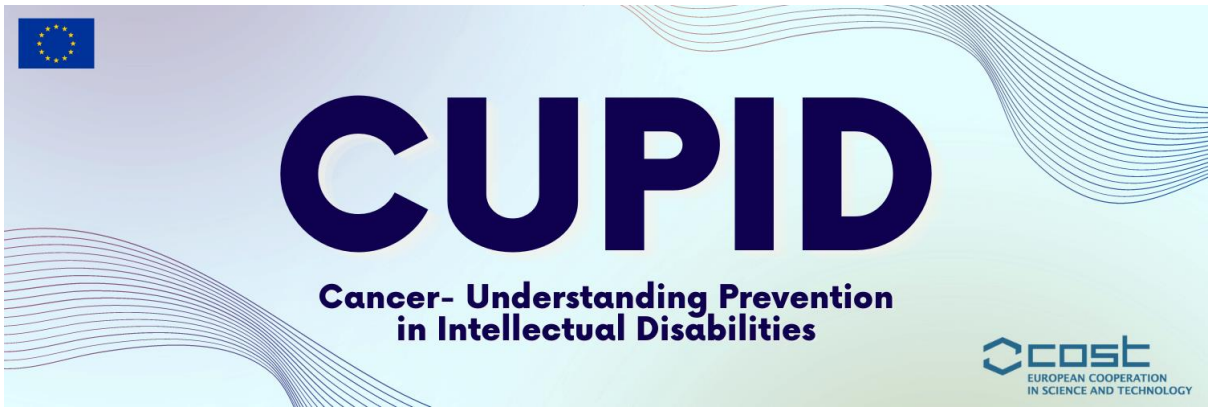


COST Action CA21123
CUPID
Cancer: Understanding Prevention in Intellectual Disability

Working Group 1: Final Report

Cancer Prevention and Screening for People with Intellectual Disabilities in Europe: Stakeholder Engagement, Cross-European Evidence, and the Development and Validation of the CUPID Evaluation Protocols

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List of Abbreviations

Abbreviation	Definition
AAC	Augmentative and Alternative Communication
COST	European Cooperation in Science and Technology
CUPID	Cancer: Understanding Prevention in Intellectual Disability (COST Action CA21123)
ECR	Early Career Researcher
EP	Evaluation Protocol
HIC	High-income country (World Bank classification)
ID	Intellectual disability
PMID	Profound or multiple intellectual disabilities
PwID	People with intellectual disabilities
STROBE	Strengthening the Reporting of Observational Studies in Epidemiology
STSM	Short-Term Scientific Mission
UMIC	Upper-middle-income country (World Bank classification)
UN CRPD	United Nations Convention on the Rights of Persons with Disabilities
WG1	Working Group 1
WHO	World Health Organisation

Executive Summary

People with intellectual disabilities (PwID) across Europe continue to face substantial inequalities in cancer prevention, screening, and early detection. Working Group 1 (WG1) of COST Action CA21123 CUPID was established to ensure that the perspectives, experiences, and rights of PwID were reflected throughout the Action. Over the four-year Action, WG1 drove co-production, stakeholder engagement, accessible communication, and knowledge translation, bringing together researchers, healthcare professionals, educators, policy experts, Early Career Researchers (ECRs), family members, service organisations, and PwID from across Europe.

WG1 pursued three overarching objectives: establish an interdisciplinary European stakeholder network; co-produce knowledge and resources with PwID and key stakeholders; and develop recommendations, educational resources, and practical tools to improve cancer prevention and screening across Europe.

Evidence generation. WG1 undertook European policy analysis, a scoping review, and stakeholder surveys. A cross-European organisational survey (69 services, 16 countries, February to March 2024) found that formal structures supporting cancer prevention are inconsistently embedded: fewer than 35% of services reported formal policies and only 20% reported audit or monitoring systems, with organisational supports and consistent implementation notably less developed in upper-middle-income countries. Barriers included inaccessible communication, variable staff training, fragmented data systems, dependence on family or paid carers to initiate healthcare access, and weak integration between disability services and mainstream screening pathways.

The CUPID Evaluation Protocols. In direct response to these findings, WG1 developed two Evaluation Protocols (EPs): an organisational EP, which is an 11-domain, scored self-assessment instrument with a Follow-On Action Plan template, and a parallel Easy-Read EP for completion by PwID themselves. Used together, they allow organisational self-assessments to be triangulated with the experiences of the people, with both higher and lower support needs, who use those services. The draft organisational EP was validated through a structured expert survey (51 respondents, 16 countries, 25 February to 15 March 2026). Ninety per cent of respondents rated it extremely or very useful, 98% agreed the domain structure was appropriate and comprehensive, and the Follow-On Action Plan templates received the most favourable rating of any item, with no negative responses. Revision priorities centred on scoring-level definitions and provision for people with profound or multiple intellectual disabilities (PMID); 82% of respondents recommended piloting before finalisation.

Capacity building and dissemination. WG1 delivered an international Training School on cancer prevention (Prague, September 2024), a Short-Term Scientific Mission (STSM) in Košice, Slovakia, webinars, workshops, scientific writing activities for ECRs, peer-reviewed publications, conference presentations, and accessible and inclusive educational resources, including Easy-Read materials and cancer prevention educational tools.

Next steps. This report sets out the revisions to be incorporated into the finalised EP and recommends a field pilot, supported by additional accessible formats, as the next phase of work. The networks, tools, and partnerships established by WG1 provide a sustainable foundation for continued implementation, validation, and future funding applications beyond the formal lifetime of the COST CUPID Action.

1. Introduction

1.1 Background and Policy Context

People with intellectual disabilities encounter significant and well-documented health disparities, including poorer overall health outcomes, reduced life expectancy, and a disproportionate burden of preventable mortality relative to the general population. Premature deaths among this group are frequently linked to conditions that are preventable, identifiable earlier, or amenable to better-quality care, a pattern increasingly recognised as a major public health and human rights concern.

Inequalities in cancer prevention and outcomes are particularly pronounced. Evidence consistently shows that PwID are less likely to receive health promotion support or participate in routine cancer screening, and more likely to experience diagnostic delay and poorer outcomes. Contributing factors include inaccessible information, communication difficulties, limited health literacy, limited support for decision-making, lack of reasonable adjustments, transport and environmental barriers, insufficient professional knowledge and training, reliance on family members or paid carers to initiate medical appointments, inconsistent national policies relating to cancer prevention, and diagnostic overshadowing, whereby physical symptoms are misattributed to a person's disability or behaviour.

International and European policy frameworks are, in principle, supportive of more equitable practice. Article 25 of the UN Convention on the Rights of Persons with Disabilities affirms the right to the highest attainable standard of health without discrimination; the World Health Organization has called for disability-inclusive health systems; and the European Commission's Europe's Beating Cancer Plan, 2025 identifies prevention, early detection, and equity as central pillars of cancer control. However, these frameworks have rarely been translated into practical, disability-sensitive prevention pathways that services can implement directly.

Services supporting PwID in residential, community, and day settings are potentially critical sites for prevention, shaping everyday opportunities for healthy eating, physical activity, smoking cessation, primary care access, and cancer screening engagement.

1.2 The Role of Working Group 1

The CUPID COST Action recognised that reducing these inequalities required more than research alone. It required meaningful collaboration with PwID, interdisciplinary partnerships, and practical resources that healthcare and support services across Europe could implement. WG1 was established to ensure the Action reflected the perspectives, experiences, and rights of PwID.

WG1 adopted an inclusive and participatory approach. Rather than positioning PwID simply as recipients of information or services, WG1 recognised their knowledge and lived experience as central to identifying what was meaningful, accessible, and relevant. PwID were actively involved in shaping WG1's direction and activities, and their perspectives, experiences, and

priorities informed the development of resources, activities, and recommendations relating to cancer prevention and screening. This ensured that WG1's work remained grounded in the voices of PwID and contributed to more inclusive, accessible, and responsive approaches.

1.3 Purpose and Structure of this Report

This report is WG1's final report. It documents the objectives, approach, activities, outputs, and impact of WG1 over the lifetime of the Action and presents together the two principal strands of WG1's research programme: the cross-European survey of cancer prevention and screening practice (Section 5) and the development and expert validation of the CUPID Evaluation Protocols (Sections 6 and 7). Section 8 integrates these findings and sets out their limitations. Sections 9 to 12 report education and capacity building, Short-Term Scientific Missions, dissemination, and impact. Sections 13 to 15 set out achievement of objectives, recommendations, and sustainability, and Section 16 concludes.

2. Objectives

WG1 had three overarching objectives:

1. **Objective 1:** To establish an interdisciplinary European stakeholder network.
2. **Objective 2:** To co-produce knowledge and resources with people with intellectual disabilities and key stakeholders.
3. **Objective 3:** To develop recommendations, educational resources, and practical tools to improve cancer prevention and screening across Europe.

These objectives were pursued through regular Working Group meetings, stakeholder consultation, Training Schools, STSMs, webinars, workshops, dissemination activities, and international peer-reviewed publications. Section 13 summarises the extent to which each objective was achieved.

3. Leadership, Collaboration and Co-Production

WG1 adopted an approach based on inclusive leadership, interdisciplinary collaboration, and shared decision-making. The Co-Leads coordinated activities across multiple European countries while ensuring alignment with the overall objectives of the CUPID COST Action.

Collaboration extended beyond academia to include clinicians, healthcare professionals, service organisations, special schools, educators, policy experts, family members, and PwID with lived experience of cancer. PwID were included as active contributors to WG1 activities, participating in discussions and activities relating to accessibility, communication, educational materials, cancer prevention, and the development and modification of the Evaluation Protocols.

A central focus of WG1 was promoting genuine engagement. People with intellectual disabilities' involvement helped ensure that WG1 outputs reflected their lived experience and service priorities, rather than relying solely on professional or academic assumptions. This

collaborative approach strengthened the relevance and accessibility of WG1 activities and contributed to the development of an interdisciplinary European network committed to improving cancer prevention and screening for PwID.

4. Work Programme Overview

The WG1 work programme focused on understanding barriers to cancer prevention and identifying strategies to improve equity and inclusive approaches. It progressed from evidence generation, through tool development and validation, to education, capacity building, and dissemination. Table 1 summarises the principal components.

Table 1. Principal components of the WG1 work programme

Component	Purpose	Reported in
European policy analysis	Examine cancer prevention and screening policies across Europe and the extent to which they address the needs of PwID	Section 4
Scoping review	Review existing evidence relating to cancer prevention and screening for PwID	Section 4
Cross-European organisational survey	Establish the current state of cancer prevention and screening practice in services supporting PwID	Section 5
Development of the Evaluation Protocols	Provide services and PwID with structured tools to assess and improve cancer prevention practices	Section 6
Expert validation survey	Obtain structured international feedback on the draft organisational EP	Section 7
Education and capacity building	Training School, ECR scientific writing activities, webinars and workshops	Section 9
Inclusive education publication	Publish the co-produced Training School approach: Denny, M., Widger, L., Kowalczyk, O., Golubovic, S., Milutinović, D. and Denieffe, S. (2026) Inclusive education for people with intellectual disabilities: insights from a COST Action training school. Public Health in Practice, 12, 100813. https://doi.org/10.1016/j.puhip.2026.100813	Section 9.1
Short-Term Scientific Missions	Extend collaboration and support practical application of WG1 work, including a workshop for PwID on cancer prevention	Section 10
Dissemination and knowledge translation	Reach academic, professional, service, policy, and community audiences	Section 11

Findings across WG1 activities consistently showed that, although cancer prevention and screening policies exist across Europe, they do not always adequately address the specific needs of PwID. Barriers identified across WG1 activities included information accessibility (including the availability of Easy-Read information), communication, staff knowledge and education, supported decision-making, reasonable adjustments, and differences in service provision and policy across countries.

These findings highlighted the need to move beyond identifying barriers towards developing practical approaches that could support improvements in cancer prevention and screening for PwID. This informed the development of educational resources and, importantly, the two Evaluation Protocols, which provide mechanisms for examining the provision of cancer prevention and screening from both organisational and service-user perspectives.

5. Cross-European Survey of Cancer Prevention and Screening Practice

5.1 Design and Methods

A cross-sectional, descriptive, and exploratory survey was conducted through the COST Action CUPID network. WG1 members developed a structured, 46-item English-language survey, informed by the relevant literature and the Action's collective expertise. It comprised five sections: organisational and respondent characteristics; organisational practices and awareness; engagement with national screening programmes; perceived barriers; and organisational supports and improvement priorities.

Organisations providing residential, community-based, or day services to adults with intellectual disabilities across Europe were invited to participate via CUPID network members, who identified and circulated the survey to appropriate respondents (managers, clinicians, or senior staff with sufficient knowledge of organisational practice). The survey was administered via Qualtrics over a two-month period (February to March 2024).

Quantitative data were analysed descriptively (frequencies and proportions, with exploratory chi-square comparisons). Qualitative open-text responses were analysed using reflexive thematic analysis (Braun and Clarke).

5.2 Sample

The sample comprised 69 responses from 16 countries: 12 high-income countries (HIC) and 4 upper-middle-income countries (UMIC) according to World Bank classification. UMIC responses, particularly from North Macedonia and Serbia, were disproportionately represented relative to their share of participating countries.

5.3 Ethics and Reporting

The study received ethical approval from the Faculty of Arts and Humanities Ethics Committee, South East Technological University, Ireland (January 2024), and is reported in accordance with STROBE guidelines.

5.4 Organisational Supports

Formal structures supporting cancer prevention were inconsistently in place across services. Audit or monitoring systems were the least commonly reported support of any type. Services in HIC were consistently more likely to report these supports than services in UMIC, a pattern broadly mirrored in regional comparisons, with Northern and Western Europe reporting more developed supports than Southern and Eastern Europe (Table 2).

Table 2. Organisational supports for cancer prevention reported by services

Organisational support	All services	HIC (approx.)	UMIC (approx.)
Staff education initiatives	55%	65%	50%
Guidelines or procedures	40%	55%	40%
Formal policies	< 35%	50%	30%
Audit or monitoring systems	20%	50%	25%

WG1 cross-European organisational survey (n = 69 services, 16 countries). Income-group values are approximate, as reported in the survey analysis.

5.5 Prevention Activities and Screening Engagement

Lifestyle-related prevention activities (healthy diet, physical activity, smoking cessation, healthy weight) were reported as consistently implemented ("most of the time") in around 40% of responses overall, with marked income-group variation: 65% of HIC responses reflected consistent implementation compared with 35% of UMIC responses.

Awareness of national cancer screening programmes was present, but variable in depth. Eighteen per cent of organisations reported uncertainty regarding service users' eligibility for screening, with several respondents describing reliance on individual staff knowledge rather than systematic tracking.

5.6 Barriers

Thematic analysis of open-text responses identified five interconnected barrier categories:

- **Organisational factors:** lack of centralised data systems to identify eligible individuals, and a lack of formal policies or structured approaches in some services.
- **Staff knowledge and training:** variable staff expertise, particularly among non-clinical staff, affecting awareness and prioritisation of screening.
- **Service user support needs:** reliance on family members or paid carers to initiate and prioritise access to screening, particularly for individuals with more complex needs.
- **Communication and health literacy:** the need to adapt information to individual understanding, alongside examples of good accessible communication practice.

- **System integration:** a mixed picture of positive inter-agency collaboration alongside persistent fragmentation and poor data sharing between disability services and mainstream healthcare systems.

5.7 Summary of Survey Findings

Cancer prevention efforts for PwID across Europe remain fragmented and insufficiently embedded within routine service provision, with more developed organisational infrastructure, though not universally, associated with higher-income settings.

6. The CUPID Evaluation Protocols

6.1 Rationale

The organisational survey findings directly motivated the development of a structured self-assessment tool. In particular, the low prevalence of audit and monitoring systems (20%), variable staff training, and fragmented data systems indicated a need for a practical instrument that services could use, without external assessment, to review their own practice against defined standards and generate a concrete improvement plan.

WG1's key output was two Evaluation Protocols: an organisational Evaluation Protocol for services and organisations, and an Easy-Read Evaluation Protocol designed specifically for PwID. PwID participated in developing and modifying the Evaluation Protocols (Section 3).

6.2 The Organisational Evaluation Protocol

WG1 developed the organisational Evaluation Protocol based on a review of empirical evidence on best practice in inclusive cancer prevention, combined with the COST Action CUPID network's collective expertise. The protocol supports structured evaluation of services' approaches to inclusive cancer prevention and screening and enables services to self-assess current practice across 11 domains (Table 3).

Table 3. The 11 domains of the organisational Evaluation Protocol

No.	Domain	Focus
1	Governance and Policy	Leadership and written policies supporting inclusive cancer prevention
2	Workforce Capability and Training	Staff skills and confidence in supporting PwID
3	Supported Decision-Making and Consent	PwID supported to understand information and make their own decisions
4	Accessibility and Reasonable Adjustments	Information, environments, and processes accessible from the outset
5	Cancer Prevention Activities	Tailored, accessible education and prevention activity

No.	Domain	Focus
6	Screening Uptake and Follow-Up	Support before, during, and after screening
7	Co-Production and Inclusion	PwID as partners in design, delivery, and evaluation
8	Quality Assurance and Improvement	Regular review and improvement of prevention activity
9	Cancer Prevention Education for PwID	Accessible, evidence-based education aligned with WHO guidance
10	Cancer Prevention Training for Staff	Accessible, evidence-based staff training aligned with WHO guidance
11	Access to External Training Resources	Staff access to appropriate external training and materials

6.3 Scoring Framework

Each domain is scored using a graduated, four-level system, comprising Level 0 (Absent) and three traffic-light levels (Levels 1 to 3):

Level	Description	Action
0. Absent	No activity or evidence in this area	Immediate action
1. Emerging	Limited or inconsistent practice	Immediate action
2. Developing	Practice is present but not embedded	Targeted improvement
3. Embedded	Rights-based, consistent and reviewed practice	Ongoing review

The scoring framework enables services to assess current practice, identify strengths and areas for improvement, and develop realistic action plans for continuous quality improvement. Summary descriptors for each level are provided in Appendix A.

6.4 Evidence Recording and the Follow-On Action Plan

Each domain includes a rationale/evidence field in which services record supporting justification for their score. Completion of the protocol culminates in a Follow-On Action Plan, which links each domain's findings to:

- the required action;
- the responsible person;
- the resources needed;
- the timescale;
- a success indicator; and

- a scheduled review date.

6.5 The Easy-Read Evaluation Protocol

An Easy-Read Evaluation Protocol was developed specifically for direct completion by PwID, using the same scoring format as the organisational protocol. It provides an accessible mechanism for PwID to express their views and experiences of cancer prevention and screening support and services and contribute directly to service evaluation. It covers equivalent themes, including supported choice, understandable information, help accessing screening, involvement in decisions, and information on lifestyle risk factors. An overview of its content is provided in Appendix B.

6.6 Complementarity of the Two Protocols

Together, the two Evaluation Protocols provide complementary perspectives. The organisational protocol enables services to examine their policies, practices, resources, and approaches to cancer prevention and screening, while the Easy-Read protocol captures PwID experiences and perspectives about cancer prevention approaches in their respective service/organisation. Using both enables triangulation between staff-reported and service-user-reported experiences of the same service and helps identify areas of agreement and difference between organisational assessments and the experiences of people using those services. The protocols thereby provide a more inclusive and comprehensive approach to cancer prevention evaluation, and a foundation for benchmarking, identifying areas for improvement, and informing future service development.

7. Expert Validation of the Evaluation Protocol

7.1 Methods

The draft organisational protocol was circulated to the COST Action CUPID network and collaborators for structured feedback via an anonymous online survey, completed between 25 February and 15 March 2026. The survey comprised five sections: overall perceptions; domain structure and content; the scoring system; practical usability; and open-ended reflections on strengths, improvement priorities, and the recommendation to pilot. All respondents confirmed consent. Quantitative items were analysed descriptively, and open-text responses were analysed using reflexive thematic analysis.

7.2 Sample

Fifty-one respondents from 16 countries completed the survey. Respondents were CUPID network members (69% of role selections) and researchers (37%), with smaller proportions of health professionals, ID service providers, and advocates/support persons. Türkiye accounted for 51% of the sample and Serbia for a further 10%, with the remaining respondents spread across the other 14 countries. Experience with cancer prevention in ID services was mixed: 78% of respondents reported five years' experience or less, and 18% reported more than ten years.

7.3 Quantitative Results

Table 4. Summary of key validation survey findings (n = 45–51)

Aspect evaluated	Key result
Overall usefulness	90% extremely/very useful (mean 4.33/5)
Relevance	94% relevant/highly relevant (mean 3.56/4)
Protocol length	90% rated "about right"
Domain clarity	96% agree/strongly agree (mean 4.35/5)
Domain comprehensiveness	98% agree/strongly agree (mean 4.43/5)
Scoring system clarity	Mean 4.16/5; the Level 0 and Level 1–2 distinction flagged for revision
Feasibility of completion	90% feasible/very feasible; most respondents estimated completion in under 2 hours
Follow-On Action Plan templates	Mean 4.27/5, the only item with 100% positive ratings and no negative responses
Content domain coverage (six areas)	88–94% rated "well"/"very well" across all six areas
Provision for PMID	80% agree adequate; lowest mean of any 5-point item (4.10/5), priority for revision
Language appropriateness	96% rated appropriate
Recommendation to pilot	82% yes, 14% maybe, 4% no

7.4 Requested Accessible Formats

Respondents identified additional formats that would support use of the protocol (Table 5).

Table 5. Additional formats requested by respondents

Format	Respondents requesting
Visual / infographic version	63%
Easy-Read version (already in parallel development)	51%
Interactive online tool	43%
Training materials	37%
Video explanations	35%
Case examples	35%
Short summary version	33%
Guidance notes for services	22%

7.5 Qualitative Findings

Strengths identified

- Rights-based, person-centred framing.
- Systems-level coverage of governance, workforce, accessibility, co-production, and quality assurance.
- Integration of cancer prevention within routine service delivery rather than as an external add-on.
- Pairing of self-assessment with structured action planning.
- Graduated performance levels supporting a sense of progress over time.
- The Easy-Read EP version enabling triangulation of staff and service-user perspectives.
- Strong perceived adaptability across diverse national contexts.

Improvement priorities identified

- Clearer definition of the lowest scoring level (Level 0) and sharper differentiation between Level 1 and Level 2.
- Guidance on interpreting total or aggregate scores.
- Reduction of overlap between the three training-related domains.
- More explicit and detailed provision for people with profound or multiple intellectual disabilities.
- Safeguards against self-report bias (for example, evidence requirements).
- Practical implementation supports, such as a step-by-step user guide, sample completed templates, and case examples.
- Scoring guidance that accommodates variation in national healthcare structures.

8. Discussion and Integration of Findings

Read together, the strands of WG1's work form a coherent evidence base. The organisational survey established that formal governance, audit, and training structures for cancer prevention are inconsistently embedded across European ID services, with the weakest infrastructure in upper-middle-income countries and audit/monitoring systems the least developed support of any type (20% of services).

The Evaluation Protocol was designed to respond directly to these gaps, and the expert validation survey indicates that it does so credibly. Respondents rated the domain structure highly comprehensive and clear and gave the strongest endorsement in the entire survey to the action-planning component, precisely the audit-and-improvement function found to be missing in current practice.

The validation survey also surfaced two convergent priorities that should shape the next iteration of the protocol before piloting. First, the scoring architecture, while broadly well rated, requires a clearer lowest-level definition, sharper Level 1/Level 2 differentiation, and guidance for interpreting total scores, to support consistent use across services and countries. Second, provision for people with profound or multiple intellectual disabilities, a population at particularly high risk of exclusion from mainstream prevention and screening pathways, received the most variable and lowest-rated response in the survey and should be strengthened with more explicit guidance before finalisation.

8.1 Limitations

- The organisational survey over-represented upper-middle-income countries, particularly North Macedonia and Serbia, relative to their share of participating countries, and was administered only in English.
- The expert validation sample was concentrated in Türkiye (51%) and Serbia (10%), which should be considered when interpreting the findings.
- Most validation respondents (78%) reported five years' experience or less of cancer prevention in ID services.
- As a self-assessment instrument, the Evaluation Protocol is potentially subject to self-report bias, which respondents identified as an area requiring safeguards.

9. Education and Capacity Building

Education and capacity building were central components of WG1 activity.

9.1 International Training School, Prague

The international Training School in Prague was one of the major educational initiatives undertaken by WG1. Participants developed knowledge relating to cancer prevention, intellectual disability, inclusive educational approaches, the lived experiences of PwID, accessibility, communication, and co-production. The programme incorporated lectures, workshops, group activities, and practical inclusive education exercises that promoted interdisciplinary learning and the exchange of knowledge and experience across countries and professional backgrounds.

9.2 Early Career Researcher Development

WG1 prioritised the development of Early Career Researchers. A scientific writing workshop in Amsterdam and publication activities provided opportunities to develop skills in academic writing, publication strategies, and peer review. These activities strengthened research capacity and encouraged continued international collaboration.

9.3 Webinars and Workshops

Webinars, workshops, and other educational activities further extended the reach of WG1, providing opportunities to share learning relating to cancer prevention and screening, accessibility, Easy-Read communication, and inclusive approaches.

10. Short-Term Scientific Missions

Short-Term Scientific Missions provided an important mechanism to extend collaboration and support the practical development and implementation of WG1 activities.

The STSM in Košice, Slovakia, demonstrated the application of Augmentative and Alternative Communication (AAC), Easy-Read resources, and participatory educational approaches with PwID and special school service providers. It also provided an opportunity to explore how both Evaluation Protocols could be evaluated in service and educational settings.

The STSM facilitated collaboration between PwID, educators, schools, universities, service providers, and technology partners. This strengthened interdisciplinary working and provided opportunities to explore how communication approaches and accessible resources could support participation in cancer prevention education and evaluation. The work undertaken through STSM activities also generated opportunities for further research, dissemination, education, and digital innovation, and contributed to the sustainability of the international networks established through the Action.

11. Dissemination and Knowledge Translation

WG1 adopted an extensive dissemination strategy designed to reach academic, professional, service, policy, and community audiences.

Table 6. WG1 dissemination channels by audience

Channel	Primary audiences
Peer-reviewed publications and conference presentations	Researchers, academic and professional communities
Training Schools, webinars, and workshops	Researchers, ECRs, healthcare professionals, educators, service organisations
Reports and stakeholder engagement activities	Service organisations, policymakers, stakeholders across the CUPID network
Accessible summaries and Easy-Read documents	PwID, families, support staff
Cancer prevention educational tools	PwID, educators, healthcare professionals, service organisations

Cancer prevention educational resources were developed in alignment with the five pillars of the World Health Organization, supporting a broad approach to cancer prevention and health promotion.

The team focused on translating evidence and knowledge into practical, accessible resources. This enabled WG1 to extend dissemination beyond traditional academic outputs and to develop materials relevant to PwID, healthcare professionals, educators, service organisations, researchers, and policymakers. PwID involvement in developing and reviewing accessible resources further supported the relevance and usability of WG1 dissemination activities.

12. Impact

WG1's work has generated scientific, educational, organisational, and societal impact (Table 7).

Table 7. Impact of WG1

Dimension	Impact
Scientific	Strengthened the evidence base for cancer prevention and screening among PwID, including the first cross-European evidence base on cancer prevention and screening practice in ID services; contributed to international publications, presentations, and collaborative research.
Educational	Increased awareness of the barriers experienced by PwID in accessing cancer prevention and screening. The Training School, webinars, workshops, STSMs, and ECR activities supported knowledge exchange and strengthened capacity among researchers, educators, healthcare professionals, and other stakeholders.
Organisational	The two Evaluation Protocols provide practical mechanisms for services to examine cancer prevention and screening provision while also capturing the experiences and perspectives of PwID. Their complementary nature enables areas of agreement and difference between organisational assessments and service-user experience to be identified.
Societal	Promoted greater recognition of the importance of accessible information, meaningful participation, supported decision-making, and appropriate service provision in cancer prevention and screening for PwID. The resources developed provide a foundation for continued improvements in policy, education, service provision, and practice.

13. Achievement of Objectives

Table 8 summarises how each WG1 objective was addressed, with reference to the activities and outputs reported in this document.

Table 8. Achievement of WG1 objectives

Objective	Principal activities and outputs	Status
1. Establish an interdisciplinary European stakeholder network	Network of researchers, healthcare professionals, educators, policy experts, ECRs, family members, service organisations, and PwID; regular WG meetings; organisational survey across 16 countries; expert validation survey across 16 countries; STSM collaboration (Sections 3, 5, 7, 10)	Achieved
2. Co-produce knowledge and resources with PwID and key stakeholders	Involvement of PwID in shaping WG1 direction, in the development and modification of the Evaluation Protocols, and in the development and review of accessible resources; Easy-Read Evaluation Protocol for completion by PwID (Sections 3, 6, 11)	Achieved
3. Develop recommendations, educational resources, and practical tools	Organisational and Easy-Read Evaluation Protocols with Follow-On Action Plan; cancer prevention educational resources and tools; Training School and ECR activities; recommendations for protocol finalisation and future work (Sections 6, 9, 11, 14)	Achieved; Evaluation Protocol revision and field pilot recommended as the next phase

14. Recommendations and Next Steps

14.1 Finalisation of the Evaluation Protocol

Based on the expert validation findings, the following revisions and actions are recommended before wider dissemination of the organisational Evaluation Protocol:

1. **Revise the scoring system:** define a clear lowest ("Level 0" / non-existent practice) category, sharpen behavioural anchors distinguishing Level 1 from Level 2, and add guidance for interpreting total or domain-level scores. Achieved.
2. **Strengthen PMID provision:** add explicit, detailed guidance and examples addressing people with profound or multiple intellectual disabilities across relevant domains. Future project.
3. **Reduce domain overlap:** review and, where appropriate, consolidate or more clearly differentiate the Workforce Capability, Staff Training, and External Training Resources domains.
4. **Add implementation supports:** develop a step-by-step user guide, sample completed protocols, and illustrative case examples, and consider requiring supporting evidence to mitigate self-report bias.

5. **Produce additional accessible formats:** prioritise a visual/infographic version and a summary version alongside the existing Easy-Read version, reflecting the formats respondents most requested.
6. **Conduct a field pilot:** pilot the revised protocol with a purposive sample of ID services across income settings and regions prior to wider dissemination, incorporating formal usability and, where feasible, reliability testing.
7. **Broaden geographic representation:** actively recruit feedback and pilot participation from under-represented countries to reduce reliance on the current sample's concentration in Türkiye and Serbia.

14.2 Longer-Term Priorities

- Further implement and validate the two Evaluation Protocols through a future funded project, examining their application across different service contexts and European countries and further developing the protocols based on implementation experience.
- Translation of the Evaluation Protocols and educational resources into additional European languages.
- Exploration of digital approaches to implementation and accessibility.
- Continued development of Easy-Read and AAC resources.
- Greater integration of PwID needs within cancer prevention and screening programmes.

15. Sustainability and Legacy

The completion of the CUPID COST Action marks the beginning, not the end, of the WG1 legacy. The networks, resources, knowledge, and collaborations established through WG1 provide a solid foundation for continued activity beyond the Action's formal lifetime.

Continued collaborative publications, dissemination, education, and knowledge exchange will further support the sustainability of WG1 outputs. The international partnerships established during CUPID also provide a foundation for future funding applications, including Horizon Europe, the COST Innovators Grant, and relevant national and international funding schemes.

16. Conclusion

WG1 has achieved its overarching objectives by establishing an interdisciplinary European network, engaging meaningfully with PwID and other stakeholders, and developing practical, educational, and scientific outputs on cancer prevention and screening.

WG1's programme of work has established, for the first time, a cross-European evidence base on the state of cancer prevention and screening practice in ID services and has translated that evidence directly into practical tools. A significant legacy of WG1 is the development of the two Evaluation Protocols: one enabling services and organisations to evaluate their cancer prevention and screening provision, and an Easy-Read Evaluation Protocol enabling PwID to

contribute their own experiences and perspectives. The organisational protocol was judged clear, comprehensive, relevant, and feasible by an international expert panel, with its action-planning component singled out as a particular strength. With targeted revisions to the scoring system and PMID guidance, followed by field piloting, the protocol is well positioned to support ID services across Europe in systematically identifying and closing gaps in inclusive cancer prevention and screening.

Through inclusive leadership, co-production, capacity building, knowledge exchange, and international collaboration, WG1 has developed resources and partnerships with the potential to contribute to continued improvements in cancer prevention and screening for PwID. The work undertaken has established a lasting European legacy and provides a durable foundation for continued development in research, policy, education, service provision, and practice beyond the completion of the CUPID COST Action.

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Appendix A — Evaluation Protocol: Traffic-Light Level Descriptors (Summary)

Table A1. Summary descriptors for each performance level

Level	Summary description
Level 0 — Absent	No activity or evidence in this area.
Level 1 — Emerging (red)	No supported decision-making; decisions made mainly by family/support persons; "one-size-fits-all" approach; no Easy-Read information or reasonable adjustments; legislative framework, if present, not implemented in practice.
Level 2 — Developing (amber)	Some decision-making guidance, but not comprehensive; decisions often based on "best interest" rather than expressed wishes; training available but not mandatory or frequent; experience inconsistent across the organisation.
Level 3 — Embedded (green)	National legislative frameworks actively used to support consent and autonomy; choices of PwID fully respected; staff upskilled annually/biannually; information available in multiple accessible formats; explicit focus on people with profound intellectual disabilities; consistent practice across the organisation.

Appendix B — Easy-Read Evaluation Protocol: Overview

The Easy-Read self-assessment was developed for completion directly by PwID, using the same red/amber/green format as the organisational protocol. It asks about:

- being supported to make choices about health;
- being given understandable health information;
- the service helping the person learn about staying healthy;
- getting help when invited for cancer screening;
- being involved and listened to about health;
- being asked how the service can improve; and
- having received information on smoking, healthy diet, exercise, alcohol, vaccination, and cancer screening.

This companion tool enables direct comparison between service-user and staff perspectives on the same organisation.

Appendix C — Data Sources

- Cross-European organisational survey manuscript (69 organisations, 16 countries, February–March 2024).
- CUPID Evaluation Protocol (draft), Working Group 1.
- Easy-Read Evaluation companion instrument, Working Group 1.
- Expert Validation Survey instrument (online; 51 respondents, 16 countries; 25 February–15 March 2026).
- Expert Validation Survey preliminary results analysis (internal circulation) and underlying response dataset.
- WG1 records of network, education, STSM, and dissemination activities, as compiled by the WG1 Co-Leads.