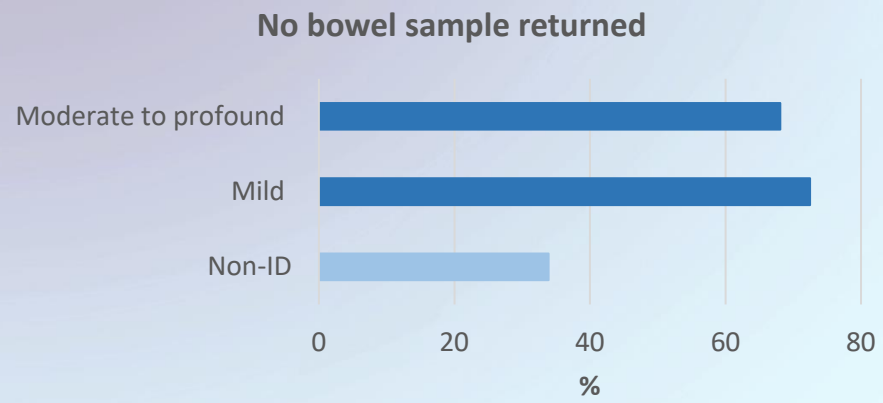
ID severity

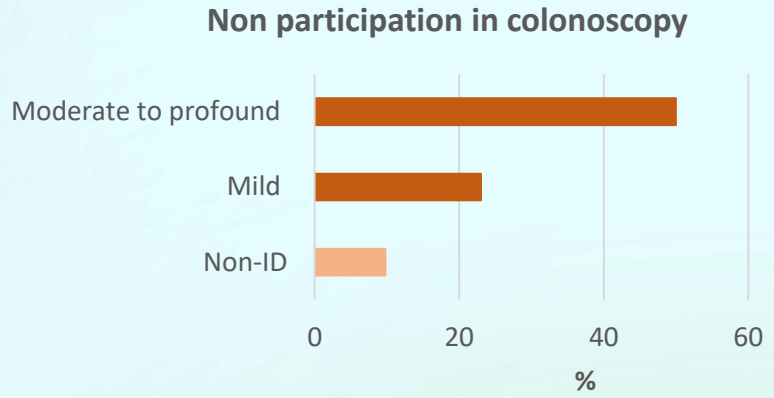


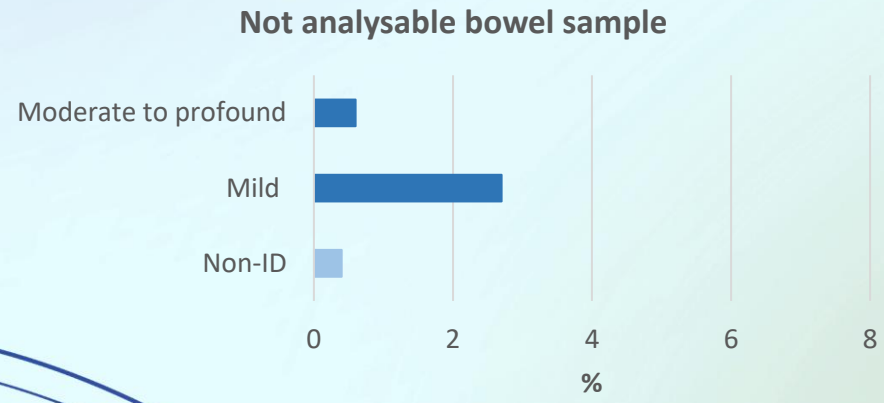


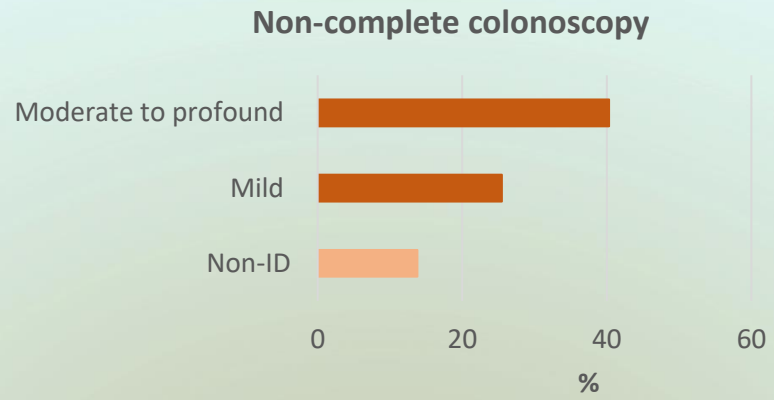
Unpublished results!

ID severity









Unpublished results!

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Discussion in groups

1. Discussion in your groups (1-6) (10 min)
2. Discussion with your partner group (1/2, 3/4, 5/6) (10 min)
3. Each group (1/2, 3/4, 5/6) share key points from their discussions in plenum

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Based on knowledge from today:

Group 1-2:

-Discuss potential barriers for screening participation among vulnerable groups in general and specifically people with ID

Group 3-4:

-Do you know of any screening policies, guidelines or initiatives in your country targeted people with ID?

-Do you have any suggestions on how to adapt existing screening procedures to people with ID?

Group 5-6:

-Discuss an optimal timing of screening for breast and colorectal cancer for people with ID

-E.g. Same age groups as the general population? Invitation procedures?

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Key Learning Takeaways from this Session

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……

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Training school: "Equitable Cancer Prevention & Screening: Advancing Inclusion for People with Intellectual Disabilities“

Cancer Prevention Policy

Prof. dr. Martin McMahon

Dr. Vladimir Vuković

Monday, May 12, 2025

14:45 - 15:45h

By the end of this session, you will:

· Have an **overview of the prevention policies available in different European countries** with the special focus on the needs of people with the intellectual disability

· Have an **input from the organizations providing services to people with intellectual disability** about their experience and opinion on cancer prevention policies for people with intellectual disability

Background, findings, and relevance

- **Cancer prevention** is the most effective and long-term strategy for **cancer control.**
- The most important **components** of a cancer prevention strategy are **national policies and programmes -** to reduce exposure to *cancer risk factors, raise awareness* by providing people with information and support their need to adopt healthy lifestyles, and *implement governance and decision-making processes* in cancer screening.

Background, findings, and relevance

- Many European countries implemented **population-based national screening** programmes for prevalent cancers, but inequalities in screening uptake are substantial, both between countries and within countries across population groups.
- On the other hand, **adequate governance, legal frameworks and policy-making structures**, as well as **quality data** on cancer prevention and screening programmes are **limited or lacking** for many countries across Europe, particularly middle income and EU candidate countries.

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- People with intellectual disabilities are often **underrepresented** in cancer prevention and screening policies or **have limited access** to these services, both of which **lead to health disparities and unfavourable health outcomes** in this population.
- It is **still unclear** to what extent existing health policies **adequately address the specific need(s)** of people with intellectual disabilities.
- Influencing, or changing policy at a societal level, **may lead to wider changes**, at a community, organisational and individual level.

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Survey

Among European organisations for people with intellectual disabilities on their opinion and experience with cancer prevention policies for people with intellectual disabilities

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Survey methodology

- Participants were **asked to select the option that best represents their organization's official position** or perspective. If organization does not have an official position on a particular question, participants provided their professional assessment as a representative with authority to respond on behalf of the organization.
- This survey defined “health policy” as the **decisions, plans, and actions** undertaken to achieve specified healthcare objectives within a society, as endorsed by the WHO.
- The **anonymity** for all collected information was maintain, analysing it in aggregate and using findings exclusively for research.

Survey methodology

- Survey was conducted **online** using a structured questionnaire during **April 2025.**
- A total of 327 organizations were directly emailed (with a gentle reminder after 7days) and also **newsletter and social network** of two umbrella organizations (EASPD and Inclusion Europe) were used to inform potential participants about the survey.

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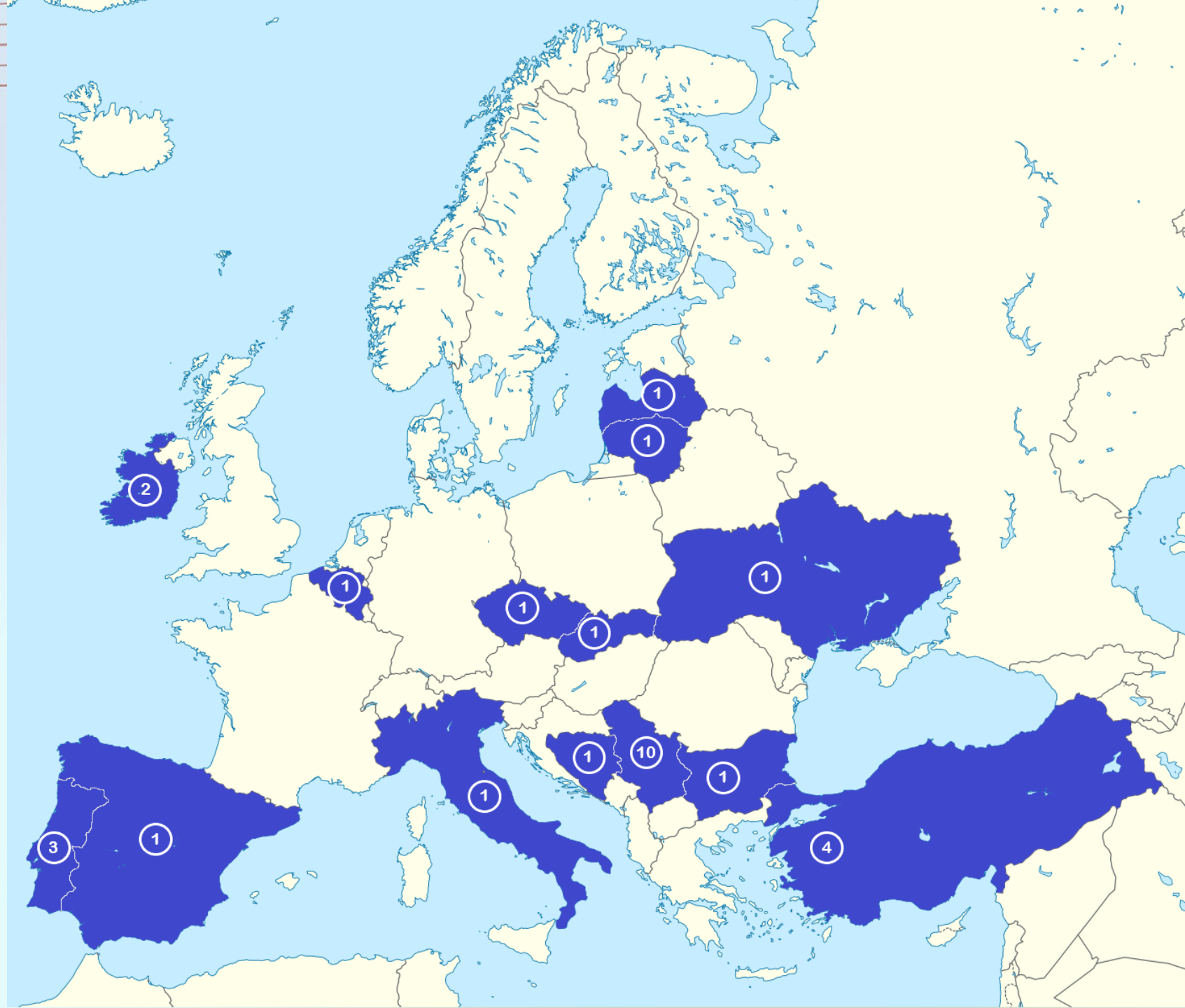
Results:
countries of the participating organizations



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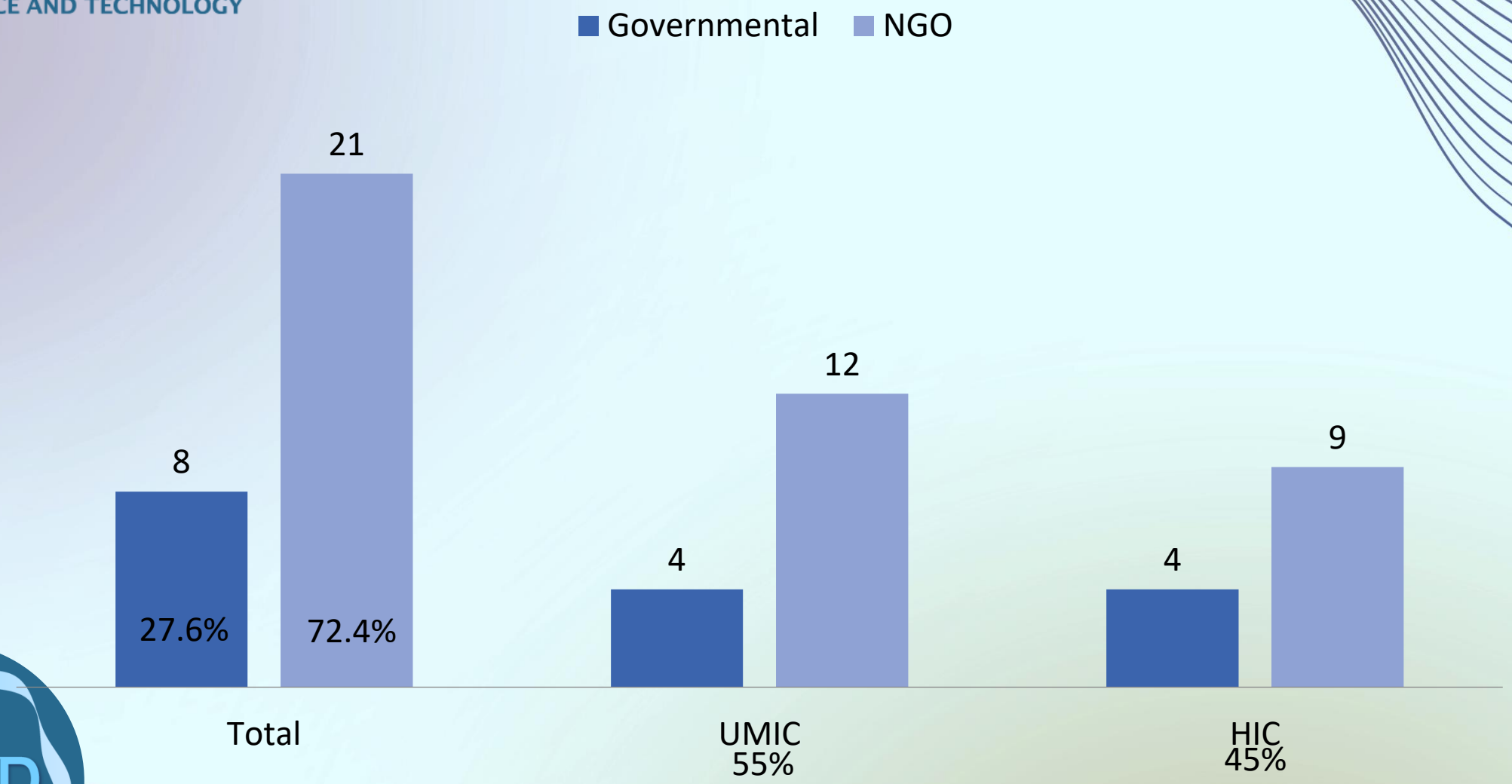


UMIC=upper-middle-income country; HIC= high-income country

Table 1. General characteristics of participating organizations

	Total, n (%)	UMIC, n (%)	HIC, n (%)	p-value
Is your organization defined as:				
Governmental	8 (27.6)	4 (25.0)	4 (30.8)	0.73
Non-governmental (NGO)	21 (72.4)	12 (75.0)	9 (69.2)	
When was your organization established? (years ago)				
<20	10 (34.5)	5 (31.3)	5 (38.4)	0.904
20-40	10 (34.5)	6 (37.5)	4 (30.8)	
>40	9 (31.0)	5 (31.3)	4 (30.8)	
What is the current number of staff working in your organization?				
<10	10 (34.5)	9 (56.3)	1 (7.69)	**0.032**
10-100	10 (34.5)	4 (25.0)	6 (46.2)	
>100	8 (27.6)	3 (18.7)	5 (38.46)	
missing	1 (3.45)	0	1 (7.69)	
What is the approximate number of users with intellectual disability attending your organization each month?				
<100	16 (55.2)	10 (62.5)	6 (46.2)	0.124
100-1000	9 (31.0)	3 (18.75)	6 (46.2)	
>1000	3 (10.3)	3 (18.75)	0	
missing	1 (3.5)	0	1 (7.69)	

*using Pearson chi2 test

	Total, n (%)	UMIC, n (%)	HIC, n (%)	p-value
What is the main source of funding for your activities?				
Fully government-funded	14 (48.3)	6 (37.5)	8 (61.5)	0.506
Partially government-funded	12 (41.4)	8 (50.0)	4 (30.8)	
Private funding	1 (3.5)	1 (6.3)	0	
Charitable funding	2 (6.9)	1 (6.3)	1 (7.7)	
How often per year does your organization interact with national government representatives regarding any topic including health policy?				
never	7 (24.1)	6 (37.5)	1 (7.7)	0.116
a few times per year	18 (62.1)	9 (56.3)	9 (69.2)	
on a monthly basis	4 (13.8)	1 (6.3)	3 (23.1)	

*using Pearson chi2 test

II. Experience with National Cancer Prevention Policy

	Total, n (%)	UMIC, n (%)	HIC, n (%)	**p-value**
Are you aware of any cancer prevention policy specifically tailored to the needs of people with intellectual disabilities in your country?				
Yes	6 (20.7)	3 (18.8)	3 (23.1)	
No	17 (58.6)	7 (43.8)	10 (76.9)	**0.047**
I am not aware	6 (37.5)	6 (37.5)	0	
If yes, please list the types of national cancer prevention policies that exist for people with intellectual disabilities (select all that apply): n=6				
Screening (breast, cervical, colorectal, etc.)	6 (100)	3 (100)	3 (100)	N/A
Lifestyle modifications (diet, physical activity, tobacco and alcohol cessation, sunprotection, HPV and Hep B vaccination, etc.)	3 (50.0)	2 (66.7)	1 (33.3)	0.99
Health education	1 (16.7)	1 (33.3)	0	0.99
Genetic predisposition testing	2 (33.3)	2 (66.7)	0	0.4
If yes, do you think it currently meets the needs of people with intellectual disabilities?				
Yes	1 (16.7)	1 (33.3)	0	
No	4 (66.7)	2 (66.7)	2 (66.7)	0.368
I don't know	1 (16.7)	0	1 (33.3)	
If no, are you aware of any national <u>initiative</u> to tailor policies for people with intellectual disabilities? n=17				
Yes	5 (29.4)	2 (28.6)	3 (30.0)	
No	9 (52.9)	4 (57.1)	5 (50.0)	0.942
I don't know	3 (17.7)	1 (14.3)	2 (20.0)	

	Total, n (%)	UMIC, n (%)	HIC, n (%)	p-value
What are the main barriers to implementing effective cancer prevention policies for people with intellectual disabilities? (Select all that apply)				
Lack of awareness among policymakers	16 (55.2)	9 (56.3)	7 (53.9)	0.897
Insufficient funding	13 (44.8)	8 (50.0)	5 (38.5)	0.534
Limited expertise	14 (48.3)	7 (43.8)	7 (53.9)	0.588
Communication challenges	14 (48.3)	9 (56.3)	5 (38.5)	0.34
Inadequate healthcare training	16 (55.2)	7 (43.8)	9 (69.2)	0.264
Competing healthcare priorities	8 (28.6)	4 (25.0)	4 (30.8)	0.99
Lack of coordination between disability and healthcare services	27 (93.1)	16 (100)	11 (84.6)	0.192
Other (please specify)	N/A	**	*	N/A
Has your organization been involved in policy-making regarding cancer prevention for people with intellectual disabilities?				
No	21 (72.4)	12 (75.0)	9 (69.2)	0.906
Yes, by reviewing draft documents	2 (6.9)	1 (6.3)	1 (7.7)	
Yes, by participating in surveys	3 (10.3)	2 (12.5)	1 (7.7)	
Yes, by working in policy groups	3 (10.3)	1 (6.3)	2 (15.4)	
Would your organization be willing to get (more) involved in national policy development?				
Yes	21 (72.4)	11 (68.8)	10 (76.9)	0.515
No	1 (3.5)	0	1 (7.7)	
I don’t know	7 (24.1)	5 (31.2)	2 (15.4)	

*lack in parents' involvement; non-functional screening register; insufficien adaptional of prevence to the specific needs of people with intelectual disabilities **Persons with intellectual disabilities are a diverse and highly heterogeneous group who, due to reduced cognitive abilities, generally lack the capacity for self-advocacy and depend on the understanding and support of their caregivers. In Bosnia and Herzegovina, this population is not viewed differently from the general population when it comes to prevention, and it is usually required that a caregiver be present except in cases of mild cognitive impairments.

Fisher's exact

III. Opinions on Cancer Prevention Policy

	Total, n (%)	UMIC, n (%)	HIC, n (%)	p-value
How important is it to tailor cancer prevention policy for people with intellectual disabilities?				
Not important	0	0	0	0.606
Minor importance	0	0	0	
Medium importance	4 (13.8)	3 (18.7)	1 (7.7)	
Major importance	25 (86.2)	13 (81.3)	12 (92.3)	
Should cancer prevention policy for people with intellectual disabilities be a separate document or incorporated into general policy?				
A separate document	9 (31.0)	6 (37.5)	3 (23.1)	0.454
Part of a general policy	20 (69.0)	10 (62.5)	10 (76.9)	
No adjustments needed	0	0	0	
Would a pan-European policy for cancer prevention for people with intellectual disabilities be useful?				
Yes	27 (93.1)	14 (87.5)	13 (100)	0.99
No	1 (3.5)	1 (6.3)	0	
I don't know	1 (3.5)	1 (6.3)	0	
Is more <u>research</u> needed in this field?				
Yes	27 (93.1)	15 (93.8)	12 (92.3)	0.99
No	0	0	0	
I don't know	2 (6.9)	1 (6.2)	1 (7.7)	
Should more <u>funding</u> be allocated for research on cancer prevention policies for people with intellectual disabilities?				
Yes	26 (89.7)	14 (87.5)	12 (92.3)	0.99
No	0	0	0	
I don't know	3 (10.3)	2 (12.5)	1 (7.7)	

	Total, n (%)	UMIC, n (%)	HIC, n (%)	p-value
Who should be responsible for initiating policy changes at the national level? (all that applies)				
Healthcare personnel	22 (75.9)	13 (81.3)	9 (69.2)	0.667
Organizations for people with intellectual disabilities	24 (82.8)	14 (87.5)	10 (76.9)	0.632
Local government	17 (58.6)	8 (50.0)	9 (69.2)	0.451
National government/ministries	26 (89.7)	15 (93.8)	11 (84.6)	0.573
EU government	17(56.8)	8 (50.0)	9 (69.2)	0.451
Research entities (universities, research centers)	23 (79.3)	13 (81.3)	10 (76.9)	0.99
Should organizations for people with intellectual disabilities be more involved in policy-making?				
Yes	28 (96.6)	16 (100)	12 (92.3)	0.448
No	0	0	0	
I don't know	1 (3.4)	0	1 (7.7)	
Is more training needed to implement cancer prevention policies for people with intellectual disabilities?				
Yes	29 (100)	16 (100)	13 (100)	N/A
No	0	0	0	
I don't know	0	0	0	
Who should be primarily responsible for ensuring implementation of cancer prevention policy for people with intellectual disabilities?				
Healthcare personnel	7 (24.1)	4 (25.0)	3 (23.1)	0.96
Organizations for people with intellectual disabilities	4 (13.8)	2 (12.5)	2 (15.4)	
Local government	2 (6.9)	1 (6.3)	1 (7.7)	
National government/ministries	15 (51.7)	9 (56.3)	6 (46.2)	
Other (please specify)	1 (3.45)	0	1 (7.7)	
Future cancer prevention policies should focus on:				
Additional adaptation of screening programs	6 (20.7)	3 (18.8)	3 (23.1)	0.99
Creating specialized communication materials for people with intellectual disabilities	4 (13.8)	2 (12.5)	2 (15.4)	
Integration of caregivers into cancer prevention	5 (17.2)	3 (18.8)	2 (15.4)	
Specific training programs for healthcare providers	14 (48.3)	8 (50.0)	6 (46.1)	
Before participating in this survey, had you heard of the COST CUPID network?				
Yes	15 (51.7)	8 (50.0)	7 (53.9)	0.837
No	14(48.3)	8 (50.0)	6 (46.1)	

Keynote takeaways

- **Low response rate** was noted (max 9%) with a total of 29 organizations from 14 European countries that participated in this survey
- Majority (72.4%) were **NGOs**, 16 (55%) from UMIC and 13 (45%) from HIC
- As per experience with National Cancer Prevention Policies - only **20% were aware of any cancer prevention** policy specifically tailored to the needs of people with intellectual disabilities in their country, mostly regarding screening and lifestyle modifications.
- Around **67% of those aware of the policy think it doesn't meet the needs** of people with intellectual disabilities
- **Lack of coordination between disability and healthcare services** (93.1%), **inadequate healthcare training** (55.2%) and **lack of awareness among policymakers** (55.2%) were marked as the top three main barriers to implementing effective cancer prevention policies for people with intellectual disabilities
- Organization in majority (72.4%) **haven't been involved in policy-making** regarding cancer prevention for people with intellectual disabilities, and the same percentage (72.4%) marked **that would be willing to get (more) involved** in national policy development

Keynote takeaways

- **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%** or 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**.

CUPID WG2 policy literature search and review -Methods and Preliminary Results-

Policy search and review: protocol

- AIM: To systematically identify, and review policies on cancer prevention across Europe and assess if Intellectual Disabilities are addressed
- All European countries, not just EU-27
- Scientific and regular web databases
- Search completed
- Extraction ongoing
- Renewed importance for current year in October and April WG2 Meeting

EUROPEAN COOPERATION IN SCIENCE AND TECHNOLOGY

Protocol

- Search
  - Scientific databases (2)
  - Generic Google search
  - Handsearch
- Uniform strategy
  - Translation and adaptation to national setting

CUPID
CANCER - UNDERSTANDING PREVENTION IN INTELLECTUAL DISABILITIES

Population	People with learning disabilities/ intellectual disabilities	(“learning disabil*” OR “intellectual disabil*” OR “developmental disabil*”)
Issue	Cancer (of any location). It was decided not to add prevention or screening-related vocabulary as this would likely be too limiting.	(cancer OR oncology OR carcinoma OR malign* OR tumor OR neoplasm*)
Context	Any publicly available relevant document that aims to inform policy or practice in any way	(Policy OR policies OR guidance* OR law* OR legal* OR guidelin* OR strateg* OR legislat* OR statutory OR governan* OR regulation* OR “health act*”)
Country	Limit to the country the search is applied for	([COUNTRY SPECIFIC TERMS]) e.g. (“United Kingdom” OR "gov.uk" OR "nhs.uk" OR "nice.org.uk" OR “parliament.uk”)

Example search for the UK:

(“learning disabil*” OR “intellectual disabil*” OR “developmental disabil*”)
AND
(cancer OR oncology OR carcinoma OR malign* OR tumor OR neoplasm*)
AND
(Policy OR policies OR guidance* OR law* OR legal* OR guidelin* OR strateg* OR legislat* OR statutory OR governan* OR regulation* OR “health act*”)
AND
(“United Kingdom” OR "gov.uk" OR "nhs.uk" OR "nice.org.uk" OR “parliament.uk”).

Inclusion and exclusion

- All cancers
- No time restriction

	Inclusion	Exclusion
Population	Must include parts or be fully focused on intellectual/learning disabilities	Does not relate to intellectual disabilities/learning disabilities
Issue	Must focus on any type of cancer, cancer prevention or cancer screening	Does not focus on cancer.
Context	Must be a policy document, piece of legislation or guidance piece. – We define policy as: "Policy is a law, regulation, procedure, administrative action, incentive, or voluntary practice of governments and other institutions" (Centre for Disease Control and Prevention, 2015). – We define legislation as "Legislation is a law or a set of laws that have been passed by Parliament." (UK Parliament, N.D) – We define guidance as "Guidelines written to give broad advise on procedure instead of precise requirements and standards" (Law Dictionary, N.D)	Systematic reviews, scoping reviews and primary research
Other	Published in any year	None.

Process

Invited individuals per country

- Countries within the Working Group (WG): 18
- Countries within CUPID: 31
- Snowballing to contacts from countries not represented

Collect findings centrally

- Coordinators are responsible for tracking progress.
  - *To be discussed*

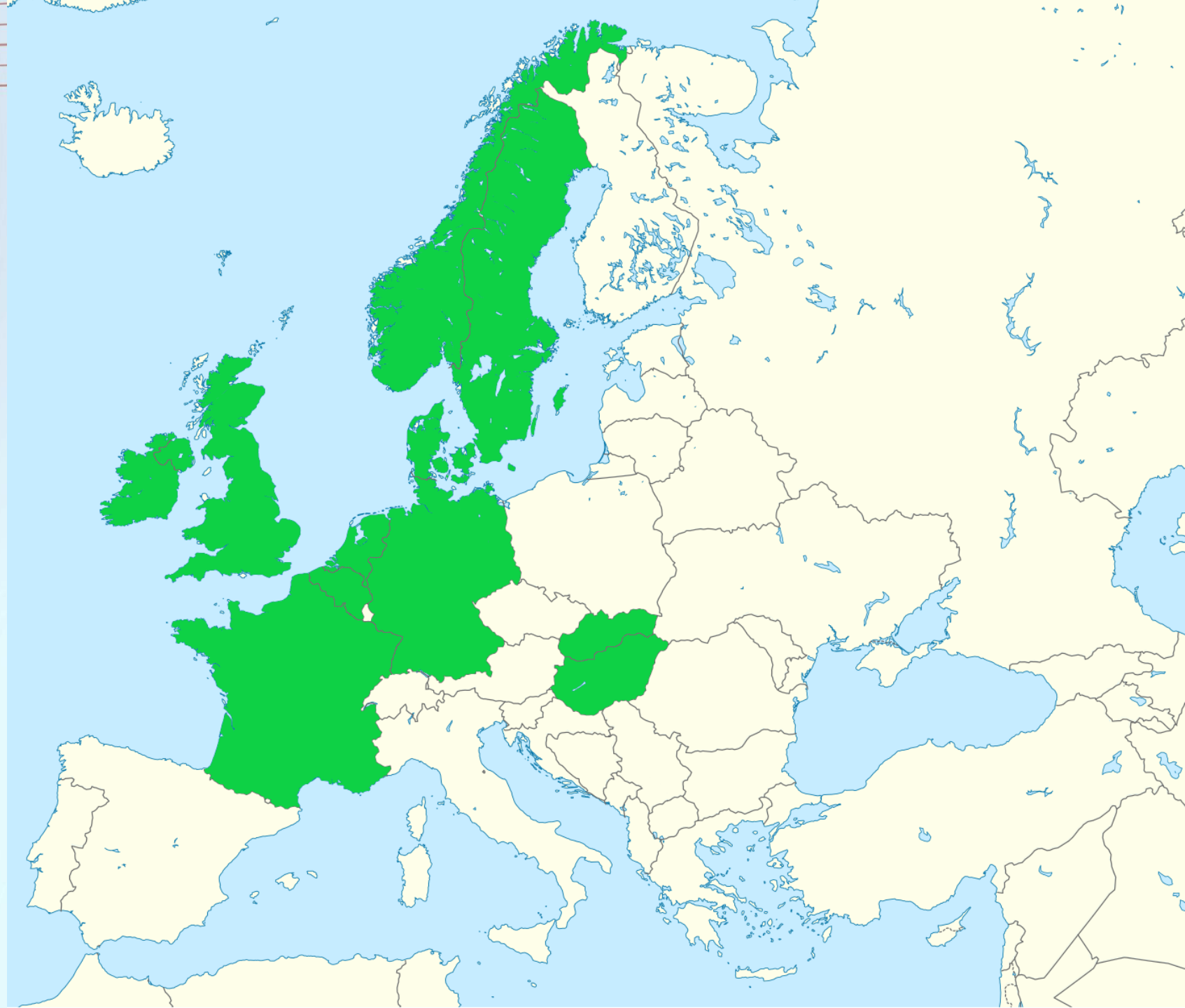
Cloud storage:

Utilised Google Drive for data management.

Issues: Challenges faced with some countries outside the EU27; a task force was established to address these issues.

EUROPEAN COOPERATION
IN SCIENCE AND TECHNOLOGY

Country's Cancer prevention policy



CUPID
CANCER - UNDERSTANDING PREVENTION IN INTELLECTUAL DISABILITIES

	• Rape Point - 2 • RCNI: Rape Crisis Network Ireland - 2 • TASC: Think-Tank for Action on Social Change - 2 • CDI: Childhood Development Initiative – 1	

Health Information and Quality Authority (HIQA)

HIQA	Search approach – hand searching	Returns
	https://www.hiqa.ie/reports-and-publications/standards	4
	https://www.hiqa.ie/areas-we-work/disability-services	3
	2 potentially relevant	1) https://www.irishstatutebook.ie/eli/2013/made/en/pdf 2) https://www.hiqa.ie/sites/default/files/202/Standards-Disabilities-Children-Adults *4.1.3 Children have timely access to screening, ea detection and the full range of health and welfare services in the community, including oral, optical aural services.* *4.1.3 Each person has access to screening, early detection and the full range of universal health ar welfare services in the community including oral, and aural services.*

Health Service Executive - National Cancer Control Programme (NCCP)

NCCP	Search approach – hand searching	Returns
	https://www.hse.ie/eng/services/list/5/cancer/pubs/reports/	27
	https://www.hse.ie/eng/services/list/5/cancer/profinfo/guidelines/guidelines.html	8
	Relevant	Relevant 1

Search Strategy CUPID

		improve equity in screening over the next five years.

Department of Health (DoH)

DoH	Search approach – hand search	Returns
	'cancer'	13
		Potentially Relevant 1 National cancer Strategy 2017-2026 Cancer awareness and prevention initiatives will prioritise disadvantaged populations and hard to reach groups.

Irish Cancer Society (ICS)

ICS	Search approach – hand searching and emailed	
	intellectual disability	Returns – nil Emailed

National Cancer Registry Ireland (NCRI)

NCRI	Search approach – hand searching and emailed	
	disability	Returns – nil

2026

ion initiatives will

ith Disability

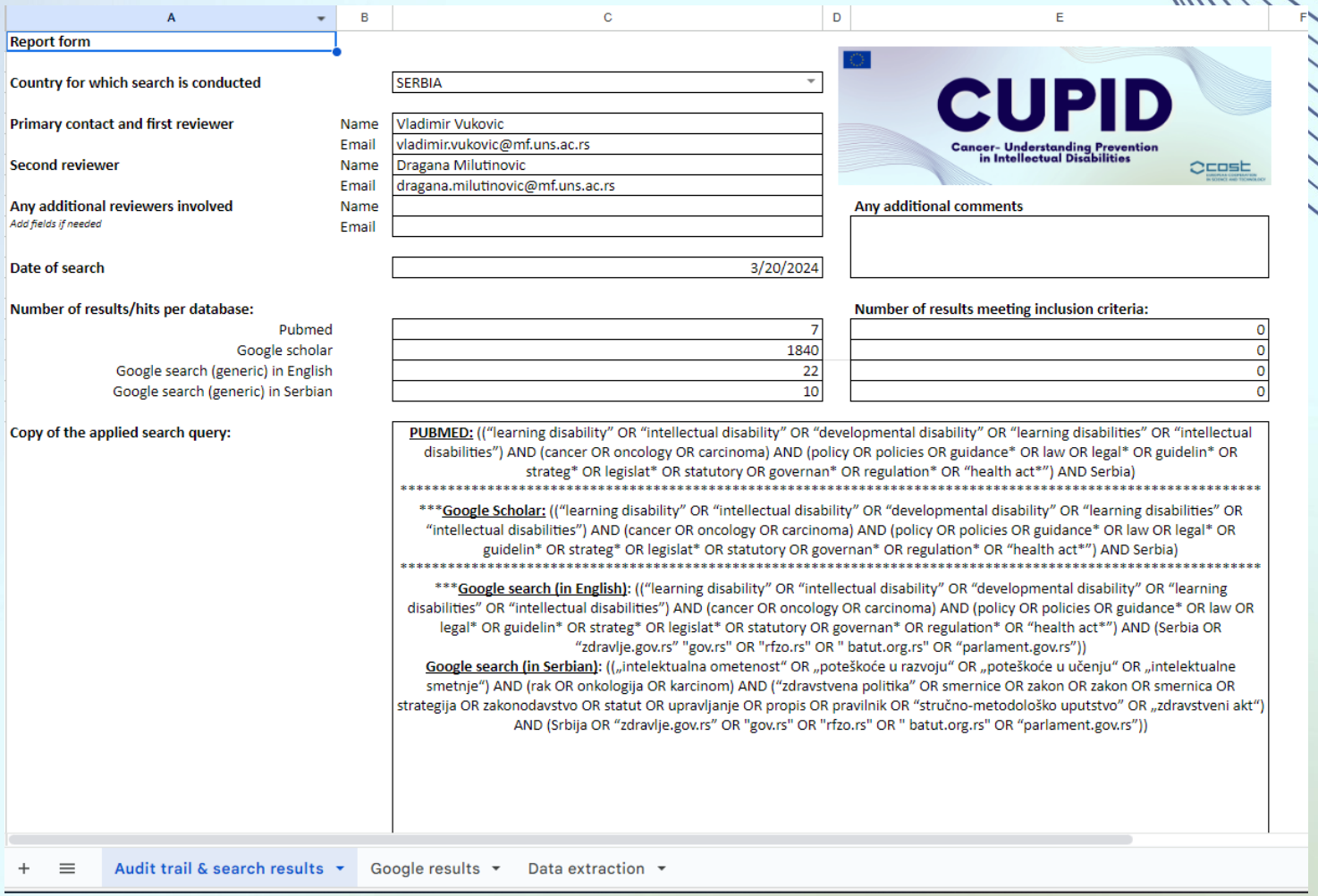
	Returns
	7
	~~None relevant~~

ation	Returns
E4MT 1Mjl3	0
E4MT 1Mjl3	0
*1u5i 1S3M MC4	0
egic ews/i	1 reference only - Our Framework will build on existing work of the National Screening Service (NSS) and will help create a roadmap for how we will understand and

	Search Hits
ctual ntal	681,658
uidelin* regulatio	6,162,649
	5,946,984
	735,805
	253

	Search Hits
llectual ental ng al OR OR AND	About 8,430 results (0.03 sec) Limited to 10 years About 4,180 results (0.08 sec)
	~~None relevant~~

	Search Hits
lity* OR R * OR	24
opment	~~None relevant~~



Report form		
Country for which search is conducted		SERBIA
Primary contact and first reviewer	Name	Vladimir Vukovic
	Email	vladimir.vukovic@mf.uns.ac.rs
Second reviewer	Name	Dragana Milutinovic
	Email	dragana.milutinovic@mf.uns.ac.rs
Any additional reviewers involved	Name	
Add fields if needed	Email	
Date of search		3/20/2024

Any additional comments

Number of results/hits per database:	**Number of results meeting inclusion criteria:**
Pubmed: 7	0
Google scholar: 1840	0
Google search (generic) in English: 22	0
Google search (generic) in Serbian: 10	0

Copy of the applied search query:

PUBMED: (("learning disability" OR "intellectual disability" OR "developmental disability" OR "learning disabilities" OR "intellectual disabilities") AND (cancer OR oncology OR carcinoma) AND (policy OR policies OR guidance* OR law OR legal* OR guidelin* OR strateg* OR legislat* OR statutory OR governan* OR regulation* OR "health act*") AND Serbia)

****

***Google Scholar:** (("learning disability" OR "intellectual disability" OR "developmental disability" OR "learning disabilities" OR "intellectual disabilities") AND (cancer OR oncology OR carcinoma) AND (policy OR policies OR guidance* OR law OR legal* OR guidelin* OR strateg* OR legislat* OR statutory OR governan* OR regulation* OR "health act*") AND Serbia)

****

***Google search (in English):** (("learning disability" OR "intellectual disability" OR "developmental disability" OR "learning disabilities" OR "intellectual disabilities") AND (cancer OR oncology OR carcinoma) AND (policy OR policies OR guidance* OR law OR legal* OR guidelin* OR strateg* OR legislat* OR statutory OR governan* OR regulation* OR "health act*") AND (Serbia OR "zdravlje.gov.rs" "gov.rs" OR "rfzo.rs" OR " batut.org.rs" OR "parlament.gov.rs"))

Google search (in Serbian): ((„intelektualna ometenost" OR „poteškoće u razvoju" OR „poteškoće u učenju" OR „intelektualne smetnje") AND (rak OR onkologija OR karcinom) AND ("zdravstvena politika" OR smernice OR zakon OR zakon OR smernica OR strategija OR zakonodavstvo OR statut OR upravljanje OR propis OR pravilnik OR "stručno-metodološko uputstvo" OR „zdravstveni akt") AND (Srbija OR "zdravlje.gov.rs" OR "gov.rs" OR "rfzo.rs" OR " batut.org.rs" OR "parlament.gov.rs"))

Audit trail & search results | Google results | Data extraction

Current state of play

The **search is complete** for all countries.

However, **data extraction has only been finalised for 11 countries**, despite repeated follow-ups.

From the extracted material, we have **some limited evidence** suggesting that cancer policies in a small number of countries **'make reference' to** the needs of people with ID – but these references are fragmented and inconsistent.

We need a coordinated approach!

The ask.....

CUPID COST Action Training School – Group Work 2 Activity

Group 1: Re-engagement & Participation

Group 2: Minimum Dataset

Group 3: Final Deliverable Vision

Group 4: Accountability & Timeline

Each group has 10 minutes together and then presents their **3-minute pitch**.

Group 1: Re-engagement & Participation

How can we re-engage those who haven't submitted data?

What communication and motivation strategies could work?

Can Training School participants assist in completing data extraction?

Group 2: Minimum Dataset

1. How should we handle missing or partial data from certain countries?
2. How do we handle language barriers?

Group 3: Final Deliverable & Equity Framing

1. What should the final output be? (e.g. we have our own thoughts)
2. Who is the target audience for this deliverable?

Group 4: Accountability & Timeline

1. What is a realistic and achievable timeline to finalise data extraction and write up?
2. What tools (e.g., tracking sheets, regular check-ins) could support this timeline?
3. How can we ensure accountability among contributors?

Group pitches

Group 1: Re-engagement & Participation

Group 2: Minimum Dataset

Group 3: Final Deliverable Vision

Group 4: Accountability & Timeline

Quick discussion with the audience (in groups)

- Are you aware of any cancer prevention policy specifically tailored to the needs of people with intellectual disabilities in your country?
  - If yes, which type of national cancer prevention policies that exist for people with intellectual disabilities (Screening; Lifestyle modifications; Health education; Genetic predisposition testing, etc)?
  - If yes, do you think it currently meets the needs of people with intellectual disabilities?
  - If no, are you aware of any national initiative to tailor policies for people with intellectual disabilities?
- What are the main barriers to implementing effective cancer prevention policies for people with intellectual disabilities?
- Should cancer prevention policy for people with intellectual disabilities be a separate document or incorporated into general policy?
- Who should be responsible for initiating policy changes at the national level?
- Is more training needed to implement cancer prevention policies for people with intellectual disabilities?
- Who should be primarily responsible for ensuring implementation of cancer prevention policy for people with intellectual disabilities?

We would like to thank all participating organization, some of which are listed:

Union of Associations for support persons with intellectual disabilities, Belgrade

Association of Citizens “RO-DE” Belgrade

All Ukrainian NGO Coalition for Persons with Intellectual Disabilities Kyiv. Ukraine

The Association for Helping Mentally Chalenged Persons of The City of Novi Sad Novi Sad

Centre for Cancer detection, Bruges, Belgium

ASSOCIAZIONE SCUOLA VIVA - ROME - ITALY

CRIT - CENTRO DE REABILITAÇÃO E INCLUSÃO TORREJANO TORRES NOVAS

Telsiai centre "Viltis„ Telsiai, Lithuania

URDOUR VRNJACKA BANJA

Cerciespinho Espinho, Portugal

Association for the Support of Individuals with Down Syndrome Novi Sad City of Novi Sad

Public Institution Center "Protect me" Banja Luka

Institute for Community-based Social Services Foundation, Sofia

SAVEZ UDRUŽENJA ZA POMOĆ MNRO U AP VOJVODINI NOVI SAD

Platform of families with children with disabilities/Platforma rodin deti so zdravotnym znevyhodnenim Bratislava

End of day 1 and Evaluation

4pm – 4:45pm

Link to evaluation of day 1

https://forms.cloud.microsoft/e/n6HZFUuVue

Social events tonight

- 5pm
- Senior Common Room
- Trinity College Dublin
- Wine and canapé reception

EUROPEAN COOPERATION IN SCIENCE AND TECHNOLOGY

Tomorrow

Date	Information
09:00 – 09:15AM	Welcome, overview of day, importance of targeted cancer prevention and screening for people with intellectual disabilities
09:15 – 10:00AM	Overview of – Cancer risk-factor and symptom awareness for people with intellectual disabilities. (Online and in person)
10:00 – 10:45AM	Inclusive and Accessible cancer screening/prevention information. (In person only)
10:45 – 11:00AM	BREAK
11:00 – 12:00PM	Health Systems across the EU (and beyond): What does cancer screening and prevention look like? (Online and in person)
12:00 – 13:00PM	Learning from WG1 – The voice of people with ID toward cancer screening and cancer prevention systems. (Online and in person)
13:00 – 14:00PM	LUNCH
14:00 – 16:00PM	Cancer screening and cancer prevention- How do these apply to people with ID and what should health systems do? (In person only)
16:00 – 16:45PM	Closing remarks and Evaluation


See you all tonight, and tomorrow 9am

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of the European Union

Acknowledgement

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CUPID supported by COST (European Cooperation in Science and Technology).

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

www.cost.eu