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

CUPID- Protocol to Evaluate the Inclusiveness of Cancer Prevention and Screening Activities in Intellectual Disability Services

November 2026

Introduction

A key deliverable from COST Action CUPID (Cancer – Understanding Prevention in Intellectual Disabilities), Working Group 1, is a protocol to help intellectual disability service providers assess the inclusiveness of cancer prevention activities within their services.

Members of Working Group (WG) 1 developed a draft protocol based on empirical evidence of best practices in providing inclusive cancer prevention activities. The Evaluation Protocol aims to support intellectual disability services in reviewing how they provide cancer prevention, education, and screening for people with intellectual disabilities. This self-assessment can identify gaps in service provision and support action plans to address them.

All COST Action CUPID members are invited to provide feedback on this draft protocol, which WG1 will then consider and incorporate into the final protocol. Feedback will also be sought from people with intellectual disabilities via an easy-read questionnaire, formal and informal carers, and intellectual disability service providers.

Explaining the Protocol

Healthy lifestyle choices can reduce cancer risk, and screening helps detect cancer early, when treatment is most effective. The Evaluation Protocol supports services for people with intellectual disabilities in self-assessing cancer prevention, education, and screening activities, with a focus on equity, accessibility, inclusiveness, and person-centred care.

The Evaluation Protocol enables organisations/services to self-evaluate their current cancer prevention, education and training, and support for cancer screening against clearly defined performance levels. Completing the self-assessment protocol helps identify gaps in autonomy, inclusivity, accessibility, and consistency of cancer prevention activities. Use of the protocol and completing the follow-on action plans will support quality improvement planning and staff development. Through self-assessment and action plans, intellectual disability services can strengthen inclusive cancer prevention and screening services for people with intellectual disabilities.

The evaluation protocol consists of eleven key question areas. Table 1 outlines each question area and explains its importance in relation to cancer prevention and screening activities.

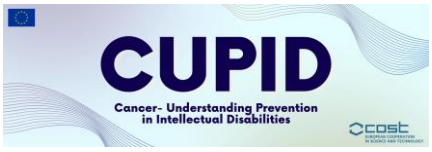
Table 1: Question area with explanation and why it matters

Question Area	**Explanation**	**Why does this matter?**
Governance and Policy	Clear written policies, and compliance with relevant legislation, support inclusive cancer prevention.	Embeds inclusive practice in services rather than relying on individual effort.
Supported Decision-Making and Consent	People with intellectual disabilities are supported to understand information and make their own decisions.	Respects autonomy and the person's will and preferences.
Accessibility and Reasonable Adjustments	Information, environments, and processes are accessible from the start.	Reduces barriers and supports equitable participation.
Cancer Prevention Activities	Prevention activities are tailored and accessible.	Tailored approaches improve understanding, confidence, and engagement.
Screening Uptake and Follow-Up	Support is provided before, during, and after screening.	Low uptake is often caused by system barriers, not lack of interest.
Co-Production and Inclusion	People with intellectual disabilities are partners in design, delivery, and evaluation.	Shared power improves relevance and effectiveness.

Quality Assurance and Improvement	Cancer prevention activities are regularly reviewed and improved.	Supports continuous improvement.
Access to External Training Resources	Staff have access to external cancer prevention training aligned with WHO guidance and national best practice.	Keeps knowledge current and supports consistent, high-quality preventive care.
Cancer Prevention Education for People with Intellectual Disabilities	Accessible, evidence-based cancer prevention education aligned with WHO guidelines.	Builds independence, supports prevention, and promotes health equity.
Cancer Prevention Training for Staff	Staff receive accessible, evidence-based cancer prevention training aligned with WHO guidelines.	Helps staff promote healthy lifestyles, recognise early signs, and support screening participation.
Involvement of Families in Cancer Prevention Activities	Families are involved in cancer prevention activities, with the consent of the person with intellectual disabilities.	Families often support healthy lifestyles and attendance at screening, which helps the person take part.

Each question is scored from 0 to 3 based on the self-assessed level.

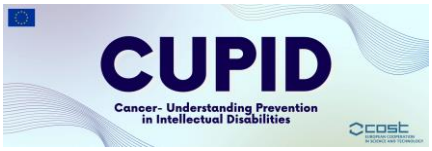
- *Level 0 – Absent: No activity or evidence in this area.*
- Level 1 – *Emerging: Limited or inconsistent practice. Significant gaps* require immediate action in cancer prevention, education, and screening.
- *Level 2 – Developing: Practice is present but not embedded. The organisation/service is developing, requiring targeted improvements* in cancer prevention, education, and screening.
- *Level 3 – Embedded: Rights-based, consistent, and reviewed practice. The organisation/service is embedded; efforts should focus on sustaining and sharing the insights gained in* cancer prevention, education, and screening.



Please note: you may need to consider cultural context and adapt to the national context and legal framework.

How to Use the Evaluation Protocol

1. Review each evaluation domain and level description in detail.
2. Identify the level that most accurately reflects current organisational practice.
3. Record evidence, examples, or observations to justify your rating.
4. Use the Level 3 descriptors as benchmarks for best practice.
5. Develop action plans for domains operating at Level 0, Level 1 or Level 2.
6. Set regular review dates to reassess and update action plans.



Self-Assessment Evaluation Domains

Name of Organisation

_____

Name of Person(s) Completing Self-Assessment

_____

_____

Consent to Take Part in the Evaluation

Please tick each box to confirm:

☐ I have read and understood the information about this evaluation of cancer prevention and screening activities.

☐ I understand that taking part is voluntary and that I can withdraw at any time without giving a reason.

☐ I agree that the information provided in this self-assessment can be used by COST Action CUPID Working Group 1 to evaluate and improve the Evaluation Protocol.

☐ I understand that the information will be stored securely and that no individual or organisation will be identified in any report or publication.

☐ I consent to take part in this evaluation.

Signature: _____ Date: _____

For each domain area, please rate your organisation's level.

1. Governance and Policy

1.1 There are written policies that support inclusive cancer prevention activities and cancer screening for people with intellectual disabilities.

Level	Score (0-3)	Rationale/ Evidence
Level 0- (Absent) Level 1 (Emerging) Level 2 (Developing) Level 3 (Embedded)		

1.2 There is a designated person responsible for cancer prevention activities in the service.

Level	Score (0-3)	Rationale/ Evidence
Level 0- (Absent) Level 1 (Emerging) Level 2 (Developing) Level 3 (Embedded)		

Legislation

1.3 The intellectual disability service complies with legislation relevant to cancer prevention and screening in its region/country.

Level	Score (0-3)	Rationale/ Evidence
Level 0- (Absent) Level 1 (Emerging) Level 2 (Developing) Level 3 (Embedded)		

2. Supported Decision-Making and Consent

2.1 People with intellectual disabilities are supported to understand information about cancer prevention.

Level	Score (0-3)	Rationale/ Evidence
Level 0- (Absent) Level 1 (Emerging) Level 2 (Developing) Level 3 (Embedded)		

2.2 People with intellectual disabilities are supported to make their own decisions about cancer prevention.

Level	Score (0-3)	Rationale/ Evidence
Level 0- (Absent) Level 1 (Emerging)		

Level 2 (Developing) Level 3 (Embedded)		

3. Accessibility and Reasonable Adjustments

3.1 Cancer prevention information is accessible for people with intellectual disabilities.

Level	Score (0-3)	Rationale/ Evidence
Level 0- (Absent) Level 1 (Emerging) Level 2 (Developing) Level 3 (Embedded)		

3.2 Cancer prevention processes are accessible for people with intellectual disabilities through reasonable adjustments being made.

Level	Score (0-3)	Rationale/ Evidence
Level 0- (Absent) Level 1 (Emerging) Level 2 (Developing) Level 3 (Embedded)		

4. Cancer Prevention Activities

Cancer prevention activities are offered to people with intellectual disabilities.

Level	Score (0-3)	Rationale/ Evidence
Level 0- (Absent) Level 1 (Emerging) Level 2 (Developing) Level 3 (Embedded)		

5. Screening Uptake and Follow-Up

5.1 Support is provided for people with intellectual disabilities before cancer screening.

Level	Score (0-3)	Rationale/ Evidence
Level 0- (Absent) Level 1 (Emerging) Level 2 (Developing) Level 3 (Embedded)		

5.2 Support is provided for people with intellectual disabilities during cancer screening.

Level	Score (0-3)	Rationale/ Evidence
Level 0- (Absent) Level 1 (Emerging) Level 2 (Developing) Level 3 (Embedded)		

5.3 Support is provided for people with intellectual disabilities after cancer screening.

Level	Score (0-3)	Rationale/ Evidence
Level 0- (Absent) Level 1 (Emerging) Level 2 (Developing) Level 3 (Embedded)		

6. Co-Production and Inclusion

People with intellectual disabilities are partners in the design, delivery, and evaluation of cancer prevention activities.

Level	Score (0-3)	Rationale/ Evidence for Score
Level 0- (Absent) Level 1 (Emerging) Level 2 (Developing) Level 3 (Embedded)		

7. Quality Assurance and Improvement

7.1 Cancer prevention education programmes delivered to people with intellectual disabilities are reviewed and updated annually.

Level	Score (0-3)	Rationale/ Evidence for Score
Level 0- (Absent) Level 1 (Emerging) Level 2 (Developing) Level 3 (Embedded)		

7.2 Staff training on cancer prevention is reviewed and updated annually.

Level	Score (0-3)	Rationale/ Evidence for Score
Level 0- (Absent)		

Level 1 (Emerging) Level 2 (Developing) Level 3 (Embedded)		

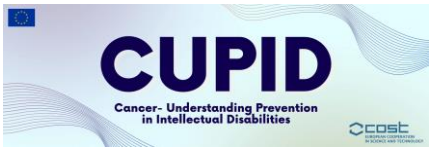
7.3 Supports for people with intellectual disabilities for cancer screening are reviewed and updated annually.

Level	Score (0-3)	Rationale/ Evidence for Score
Level 0- (Absent) Level 1 (Emerging) Level 2 (Developing) Level 3 (Embedded)		

8. Access to External Training Resources

8.1 Access to external training resources related to cancer prevention is available within the organisation.

Level	Score (0-3)	Rationale/ Evidence for Score
Level 0- (Absent) Level 1 (Emerging) Level 2 (Developing) Level 3 (Embedded)		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8.2 Access to external training resources related to cancer prevention is utilised within the organisation.

Level	Score (0-3)	Rationale/ Evidence for Score
Level 0- (Absent) Level 1 (Emerging) Level 2 (Developing) Level 3 (Embedded)		

9. Education on cancer prevention is provided to people with intellectual disabilities

Accessible education on key areas of cancer prevention, based on WHO guidelines, is provided to people with intellectual disabilities.

Education Area	Score (0–3)	Rationale / Evidence for Score
Promotion of a healthy weight		
Physical activity		
Smoking cessation		
Healthy diet		
Sun protection		
Limited alcohol intake		
Vaccination (HPV)		
Stress management		

Healthy sleep habits		
Routine health check-ups		
Early help-seeking behaviour		
Mental well-being / self-care		

10. Training on cancer prevention is provided to staff supporting people with intellectual disabilities

Staff receive accessible, evidence-based training in the key areas of cancer prevention and healthy lifestyles, aligned with WHO guidelines.

Training Area	Score (0–3)	Rationale / Evidence for Score
Promotion of a healthy weight		
Physical activity		
Smoking cessation		
Healthy diet		
Sun protection		
Limited alcohol intake		
Vaccination (HPV)		
Stress management		
Healthy sleep habits		
Routine health check-ups		
Early help-seeking behaviour		
Mental well-being / self-care		

11. Involvement of Families in Cancer Prevention Activities

Families of the people with intellectual disabilities are involved in cancer prevention activities in your service.

Area	Score (0–3)	Rationale / Evidence for Score
Involvement of families in cancer prevention activities		

Conclusion and Follow-On Action Planning

Completing the Evaluation Protocol provides organisations with a structured overview of their current performance in inclusive cancer prevention, education, and screening for people with intellectual disabilities. The 0–3 level scoring system helps services identify strengths, areas for further development, and areas needing immediate action.

This self-evaluation aims not only to measure performance, but to drive meaningful quality improvement. Domains scored at Level 0 (Absent) or Level 1 (Emerging) indicate priority areas with significant gaps that require targeted action without delay. Domains scored at Level 2 (Developing) highlight practices that require consolidation, consistency, and embedding across the organisation. Domains scored at Level 3 (Embedded) reflect good practice that organisations should sustain, review, and share.

After completing the self-assessment, organisations are expected to develop a follow-on action plan. This plan should translate evaluation findings into clear, time-bound actions that strengthen inclusivity, autonomy, accessibility, and equity in cancer prevention and screening pathways for people with intellectual disabilities. Action planning should be proportionate, realistic, and aligned with organisational governance structures, workforce development plans, and quality improvement systems.

Where possible, involve people with intellectual disabilities, family members, and staff in developing and reviewing action plans to ensure improvements are co-produced and grounded in lived experience. Organisations should regularly monitor progress against the action plan and review it as part of ongoing quality assurance and service development.

How to Reach Level 3 Standards

To reach Level 3 standards, organisations must transition from a ‘best interest’ model to a supported decision-making framework. This involves shifting from inconsistent experiences or ‘one-size-fits-all’ approaches to a system in which people with intellectual disabilities' autonomy and choices are the primary drivers of all cancer prevention interventions.

Specific action points which may help to achieve this standard include:

1. Standardise Legal Compliance and Autonomy

- Implement National Frameworks (where available): Formally adopt national legislative frameworks that support consent and autonomy specifically for cancer prevention, education, and screening.

- Respect Personal Choices: Establish protocols to ensure that the decisions of people with intellectual disabilities are fully respected, even if they differ from what support persons might previously have deemed to be in their ‘best interest.’

2. Implement a Programme of Staff Training on Cancer Prevention

- Frequent Upskilling: Move beyond infrequent, optional training to mandatory (where possible) annual or biannual upskilling for all direct support staff.

- Focus on Supported Decision-Making: Training must specifically educate staff on how to facilitate supported decision-making with people with intellectual disabilities, rather than making decisions for them.

3. **Enhance Information Accessibility**

- Diverse Formats: Replace standard documents with information available in multiple accessible formats to ensure people with intellectual disabilities have the tools they need to give informed consent.

- Decision Support: Tailor these formats specifically to support the person's ability to navigate cancer prevention and screening options independently.

4. **Expand Inclusivity and Perspectives**

- Supporting people with severe to profound intellectual disability: Develop specific strategies to consider multiple perspectives when supporting people with profound intellectual disabilities.

- Consistency Across the Organisation/Service: Audit all departments in the service to ensure that cancer prevention activities are consistent across the entire organisation, eliminating the varied experiences found in Level 2.

Follow-On Action Plan Template

Complete this follow-on template after the Evaluation Protocol and update it as actions are implemented.

Domain	**Score (0–3)**	**Summary of Self-Assessment Findings**	**Action Plan Yes/ No**	**Next Review Date**
Governance and Policy				
Supported Decision-Making and Consent				
Accessibility and Reasonable Adjustments				
Cancer Prevention Activities				

Screening Uptake and Follow-Up				
Co-Production and Inclusion				
Quality Assurance and Improvement				
External Training Resources				
Education for people with intellectual disabilities				
Staff Training				
Families involved in cancer prevention				

An action plan can then be developed for each area as needed. A sample action plan is shown below.

Sample Action Plan

Domain	**Identified Gap / Issue**	**Action Required**	**Responsible Person(s)**	**Resources Required**	**Timescale**	**Success Indicator**
e.g. Supported Decision-Making	*Limited use of accessible consent materials*	*Develop and implement easy-read consent resources*	*Service Manager / Clinical Lead*	*Easy-read templates, staff time*	*6 months*	*People with intellectual disabilities report improved understanding and involvement.*

Appendix 1: Explanation of the Levels

Level 0: Absent

At this level, there is no activity or evidence of cancer prevention, education, or screening support for people with intellectual disabilities within the organisation/service.

Level 1: Emerging-Basic/non-compliant

At this level, the organisation/service lacks person-centred support and does not involve the person in their own healthcare decisions.

Decision-Making: The organisation/service provides no supported decision-making for people with intellectual disabilities.

Authority: Family members or support persons primarily make decisions regarding cancer prevention and screening; the person may not be consulted at all.

Approach: The organisation/service applies a 'one-size-fits-all' or blanket approach to cancer education and screening.

Accessibility: Information is not available in easy-read formats, and the organisation provides no reasonable adjustments.

Legal Context: While a legislative framework for supported decision-making may exist, the organisation is not implementing it for the person.

Level 2: Developing/Inconsistent

This level represents a 'middle ground' where some systems exist for cancer prevention, education, and screening, but they are not applied consistently or with full respect for autonomy.

Decision-Making: Some guidance supports decision-making, but it is not comprehensive.

Conflict of Wishes: Decisions are made in the 'best interest' of the person, which may result in actions taken against their expressed wishes.

Staff Training: Training is available but not mandatory and occurs infrequently.

Consistency: The person's experience varies across different parts of the organisation.

Level 3: Embedded-Advanced/Best Practice

At this level, the organisation/service is fully aligned with national legislation and prioritises the autonomy and rights of people with intellectual disabilities in cancer prevention, education, and screening.

Decision-Making and Autonomy: National legislative frameworks support consent and autonomy. The choices and decisions of people with intellectual disabilities are fully respected.

Staff Expertise: Direct support staff are highly informed and upskilled annually or biannually, specifically on supported decision-making for people with intellectual disabilities.

Accessibility: Organisation/service information is available in multiple accessible formats to ensure the person can make informed choices.

Inclusivity: The organisation/service considers multiple perspectives, with a specific focus on supporting people with higher support needs.