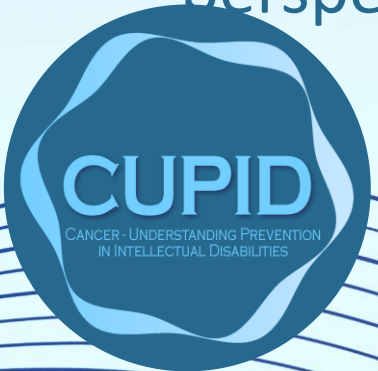


Pan-European Perspective on Cancer Prevention in Persons with Intellectual and Developmental Disabilities (IDD): Challenges and Solutions.



Introduction

- Cancer prevention is a critical public health priority, yet persons with IDD remain an underserved and a vulnerable group. In Europe, disparities in cancer prevention, screening, and early detection for those with IDD arise from systemic, cultural, and educational barriers.
- This presentation addresses the challenges in cancer prevention for this population and presents the work from an EU funded project which is seeking to bridge these gaps from a pan-European perspective.



Increased Cancer Mortality Rates

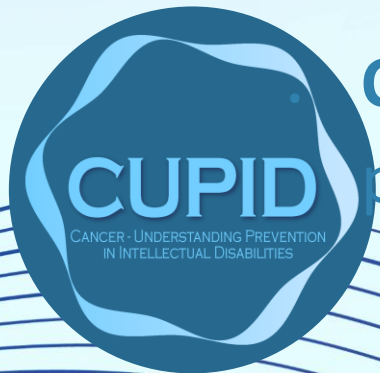
- Research consistently shows that persons with IDD have **higher cancer-related mortality rates** than the general population.
- It was also known that sometimes persons with IDD are diagnosed **only after behavioural distress or physical symptoms appear**, rather than through regular preventive screening (Satgé et al., 2022).



Lower Cancer Screening Participation

- Despite the fact that **40% of all cancers are preventable**, persons with IDD **participate in cancer screening at much lower rates** than the general population (European Cancer Organisation, 2021). Studies indicate that:
 - Women with IDD are **significantly less likely** to participate in **breast cancer screening programmes** (Søndergaard et al., 2022).

Colorectal and cervical cancer screening rates are similarly lower in persons with IDD (Banda et al., 2025).



The COST Action CUPID Project



CUPID establishes active working partnerships with academics, researchers, non-governmental organisations, carers, people with intellectual disabilities and policy makers.

CUPID will establish a research agenda and exchange information regarding cancer prevention in the intellectual disability population.

Scientific meetings, short term scientific exchanges, training schools, conferences and webinars.



Current CUPID Project Status

Now entering our third year, we are making excellent progress toward achieving our goals and deliverables. Our membership continues to grow — we now have 254 members from 38 countries — and we are proud to be building a strong, collaborative international network.



What we have been doing?



Establishing a European-Wide Research and Policy Network

The project has established four working groups (WGs):

- WG1: Co-Production
- WG2: Policy audit and evaluation.
- WG3: Developing a universal EU cancer prevention strategy.
- WG4: Dissemination and outreach.



Working Group 1

Led by Dr Margaret Denny and Dr Oliwia Kovalcyck

Key activities include networking meetings, grant applications, publications and a very successful training school held last September.



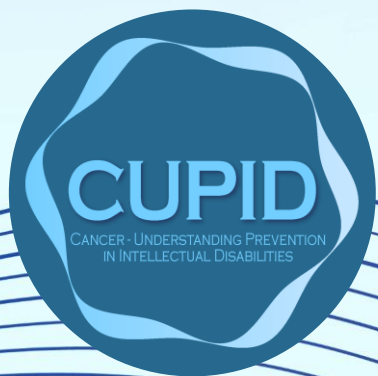
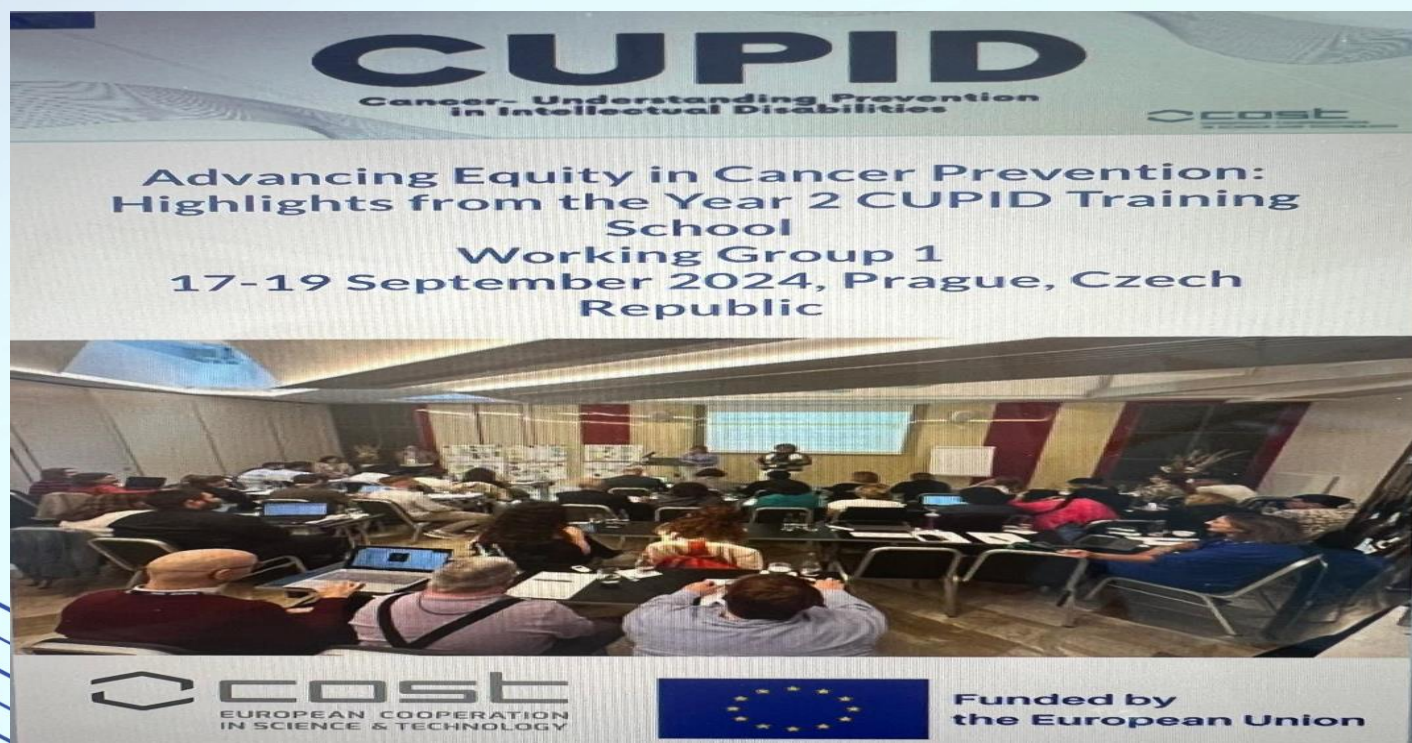
TRAINING SCHOOL TUESDAY 17 - THURSDAY 19 SEPTEMBER 2024

The CUPID Working Group 1-Interdisciplinary Co-Production Team is coordinating a Training School (TS) in Prague, which will combine in-person and virtual participation. The TS will include People with Intellectual and Developmental Disabilities (PWIDD) and their support persons. The program features cancer prevention educational training alongside five virtual presentations tailored to a diverse audience.



WG1 Training School in Prague

<https://read.bookcreator.com/KIbzV5JSoAOpDDDtdGvXM4gnC5z1/56xJxBtmSAKGvrhrAO5plA>



Prague Training School

- Involved persons with IDD and their caregivers to ensure their perspectives were included.
- Provided **hands-on training** for healthcare professionals on **adaptive screening methods** and **inclusive communication**.
- Highlighted the need for **longer appointment times**, **alternative screening methods**, and **specialised support staff**.



WG1- Cross European Survey of Service Providers

To gain a broad understanding of Intellectual Disability service provider organisations cancer prevention activities



Methodology

Questionnaire preparation

Ethical approval

Recruitment of intellectual disability services to complete questionnaire



Some Findings

1. Information on the Respondents
2. Information on the Services
3. Cancer Prevention Activities
4. Cancer Screening in the organisations
5. Other results- including perceived barriers to cancer prevention and screening activities



Respondents

Number of respondents

Country

Role of person completing



Respondents' awareness of Cancer Prevention



Lifestyle Modifications:

- **Avoidance of Tobacco:** Many responses highlight the importance of not smoking or using tobacco products.
- **Healthy Diet:** Consuming a balanced diet rich in fruits, vegetables, and fibre while reducing the intake of red meat and fatty foods.
- **Physical Activity:** Regular exercise is frequently mentioned as a preventive measure.
- **Weight Management:** Maintaining a healthy weight is also a common theme.
- **Limiting Alcohol:** Reducing or abstaining from alcohol consumption is advised.

Protection from Environmental Factors:

- **Sun Protection:** Using sunscreen and avoiding tanning beds to prevent skin cancer.
- **Avoidance of Risky Behaviours:** This includes preventing sexually transmitted infections and reducing exposure to known carcinogens.

Respondents' awareness of Cancer Prevention

Screening- Vaccinations

- Regular Screenings: Routine health checks, such as breast and colon screenings, are widely recommended;
- Vaccinations: Immunizations, particularly against HPV, are noted as preventive measures.

Health Education and Awareness

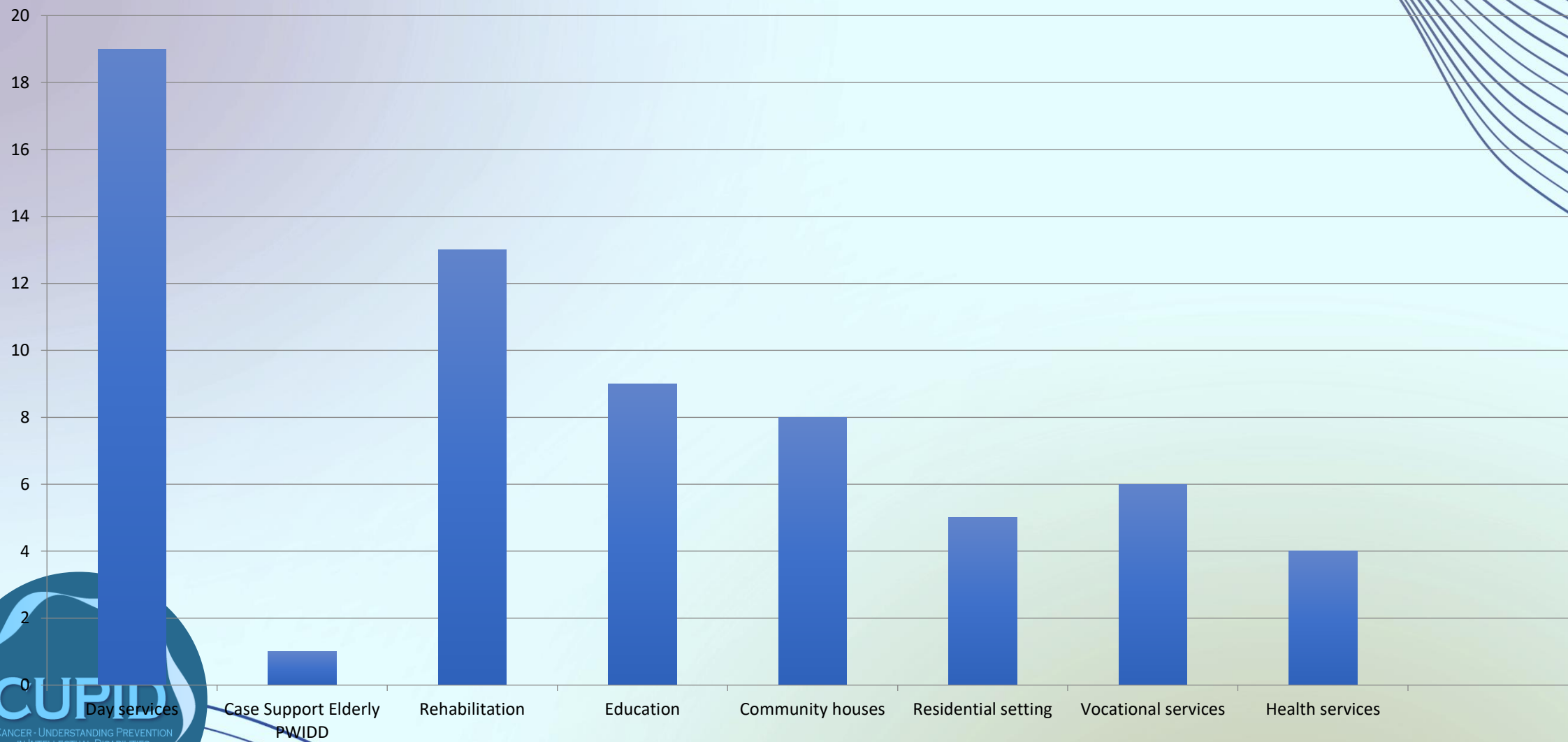
- Awareness Campaigns: Many responses mention the importance of educational programs, workshops, and campaigns to raise awareness about cancer prevention;



The Surveyed Services



Type of Service



Number of Services						
Level of IDD	1-10	11-20	21-40	41-60	60+	100+
Mild	8	13	7	12	3	5
Moderate	25	13	5	2	3	6
Severe	15	10	4	4	2	6
Profound	3	2	2	4	2	4

PWIDD Numbers attending Services

Mild IDD:

2,055
service
users

Moderate IDD:

1,732.5
service
users

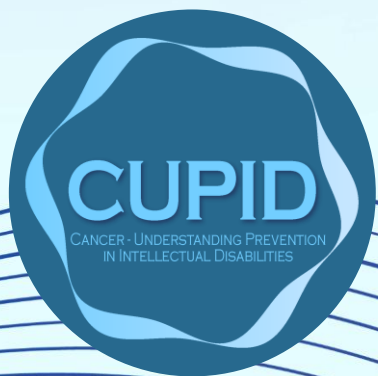
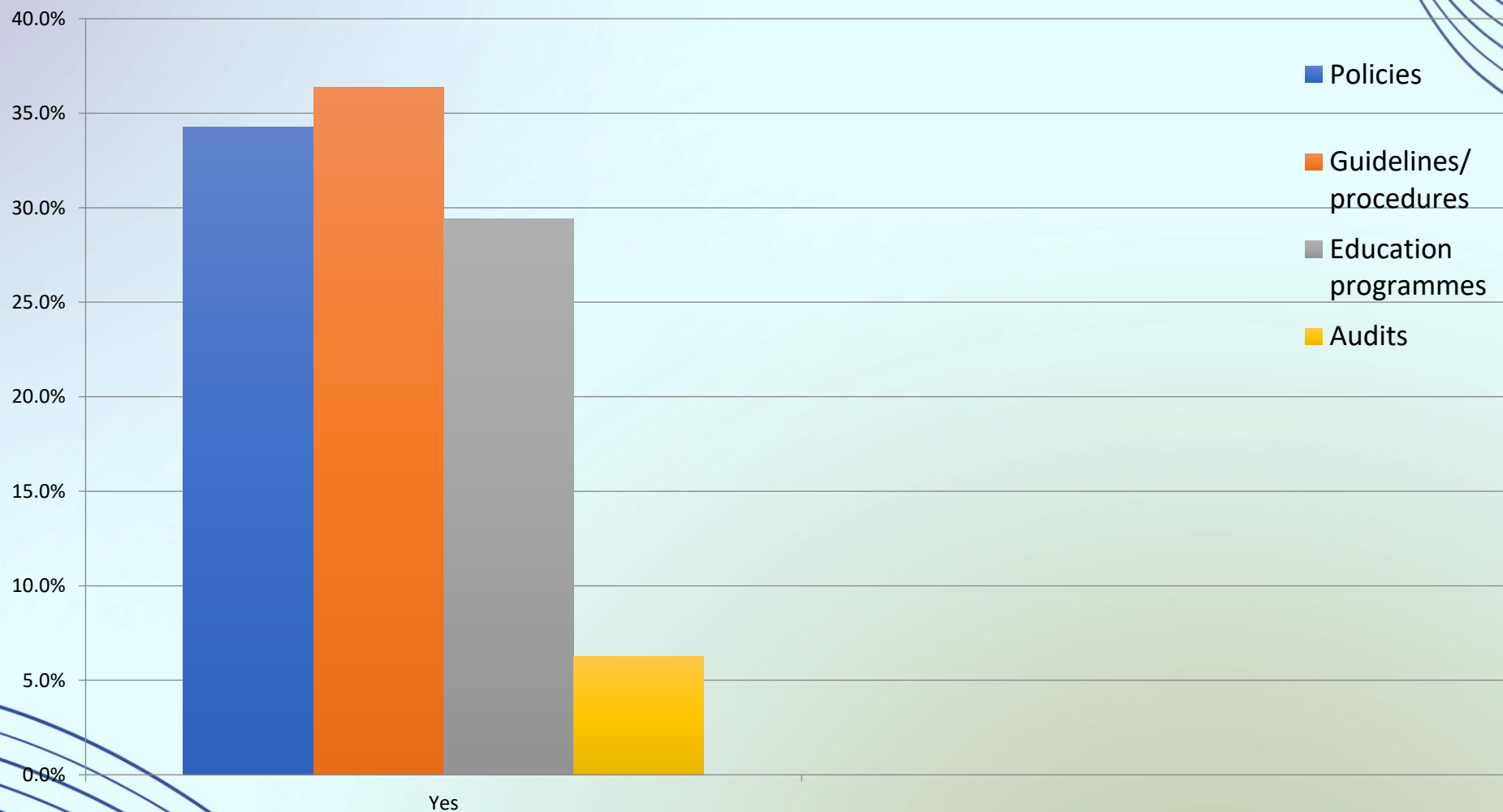
Severe IDD:

1,621.5
service
users

Profound IDD:

1,070.5
service
users

In Place for Cancer Prevention Activities



Policies in relation to cancer prevention

Answered by 17 respondents



Seven responses reflect the standard health advice and awareness of key points: Avoidance of smoking: Healthy weight: Exercise regularly: Healthy diet: Moderation in alcohol consumption; Protection from the sun; Infection protection and regular screenings

Other comments made in relation to Policies

National guidelines and service provision;

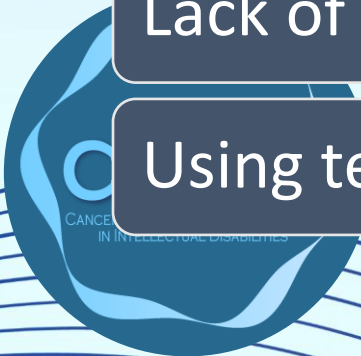
Health literacy;

Quality standards;

Need for multi-agency; collaborations

Lack of policies;

Using technology or apps.



Cancer Prevention Guidelines

- Answered by 17 respondents: Two responses were there were no guidelines in place
- Other guidelines mentioned- Avoiding tobacco products, maintaining a healthy weight, staying active throughout life, and eating a healthy diet aligning with standard global health recommendations.
- The need for a clinical lead support and staff training identified as playing an essential role in implementing cancer prevention guidelines
- Other respondents acknowledged a lack of specific guidelines for individuals with intellectual disabilities (ID), suggesting that they tailor information to meet the needs of their specific population



Cancer Prevention Education

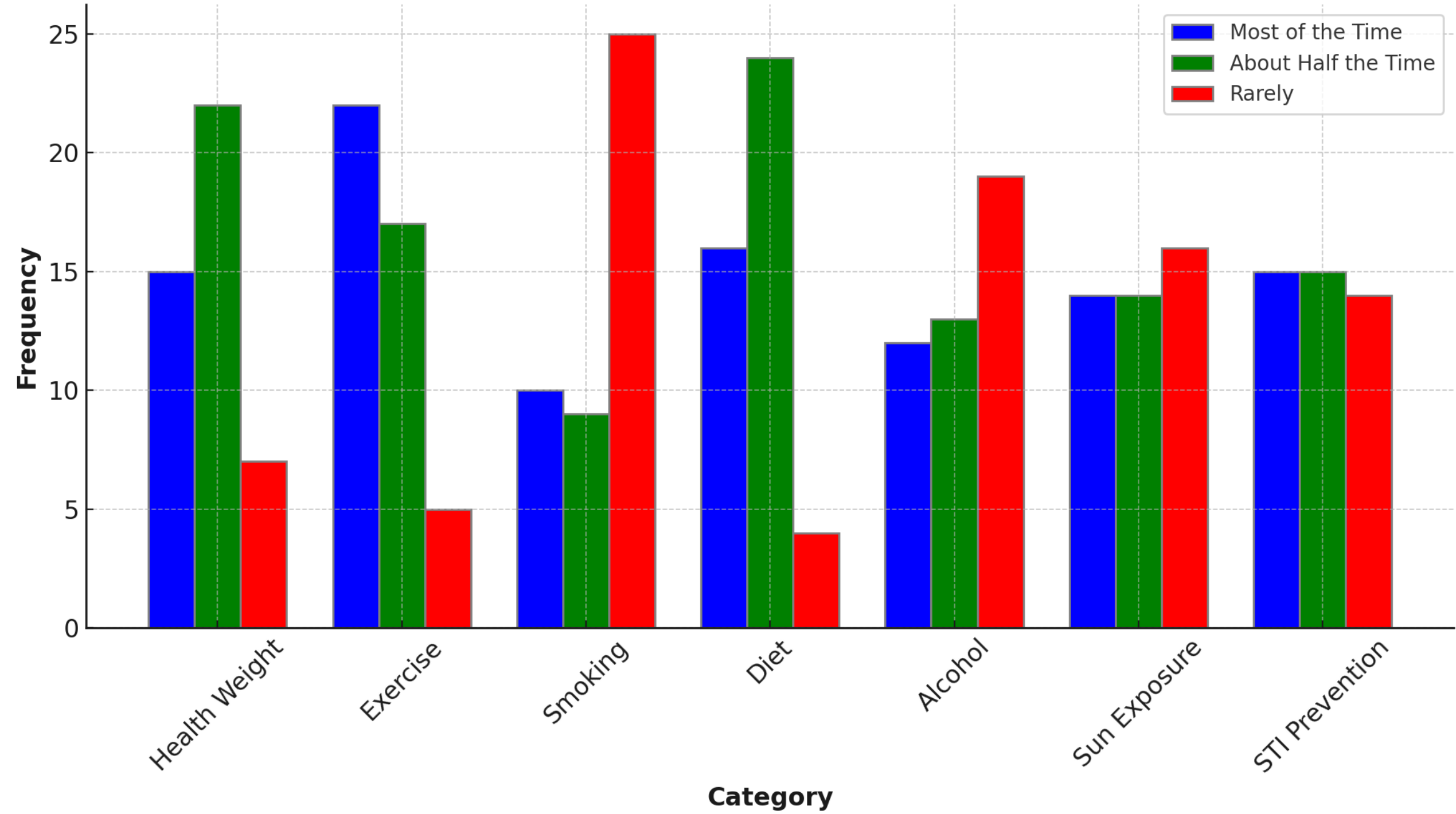


- Answered by 19 respondents
- The programmes being delivered appeared to target individuals with disabilities of all ages, as well as their caregivers and staff (teachers, social workers, psychologists). Education is delivered both in theoretical and practical formats, with cooperation from external experts and agencies
- Evaluation by PWIDD of education programmes provided was included in one respondent (. A scale from brilliant to not okay used to gauge comprehension)
- But many responses focused on challenges and gaps: e.g internal staff may not always have specialized knowledge in the area or lack of specialized programs specifically tailored for cancer prevention

Audits in relation to Cancer Prevention Activities



- Answered by 5 respondents-
- Weight and exercise data were the primary focus of audits for PWIDD.
- Medication: There is some data collection around medications that clients are taking.
- Several responses suggested that no formal audits are conducted on cancer prevention activities within the organization.
- This low response to this question and the responses given indicate a lack of standardized monitoring processes for cancer prevention in ID services

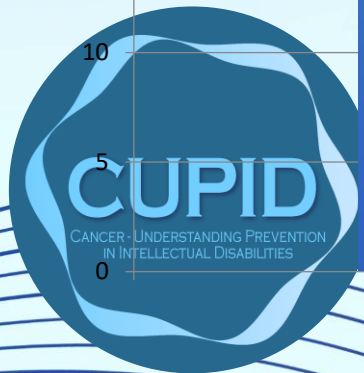




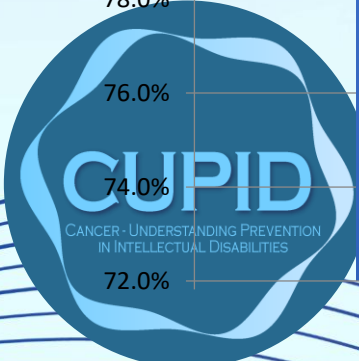
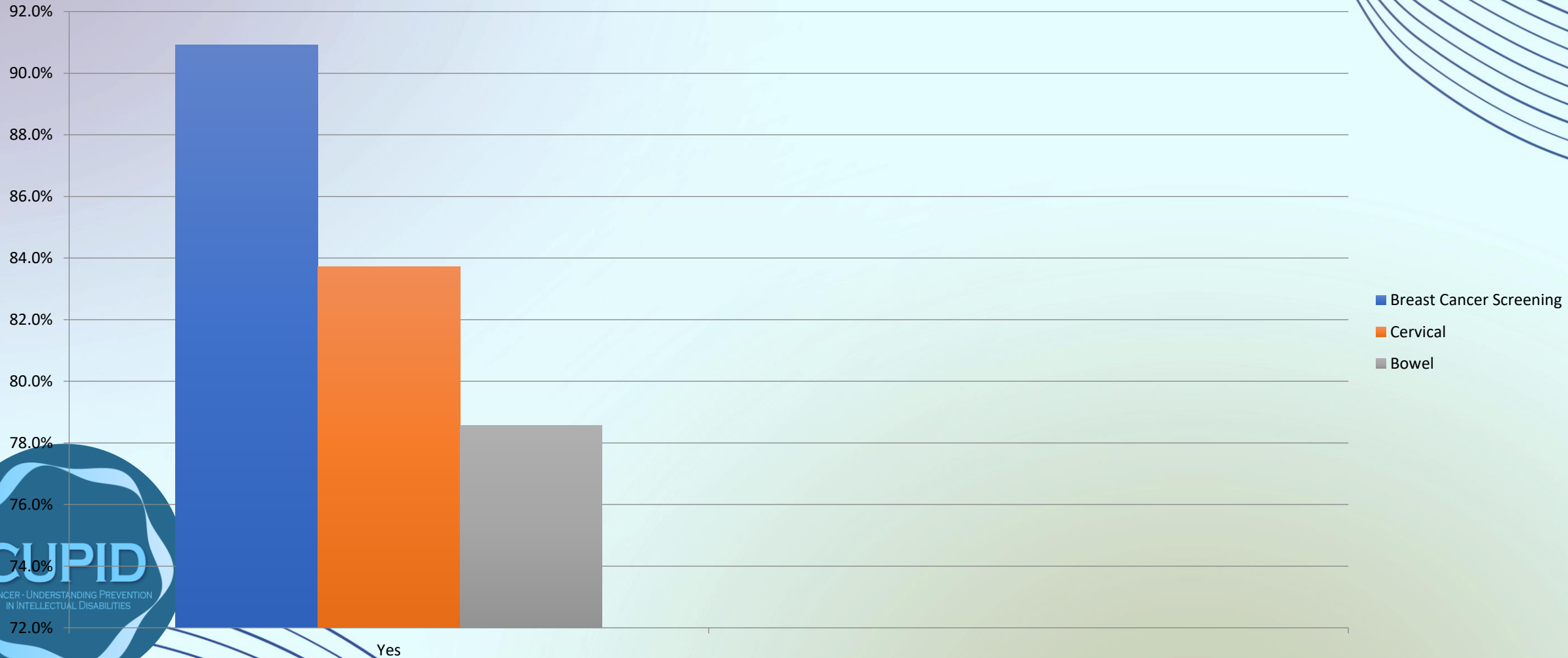
Screening For Cancer



Awareness of National Screening



Awareness of Specific Screening Programmes



PWIDD within service meeting National Cancer Screening Age Criteria

Question answered by 44/63 respondents

```
graph TD; A[Question answered by 44/63 respondents] --> B[Did not know did not know the answer (n=2)]; B --> C[Did not provide this service (n=1)]; C --> D[No one in their service was of an age to take part in a national cancer screening programme (n=3)]; D --> E[Aware of the number of PWIDD who could take part (n=38)];
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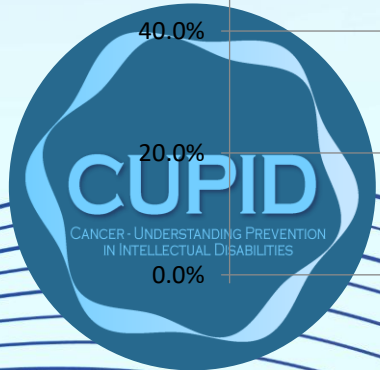
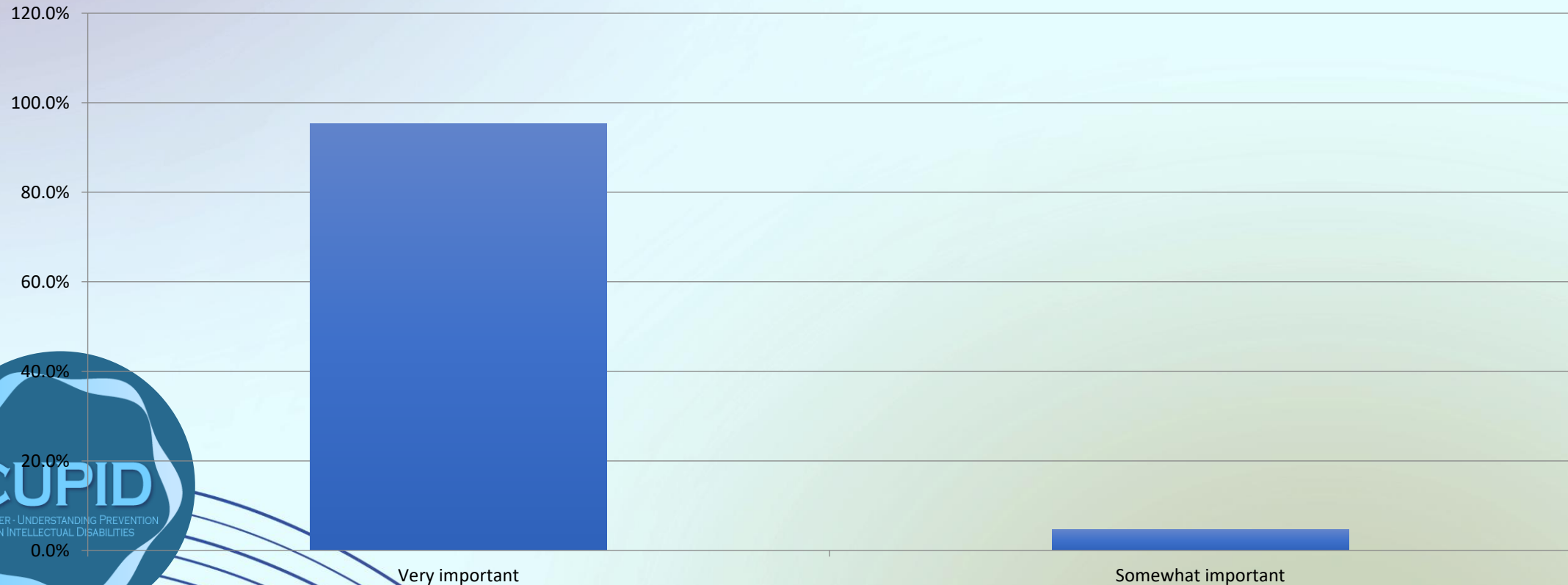
Did not know did not know the answer (n=2)

Did not provide this service (n=1)

No one in their service was of an age to take part in a national cancer screening programme (n=3)

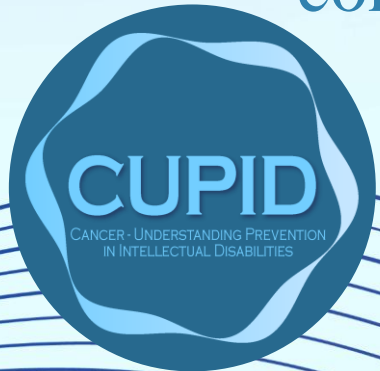
Aware of the number of PWIDD who could take part (n=38)

Importance of Education of PWIDD about Cancer Prevention and Screening



Awareness of Barriers which may impede a PWIDD participating in Cancer Prevention activities?

- Answered by 44 respondents- 41 said yes.
- When asked to give more detail: obstacles faced by individuals, included transportation, health literacy, caregiver biases, communication challenges, and socio-economic inequalities.



Suggestions to Cancer Prevention Activities

- **Education and accessibility**
- **Collaboration between healthcare providers, families and other specialists**
- **Simplicity in communication—**
- **Psychological support and reducing prejudice**



WG2

Led by Dr Martin McMahon and Dr Vladimir Vukovic



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



Working Group 2 and 3 Joint Training School



School of Nursing and Midwifery, 24 D'Olier Street
Monday, 12th – Tuesday, 13th May 2025



WG3

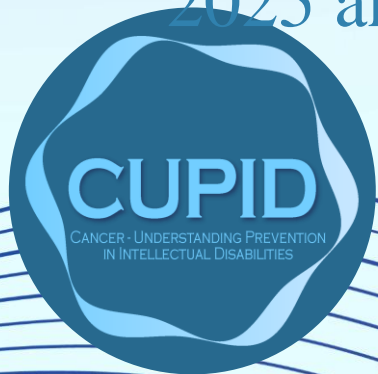
Led by Dr Kate Sykes and Dr Vera Dimitrievska



Ongoing Work- Early Career Researchers

Developing an ‘Early Career Researchers’ (ECRs) network for the project.

WG1 and WG3 are planning a mentorship workshop and programme that includes networking, skills training in writing, grant applications, and communication. This is scheduled before October 2025 and to create a resource section on the CUPID website for ECRs.



WG4

Led by Prof Dr Vladimir Trajkovski and Prof Jean Calleja Aguis



Website and Social Media Platforms

To disseminate research findings and engage with stakeholders, CUPID has developed:

- A dedicated **website** (cupidproject.eu).
- Active **Facebook, Twitter, and Instagram** accounts to **share real-time updates**.



Conducting International Research and Knowledge Sharing

CUPID has facilitated **Short-Term Scientific Missions (STSMs)** to:

- Allow researchers and practitioners to **exchange knowledge across Europe**.
- Develop **collaborative research projects** on **inclusive cancer prevention strategies**.
- Strengthen **cross-border partnerships** in cancer prevention for persons with IDD.



Strengthening Policy Engagement and Advocacy

CUPID continues to engaged with policymakers, NGOs, and healthcare institutions to advocate for:

- EU-wide guidelines for cancer prevention for persons with IDD.
- Increased accessibility in national cancer screening programmes.
- The integration of IDD-specific training into medical education curricula.
- Development of accessible, easy-to-understand educational materials on cancer prevention.
- Training programmes for support persons/caregivers and healthcare providers to enhance awareness and early detection efforts.



Organising High-Impact Conferences and Workshops

CUPID members have presented at major international conferences, forming partnerships with:

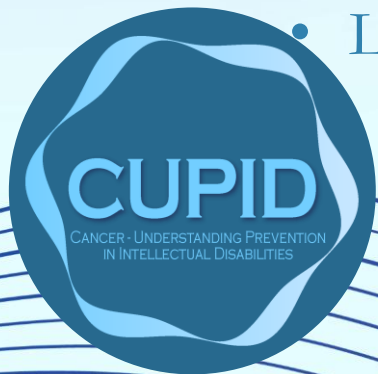
- The **International Cancer Control Partnership (ICCP)** to align persons with IDD-specific policies with global best practices.
- The **World Cancer Congress**, where CUPID researchers discussed strategies for inclusive cancer screening.



Conclusion: A Call to Action

The **COST Action CA21123 (CUPID)** initiative has made incredible strides, but there is still much work to be done.

- The strong message from CUPID's co-production approach is: **"Nothing about us, without us."** **Persons** with IDD must be involved in shaping the policies that affect them.
- This is not just a healthcare issue—it is a human rights issue.
- Let us commit today to turning research into action.
- Let us ensure that cancer prevention **for all** is truly inclusive across Europe.



Thank You



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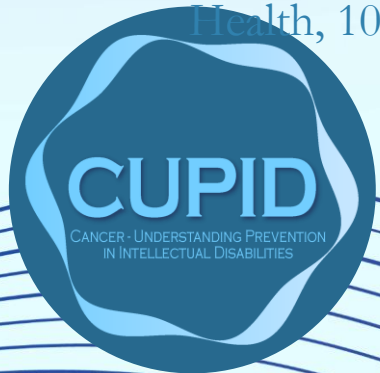
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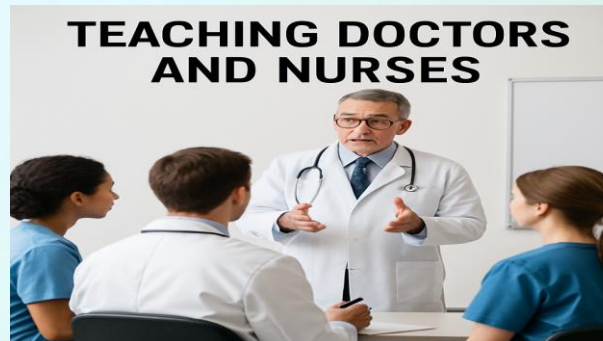


SUMMARY



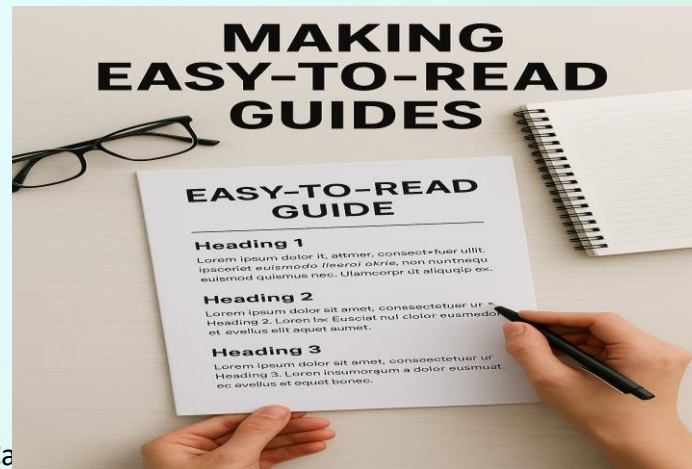
Why We Are Here

- ◆ **People with disabilities can get cancer.**
- ◆ **Screening helps find cancer early.**
- ◆ **But many people do not get screened.**



Problems People Face

- ◆ **Hard to get to hospitals.**
- ◆ **Hard to understand doctors.**
- ◆ **Clinics are not easy for everyone.**



How We Are Helping

- ◆ Teaching doctors and nurses.
- ◆ Making easy-to-read guides.
- ◆ Talking to leaders to change rules.

