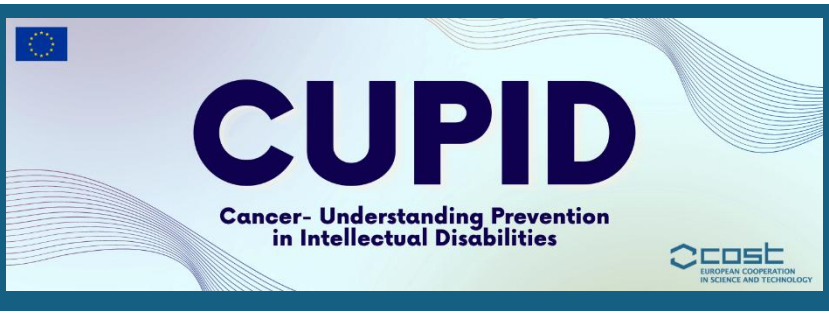


TOWARDS EQUITABLE CANCER PREVENTION AND SCREENING FOR PEOPLE WITH INTELLECTUAL DISABILITIES: WORKING GROUP 3 REPORT

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Contents

About CUPID and Working Group 3 2
WG3 members who contributed 3
WG3 deliverables 4
Background 5
Defining and understanding intellectual disability 5
Health inequalities and cancer risk 5
Cancer epidemiology and diagnostic disparities 6
The broader context of cancer prevention and screening 7
Barriers to cancer screening 7
The need for a research agenda 8
Deliverable 1: Research Agenda 9
Subsection 1a: Systematic Review of Reviews: 11
Subsection 1b: CUPID Website 15
Subsection 1c: CUPID Conference 16
Subsection 1d: Policy Review 17
Next steps 18
Deliverable 2: Training school 20
Other WG3 activities 21
Short Term Scientific Missions 21
Lunch and Learn Series 21
Thank you and acknowledgements: 22
References 23

About CUPID and Working Group 3.

CUPID (Cancer Understanding Prevention in Intellectual Disabilities (ID)) is a COST Action (CA21123) funded by the European Union, bringing together a European network to build a shared research agenda and knowledge base on cancer prevention among people with an ID. The Action responds to evidence that cancer in this population is often only recognised once it presents through behavioural distress or physical changes, rather than through routine screening, and that people with an ID can die of cancer up to two decades earlier than the general population. It is grounded in Article 25 of the United Nations Convention on the Rights of Persons with Disabilities and the Council of Europe Disability Strategy 2017–2023, both of which highlight ongoing gaps in how health systems engage with people with disabilities. CUPID connects academics, researchers, service providers, non-governmental organisations, carers, people with an ID, and policymakers, with objectives spanning research coordination; developing a shared knowledge base and a targeted research agenda; and capacity building, including training schools, researcher mobility, and the development of postgraduate and continuing professional development opportunities in this field. Further information about the CUPID Action can be accessed here: https://cupidproject.eu/

The CUPID Action is split into four Working Groups (WGs), each with a set of tasks and deliverables. WG3 focused on combining the outcomes from WG1 and WG2 into a comprehensive plan for a multidisciplinary approach to develop a research agenda for a universal EU cancer prevention guideline that is responsive to the unique needs of people with an ID. Development of this strategy takes into account the following key areas: 1) improving the overall health of people with an ID, taking into account the recommendations of the European Code Against Cancer; and 2) responsiveness to ensure all people with an ID have the same right to access cancer screening programmes, and that their unique needs are taken into account in the ecological approach to care provision, including economic and literacy requirements.

WG3 members who contributed

Below is a list of WG3 members who have specifically contributed to the work reported in this report. Names are listed in alphabetical order by last name.

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22. Pinar Soylar
23. Chris Stinton
24. Kate Sykes
25. Dušanka Tadić
26. Lau Caspar Thygesen
27. Bilge G. Tuna
28. Gulcan Turan
29. Barrie Tyner
30. Vladimir Vukovic

We would like to thank all members of WG3 for their input and time throughout the CUPID project, and for enabling the completion of WG3 tasks and deliverables.

WG3 deliverables

1) To develop a research agenda for EU-wide cancer prevention guidelines for people with an ID.
2) Organisation of a Training School about health system goals for targeted cancer prevention and screening programmes for people with an ID.
3) Liaise with WG4 to ensure reports are published from working group meetings and information is disseminated through the Action's website and social media accounts; together with the other working groups, and overseen by the Management Committee, participate in organising the Action conference.

Below is a summary of whether the deliverables have been achieved:

	Status	Notes
1) To develop a research agenda for EU-wide cancer prevention guidelines for people with an ID.	Ongoing	We are in the process of completing a review of systematic reviews exploring the barriers and facilitators to cancer screening and cancer prevention for people with an ID. Alongside this, we are triangulating the results from the WG2, CUPID website, and the final CUPID conference. See deliverable 1 for more information.
2) Organisation of a Training School about health system goals for targeted cancer prevention and screening programmes for people with an ID.	Completed	"Equitable Cancer Prevention and Screening: Advancing Inclusion for People with Intellectual Disabilities" was organised by WG2 and WG3, and held at Trinity College Dublin. WG3 day was Tuesday 13th May 2025. See deliverable 2 for more information.
3) Liaise with WG4 to ensure reports are published from working group meetings and information is disseminated through the Action's website and social media accounts.	Completed	We have engaged with WG4 to ensure reports are published from working group meetings and information is disseminated through the Action's website and social media accounts. WG3 also had a key role in organising and presenting at the final conference in Brussels.

Background

Defining and understanding intellectual disability

Intellectual disability (ID) is a neurodevelopmental condition that originates before the age of 18. It is characterised by significantly below-average intellectual functioning alongside limitations in adaptive behaviour (Luckasson, 2023). The World Health Organisation International Classification of Functioning, Disability and Health (WHO-ICF) (2007) and DSM-5 (American Psychiatric Association, 2013) define it similarly, as deficits in mental functioning such as reasoning, problem-solving, planning, judgment, and learning. The DSM-5 classifies ID into four levels based on intellectual functioning: mild (IQ 50-55 to ~70), moderate (IQ 35-40 to 50-55), severe (IQ 20-25 to 35-40), and profound (IQ below 20-25). Support needs increase with severity (Lee et al., 2021).

The aetiology varies and is not fully understood but can involve genetic factors (e.g., chromosomal abnormalities, autosomal trisomies, X-chromosome aneuploidies) and environmental and perinatal factors (e.g., intrauterine infection, teratogen exposure, perinatal trauma, prematurity, childhood malnutrition, brain infections). ID frequently co-occurs with other neurodevelopmental conditions, including autism spectrum disorder and cerebral palsy (O'Reilly et al., 2024; Maulik et al., 2011). Roughly 1% of the global population meets formal diagnostic criteria, but under-recognition and under-reporting mean the true figure is likely higher, with some estimates of 2-3% (van den Bemd et al., 2022; Cuypers et al., 2021; Luckasson, 2023; Thygesen et al., 2024).

Health inequalities and cancer risk

People with an ID experience substantial and largely avoidable health inequalities across the life course, resulting in poorer physical and mental health and reduced life expectancy (WHO, 2023; O'Leary et al., 2018). Contributing factors include difficulty recognising and communicating symptoms, which delays diagnosis and treatment (Evenhuis et al., 2012; Landes, 2017); higher rates of physical inactivity, unhealthy diet, and tobacco and alcohol use; and structural barriers in healthcare, including clinicians' limited knowledge of this population's needs (Landes, 2017; van den Bemd et al., 2022; Sonderlund et al., 2024; WHO, 2024). Multimorbidity is common, frailty develops around 15 years earlier than in the general population (Evenhuis et al., 2012), and avoidable mortality from respiratory disease, epilepsy, cardiovascular disease, and sepsis is disproportionately high (O'Leary et al., 2018; Heslop & Lauer, 2024; Thygesen et al., 2024). Cancer-related mortality is approximately 1.5 times higher than in the general population (Cuypers et al., 2020).

Addressing these inequalities requires inclusive and accessible health systems, reasonable adjustments, better professional education, and equitable access to preventive and primary care (Kuper et al., 2024; Sonderlund et al., 2024; WHO, 2024).

Cancer is a particularly important focus because inequality occurs across the entire care pathway, from lower screening participation to delayed diagnosis and restricted access to treatment (Banda et al., 2024; Yang et al., 2025).

Cancer epidemiology and diagnostic disparities

Reported cancer incidence is inconsistent. A systematic review of prevalence and incidence found that comparisons across studies are limited by differences in how ID is defined, in study settings and in how cancer cases are identified (McMahon et al., 2025). Overall incidence is often lower than or similar to that of the general population (Cuypers et al., 2025), but risk varies considerably by ID-related syndrome, increasing for some cancers and decreasing for others (Banda et al., 2024). A Danish nationwide cohort found incidence elevated in children, modestly elevated in adults under 60 and reduced from age 60. It was close to the general population for people with mild ID and reduced for those with moderate to profound ID (Sørensen et al., 2026). People with an ID therefore should not be treated as a uniform group with respect to cancer risk. Lower reported incidence may also partly reflect under-ascertainment rather than true lower risk (Cuypers et al., 2020, 2022; Sappok et al., 2025).

The evidence is more consistent on disadvantage along the care pathway. A systematic review of cancer diagnostics found consistently lower screening participation and more frequent diagnosis at an advanced or unknown stage (Harmsen et al., 2026). Participation in national breast, cervical and colorectal screening is significantly lower (Cuypers et al., 2020; Sappok et al., 2025; Horsbøl et al., 2023, 2026; Banda et al., 2025), and screening-targeted cancers such as colorectal cancer are more often diagnosed at an advanced stage (Heslop et al., 2022). Diagnosis often occurs at a younger age but a later tumour stage (Cuypers et al., 2020, 2022; Sappok et al., 2025). Symptoms may go unrecognised by caregivers or clinicians, or be misattributed to the ID (often called diagnostic overshadowing) (Cuypers et al., 2020, 2022).

Although primary prevention may not be feasible for genetically determined risks, equitable access to early detection remains critical. Despite well-documented general health disparities, cancer in people with an ID has received insufficient attention in research and policy, leaving substantial gaps in knowledge about epidemiology, care pathways and effective interventions (Stirling et al., 2021; Vukovic et al., 2026b; Cuypers et al., 2020, 2022). Across disability groups, these inequities are associated with lower-quality care, delayed treatment, more limited access to curative therapies and lower survival (Hughes et al., 2022; Kuper et al., 2024a; Tosetti and Kuper, 2023; Yang et al., 2026; WHO, 2026). Closing these gaps, through better understanding of diagnostic disparities, adapted screening programmes and improved access to specialist oncology, should be a priority.

The broader context of cancer prevention and screening

Cancer prevention is key to reducing the global burden: approximately 37% of new cases in 2022 (around 7.1 million) were attributable to preventable causes (WHO, 2026). Primary prevention includes avoiding tobacco, maintaining a healthy weight, eating well, staying active, limiting alcohol, HPV and hepatitis B vaccination, UV protection, and minimising exposure to environmental and occupational carcinogens (WHO, n.d.-a, n.d.-b). Mortality can also be reduced through early detection, which comprises early diagnosis of symptomatic disease, screening for asymptomatic or precancerous change, and timely treatment (WHO, n.d.-b). The WHO Regional Office for Europe (2022) recommends organised, high-quality screening for cervical, breast and colorectal cancer, with appropriate follow-up and timely treatment.

Screening programmes are among the most effective public health interventions for reducing cancer incidence, morbidity and mortality (Eren, 2017; Xia et al., 2023; Yasin and Şeker, 2021; WHO, 2022), and most developed countries offer them (WHO, 2026). Even so, people with disabilities, including those with intellectual disabilities, face substantial inequalities in access to screening. Reported barriers include inaccessible facilities, inadequate accommodations and stigma (Kuper et al., 2024a, 2024b). Pooled evidence shows lower odds of attending breast and cervical screening among women with disabilities (Andiwijaya et al., 2022). This evidence comes mainly from high-income countries, and data from low- and middle-income countries remain limited (Andiwijaya et al., 2022; Kuper et al., 2024b).

Barriers to cancer screening

The evidence points to several recurring barriers:

- fear, distress, and previous negative experiences with screening or professionals (Chan et al., 2022)
- limited knowledge of screening among people with ID, caregivers, and professionals (Chan et al., 2022; Golubović et al., 2024)
- communication difficulties and low health literacy (Chan et al., 2022; Zeilinger et al., 2026)
- physical and logistical obstacles, including mobility, transport, and inaccessible settings (Chan et al., 2022; Sonderlund et al., 2024; Zeilinger et al., 2026)
- difficulties with informed consent, particularly for people with more severe disability (Chan et al., 2022)
- systemic issues, including paternalistic attitudes, non-inclusive health systems, insufficient reasonable adjustments, inadequate professional training, lack of evidence to guide clinical decisions, and the exclusion of people with an ID from designing and delivering prevention services (Tuffrey-Wijne et al., 2013; Tosetti & Kuper, 2023; Sonderlund et al., 2024; WHO, 2022)

- family caregivers highlight a lack of tailored prevention information and limited caregiver knowledge (Golubović et al., 2024)
- living circumstances, age, and life expectancy also contribute to delayed diagnosis (Smihula et al., 2026).

It is reasonable to assume that these barriers translate into worse outcomes, although direct evidence linking them to outcomes is limited.

The need for a research agenda

Despite growing recognition that prevention and early detection are central to reducing cancer inequalities, people with an ID continue to face disparities in access to, participation in, and outcomes from screening and prevention (Heslop et al., 2014; Krahn et al., 2015; WHO, 2022). Important gaps remain in understanding risk factors, screening experiences, prevention behaviours, and interventions tailored to their needs and preferences (Flynn et al., 2017; Wilkinson et al., 2007). An editorial on research priorities across the cancer continuum (Cuypers et al., 2024) extends this to screening. It calls for better epidemiological evidence on who should be screened, at what ages and for which cancers. It also calls for research on alternative methods where standard tests are not feasible, on supported decision-making with accessible information about the benefits and risks of screening, and on implementation approaches that remove existing barriers (Cuypers et al., 2024). CUPID aims to build on these priorities by drawing together evidence from across the Action to identify research and practice recommendations for screening and prevention that reduce disparities for people with an ID.

Research agendas are collective, action-oriented tools for planning, priority-setting, and evaluating outcomes. Most guidance on developing them comes from outside health research (Nasser et al., 2013), and in contemporary health research, involving beneficiaries directly is now considered a prerequisite. For people with an ID, an equity-focused agenda is likely to be most useful, whether grounded in guiding principles (Townsend, 2011) or organised around key areas of inequity (Bogenschutz, 2024). Such agendas help stakeholders agree on priorities and can reduce research waste (Chalmers, 2014).

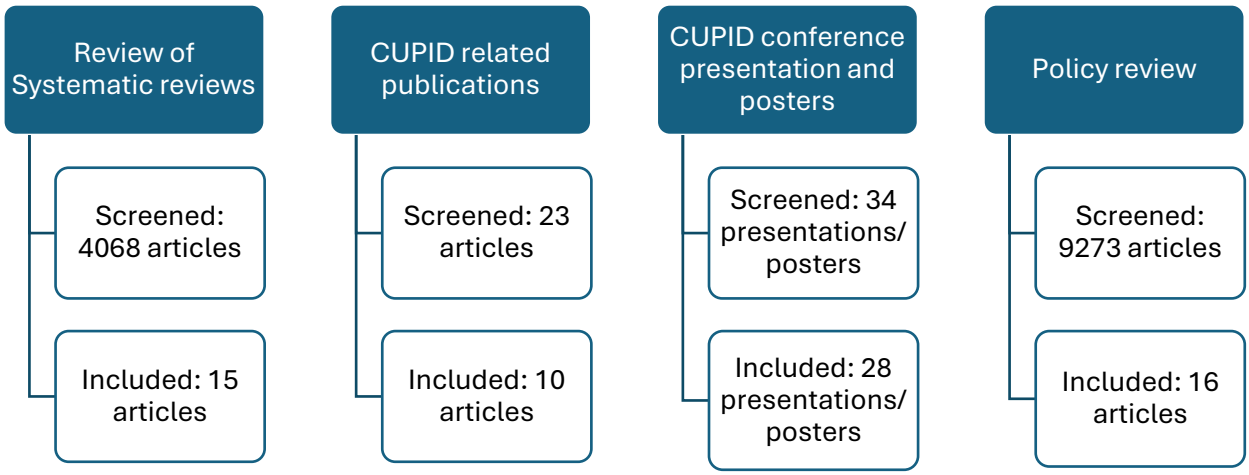
A dedicated research agenda is therefore needed to identify evidence gaps, set priorities, and guide collaborative research on equitable access to cancer prevention and screening. It should bring together multidisciplinary expertise and, above all, the voices of people with an ID, alongside families, carers, healthcare providers, policymakers, and researchers, to support inclusive, evidence-informed strategies that reduce cancer-related inequalities and improve outcomes and quality of life.

Deliverable 1: Research Agenda

This research agenda will be developed through a systematic, collaborative process across the CUPID Action. Working groups WG1 and WG2 generated findings relevant to cancer prevention and screening for people with ID within their respective remits. These findings were fed into WG3, which screened, extracted, and synthesised the information alongside a review of systematic reviews, before triangulating it across data sources to inform the development of this research agenda and its recommendations. To develop the research agenda and recommendations, four data sources were triangulated (Figure 1):

- WG3 review of systematic reviews (Section 1a);
- Publications from the CUPID project website (https://cupidproject.eu/publications/) (Section 1b);
- Presentations and posters submitted to the CUPID conference held in June 2026 (https://cupidproject.eu/cupid-final-conference/) (Section 1c);
- WG2's independently published policy review (Vukovic et al., 2026a) (Section 1d).

Figure 1 Summary of data sources triangulated to develop the research agenda and recommendations.



Multiple members of WG2 and WG3 (primarily KS, VD, VV, MMc, OK, PN, DM, ES, BA) were involved in the identification of sources. Some sources from the CUPID website and conference posters/presentations were excluded, either because they were protocol papers, were not specifically focused on ID and cancer screening/prevention or had already been captured through a different source-identification route.

From each of the sources, different information was extracted depending on the source, as some data items were not consistently available or applicable across all four

sources. The core data extracted related to country, participants, results, and recommendations. Data extraction was conducted using two methods: findings from the review of systematic reviews were extracted using Covidence software, while data from the remaining three sources (the CUPID website, CUPID conference, and policy review) were extracted using Microsoft Excel. Following extraction, and prior to analysis, the data were categorised into primary cancer prevention and cancer screening and merged across the four data sources. For each category (cancer prevention and cancer screening), findings from all four sources were compared side by side using a grid developed in Microsoft Word. Recommendations for policy, practice, and future research were also recorded, noting where these were repeated across multiple sources. Findings were then mapped onto the five levels of the Social Ecological Model (SEM) (Figure 2; Table 1). In line with the aims of this agenda, synthesis of the SEM-mapped findings then focused on two areas. The first was recommendations to improve screening and prevention initiatives, highlighting the reasonable adjustments, and the knowledge, skills, and competencies needed to implement them into policy and practice. The second was research gaps, identified either from direct recommendations made in the sources or from silences (i.e., gaps) in the screening and/or prevention findings; these gaps were used to develop research questions and inform methodology design.

Figure 2: Social Ecological Model (source: Kilanowski (2017))



Table 1: Definitions of model (Obtained from Sykes et al. (2024))

Levels of the SEM	Definition
Individual	Individual-level factors embody characteristics of the individual's knowledge, attitudes, behaviour, developmental history, and demographic characteristics such as gender, race/ethnicity, economic status, and health literacy
Interpersonal	Interpersonal factor includes influences, interactions, and relationships with immediate surroundings, as well as the impact of social networks and support systems including family members, co-workers, and friends
Organisational	Organisational level factors relate to characteristics of social institutions, incorporating organisational characteristics and operational rules and regulations.
Community	Community-level factors encompass the relationships among organisations, institutions, and informational networks.
Policy	At the policy level of the SEM, it relates to local, state, national, and global laws and policies.

Subsection 1a: Systematic Review of Reviews:

The aim of the systematic review of reviews is to explore what can help people with intellectual disabilities prevent cancer and be screened for cancer. To achieve this aim, there are two overarching objectives:

1. To identify the barriers and facilitators relating to cancer prevention and/or cancer screening programmes for people with intellectual disabilities;
2. To identify research gaps and recommendations for future research to improve equity and access to cancer prevention initiatives and screening for people with intellectual disabilities.

Please note, we have purposively omitted detail from the following sections to not restrict our ability to publish this review in an academic journal. If you are interested in the results, please contact the corresponding authors (emails on the first page)

Methods

The review is registered on PROSPERO (https://www.crd.york.ac.uk/PROSPERO/view/CRD420251140644). In October 2025, nine sources were searched: CINAHL Ultimate, AMED, ProQuest Dissertations & Theses

Global, Medline, APA PsycArticles, ASSIA, Scopus, the Cochrane Library, and the first 100 Google Scholar hits for grey literature. The search was framed using the Population, Interest, Context (PICo) framework and supplemented by backwards and forwards citation searching, yielding 4,068 records (3,837 from databases and 231 from citation searching). Eligible reviews were systematic reviews of any design, country or year that included or focused on people with an intellectual disability and addressed cancer prevention and/or screening, including carer or professional perspectives where data relating to ID could be extracted.

Records were managed in Covidence. Titles, abstracts and full texts were each screened independently by two reviewers, with disagreements resolved by a third (moderate inter-rater agreement; Cohen's kappa 0.50 and 0.45). Of 194 full texts reviewed, 15 systematic reviews published between 2016 and 2025 were included (Andiwijaya et al., 2022; Banda et al., 2024; Buckley et al., 2025; Byrnes et al., 2020; Cantrell et al., 2020; Chan et al., 2022; Cithambaram et al., 2025; Elmadani et al., 2024; Klara et al., 2024; Ní Shé et al., 2021; Orji et al., 2023; Pitt et al., 2025; Power et al., 2024; Satgé et al., 2023; Scott & Havercamp, 2016). Ten focused specifically on ID and the remainder covered broader disability groups. Most addressed screening, with fewer covering prevention or both. The reviews included between 8 and 107 studies each, of which 1 to 32 were relevant to ID and cancer screening or prevention. These primary studies were mostly qualitative, cross-sectional or cohort designs, with few randomised controlled trials, and were conducted mainly in the USA and UK.

To assess the extent to which reviews drew on the same evidence, data were extracted from the included reviews, and their primary studies were compiled into a citation matrix, from which the 'corrected covered area' was calculated. Overlap was low: of 102 unique primary studies, 70 appeared in only one review and 14 in two, and the most widely cited studies, McIlfatrick et al. (2011) and Willis et al. (2015), each appeared in six reviews.

Quality appraisal

Methodological quality was assessed independently by two reviewers using the 11-item JBI Critical Appraisal Checklist for Systematic Reviews and Research Syntheses, with discrepancies resolved by a third reviewer. Quality was generally high: nine reviews met at least 10 of the 11 criteria, and one (Power et al., 2024) met all 11. The weakest areas were assessment of publication bias, met by only one review, and independent critical appraisal by two reviewers, not met by five. There were 27 disagreements between appraisers, all resolved by a third reviewer.

Results

Preliminary analysis of the 15 included reviews showed that barriers and facilitators to cancer screening and prevention for people with intellectual disabilities operated

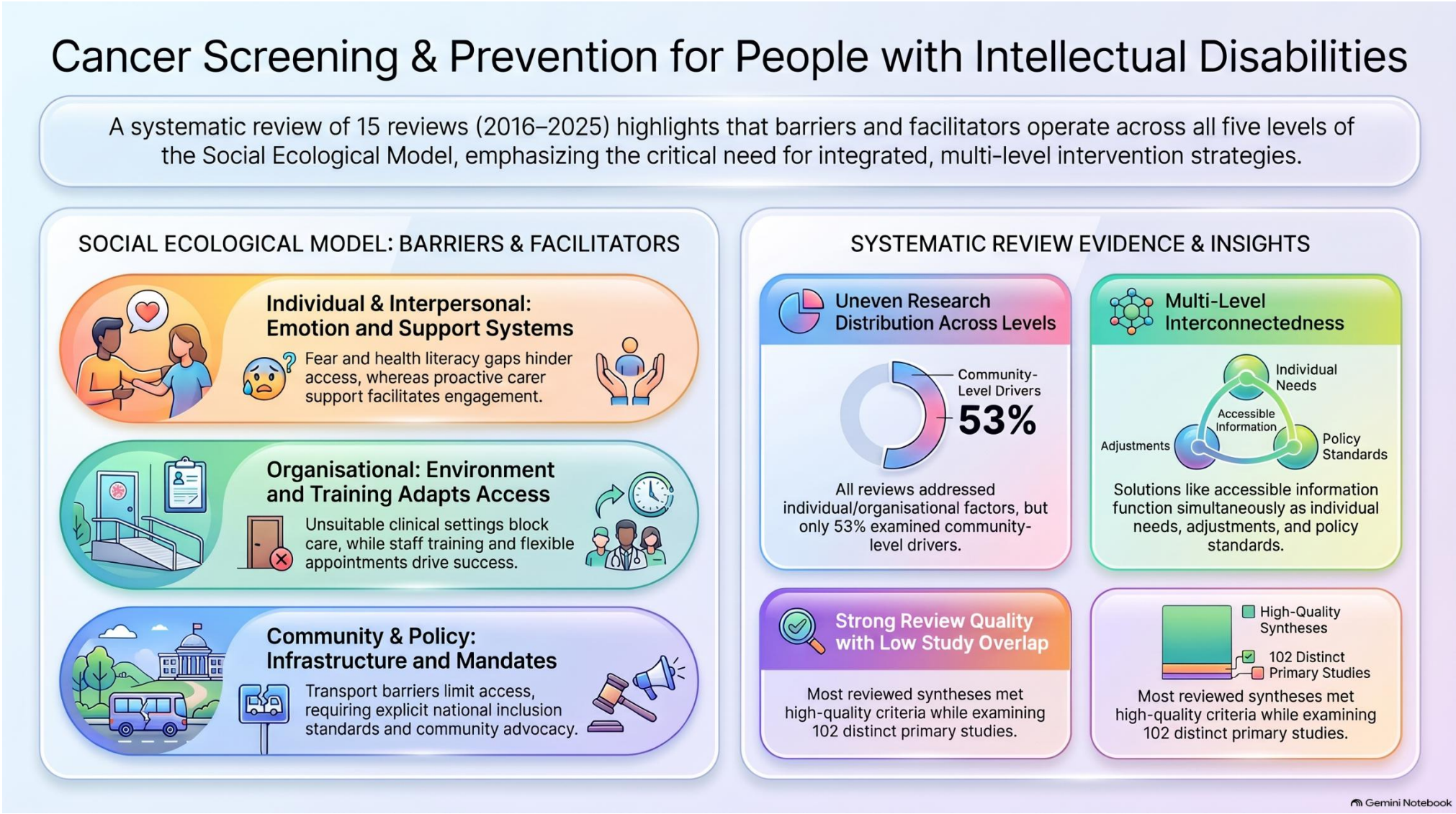
across all five levels of the Social Ecological Model, although the evidence was unevenly distributed. Individual and organisational factors were reported in every review, interpersonal factors in 14, policy-level findings in 10, and community-level factors in only eight, making the community level the least represented. At the individual level, fear, anxiety, embarrassment and pain, limited knowledge and health literacy, and difficulties with communication and consent were the main barriers. Education that built knowledge and confidence, and support for autonomy and informed choice, acted as facilitators, although few reviews measured whether these improvements translated into screening uptake. Personal characteristics, such as disability type or syndrome, were also linked to lower uptake or different cancer risk, but this evidence was limited and largely descriptive.

The interpersonal level centred on the role of others. Family members and carers were the most reported facilitators, providing practical, emotional and decision-making support, and good rapport and continuity with health professionals also helped. However, carers and professionals could act as gatekeepers through assumptions and substitutive decision-making, and limited carer knowledge, high staff turnover and unclear responsibilities weakened the support available. At the organisational level, staff training and reasonable adjustments, including accessible information and longer or flexible appointments, were the most frequently reported factors, with unsuitable environments, weak identification and referral systems, and paternalistic service cultures acting as barriers. Community-level findings were fewer, and related to transport, cost and geography, coordination between health and disability services, and the value of advocacy, outreach and co-designed approaches. Policy-level findings were mainly recommendations, calling for explicit inclusion of people with intellectual disabilities in national programmes, supported by mandates, standards, funding and better data, rather than evidence of tested policy effects.

Taken together, the findings suggest that barriers and facilitators were closely connected across levels rather than acting in isolation. Accessible information, for example, appeared as an individual need, an organisational adjustment and a policy standard, and carers were both the most common facilitator and a potential barrier. These cross-level links point to the importance of multilevel approaches, and to the need for further research at the community and policy levels.

The results of the review are currently being confirmed and written for academic publication. This information is summarised in the infographic below.

Figure 3: Review of Systematic Reviews Preliminary Findings (made by Gemini Notebook (an AI tool))



Subsection 1b: CUPID Website

Method

During an in-person meeting held in Newcastle upon Tyne in May 2026, members of WG3 (KS, VD, PK, DM, VV, ED, BA, DT) reviewed and screened the resources on the 'Publications' page on the CUPID website - https://cupidproject.eu/publications/. The resource information was captured on a bespoke Microsoft Excel document. Data extraction focused on: Title & authors; Document type; Year of publication; A short AI summary generated by Claude for Education; the Language written in, and the direct link to the resource on the CUPID website. There was also room for any comments. The broad inclusion criteria were that resources had to be based on primary empirical data, focus on cancer screening and/or prevention initiatives, and be related to ID. To determine eligibility for inclusion in the research agenda, the assigned WG3 member noted whether they believed the resource was or was not eligible. They provided one of the following answers: Yes; No; Yes - for info/background; Yes - data inclusion; To be confirmed. If to be confirmed was noted, a second person made the decision whether to include the data in the research agenda.

Results

A total of 23 documents were identified from the CUPID website. They were published between 2023 and 2026, mostly in 2025 (n=12; 2023 n=4, 2024 n=6, 2026 n=1), and were mainly written in English (n=20), with two in Polish and one in German. They comprised research papers (n=13), commentaries (n=2), a literature review, a short communication, a policy report, a training school report, two brochures (one in easy-read format), and a magazine and a newspaper article. Sixteen were judged relevant for data inclusion, four were retained as background (the founding CUPID paper, the standard and easy-read brochures, and a European Cancer Organisation report on women and cancer), and three were not relevant (a review of autism and cancer, which did not concern ID, and the Polish magazine article (no primary research) and Maltese newspaper article (no primary research)). On full-text review, three of the 16 were excluded: two surveys of medical and healthcare students because they contained no specific data on screening or prevention, and one protocol outlining the aims of the CUPID policy working group. Together the included papers cover barriers and facilitators at the interpersonal, organisational, individual and policy levels of the SEM, and the epidemiological data on incidence, stage at diagnosis and care disparities can be used for triangulation. Analysis to be completed alongside data from other sources.

Subsection 1c: CUPID Conference

Method

Conference contributions were identified from the submissions to the final CUPID conference, which was held in Brussels in June 2026. A spreadsheet recorded each submission's contributor, submission type, whether they had been emailed, and their response.

Submissions were screened for relevance to cancer prevention and screening among people with an ID. Five were excluded: two were study protocols without results, two fell outside the scope (one on cancer and depression, one on cancer care more generally), and one was excluded without a recorded reason. The remaining 28 were marked for inclusion.

All contributors were emailed by KS to complete the data extraction form. There was one version for presentations and one for posters. The completed form was then provided to KS. The form asked for the title, the focus of the work (screening, prevention or both), the participants (number, country and category), the methods, the key results, any recommendations for practice or policy, and which levels of the Social Ecological Model (SEM) the results aligned to. Contributors could tick more than one level and were asked to explain each tick. A definitions page for the five SEM levels (individual, interpersonal, organisational, community and policy) was included. The forms were completed either by the presenters themselves, or by two members of the research team (KS and OK) from the abstract, presentation or poster where forms were not returned. The completed forms were transposed verbatim into a single Excel workbook, with one row per contribution (28 rows: 16 posters, 8 five-minute presentations and 4 ten-minute presentations). Each row was linked back to the tracking spreadsheet. Where information was not available, such as no human participants for reviews and bibliometric analyses, or no recommendation stated, this was recorded as not applicable or not stated. Queries for presenters were noted in the relevant row.

The data were analysed descriptively. Where a contribution had not specified a focus, the research team classified it as screening, prevention or both using its title and content. The number and percentage of contributions addressing each SEM level were calculated overall and by focus. A contribution could address more than one level, so the percentages do not sum to 100%. The findings were then compared with the SEM levels identified in the review of reviews.

Results

Of the 28 conference contributions (16 posters and 12 oral presentations), 12 (42.9%) focused on screening only, 9 (32.1%) on both screening and prevention, and 7 (25.0%) on prevention only; seven contributions that had not specified a focus were classified

by the research team from their titles and content. Across all contributions, the individual (85.7%, n=24), organisational (82.1%, n=23) and interpersonal (78.6%, n=22) levels were most often addressed, followed by policy (71.4%, n=20). Community was addressed least (25.0%, n=7). Screening-only contributions most often addressed the individual (91.7%) and interpersonal (83.3%) levels, and less often the organisational and policy levels (both 66.7%). Prevention-only contributions addressed the organisational level in every case (7/7) and had the highest community coverage (3/7, 42.9%). Contributions covering both topics most often addressed the organisational level (88.9%), followed by the individual and policy levels (77.8% each). Community was the least addressed level in every group. Community was also the least represented level in the review of reviews (eight of 15 reviews), whereas the individual and organisational levels were the most consistently addressed across both sources, pointing to a shared evidence gap at community level.

Subsection 1d: Policy Review

Methods

As part of WG2, a policy review has been completed. This has now been published (Vukovic et al., 2026a) and is available at https://www.frontiersin.org/journals/public-health/articles/10.3389/fpubh.2026.1925665/full. This review aimed to identify and synthesise European national and international policy frameworks, guidelines, and recommendations for cancer prevention and screening that address this population. A systematic search of policy, recommendation and guideline documents across academic databases, grey literature portals, and organisational sources, to August 2025 was undertaken. The Population, Concept, Context (PCC) framework guided eligibility. Two reviewers per country screened, extracted, and appraised documents independently using the Authority, Accuracy, Coverage, Objectivity, Date, Significance (AACODS) checklist. Synthesis was narrative, stratified by cancer site and cancer control focus.

Results

Sixteen documents met the inclusion criteria, originating from five locations: the UK, the Netherlands, Belgium, Denmark, and the European Union (as a supranational body). No eligible guidance was found for the remaining EU/European member states, including Germany or Ireland. In terms of focus, 15 of the 16 documents addressed cancer screening; of these, one also covered prevention (lifestyle/risk-factor guidance) and two also touched on clinical monitoring/surveillance (for Cowden syndrome and Down syndrome specifically) — these foci are not mutually exclusive, as a single document could address more than one. The included documents span 2003 to 2026. Overall, the review concludes that policy provision for this population is fragmented, concentrated

in a handful of higher-income systems, and skewed almost entirely toward screening access rather than the full cancer care continuum.

Next steps

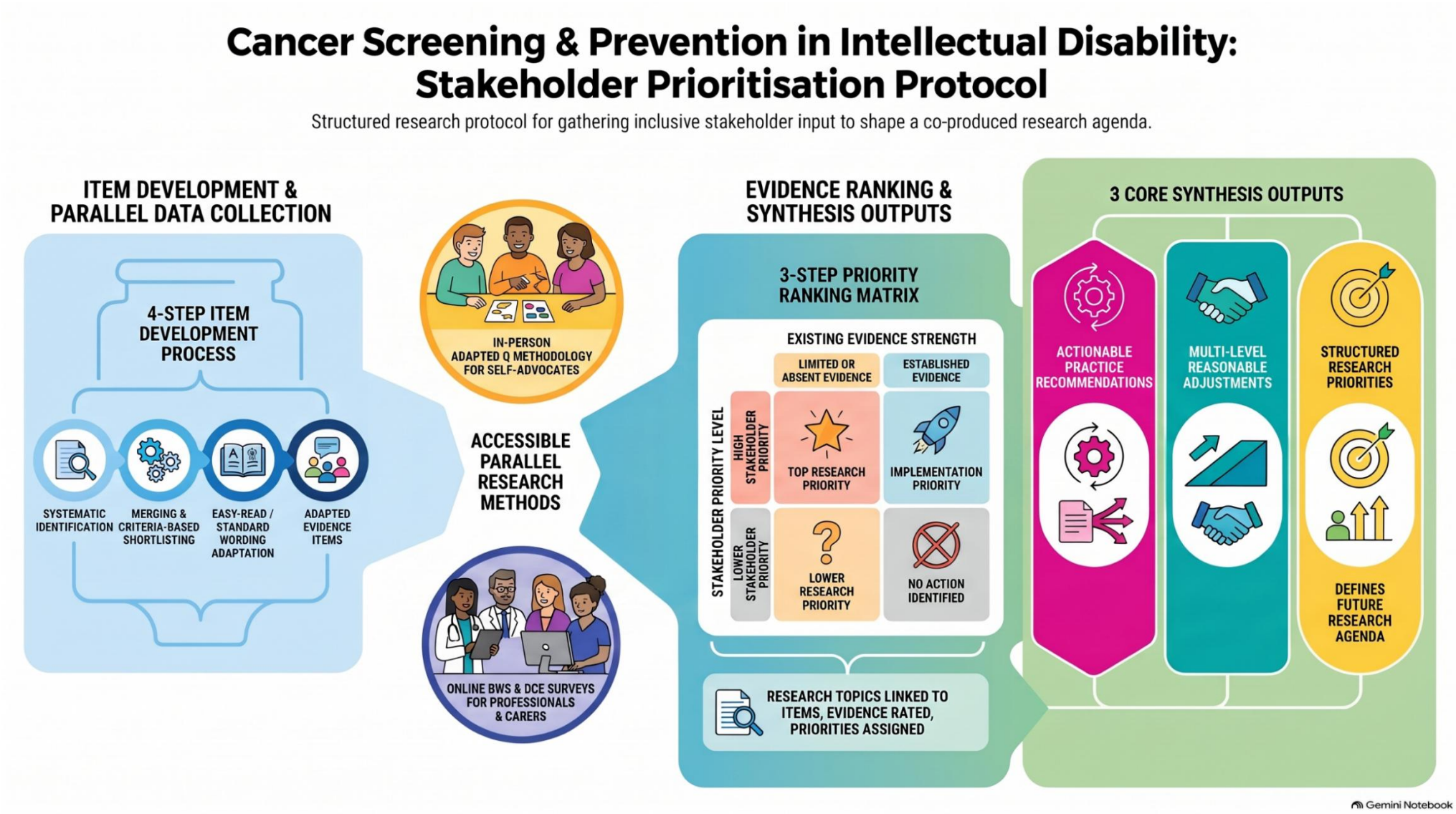
Approximately one year has passed since the searches for the review of systematic reviews were run. The academic database searches will therefore be updated to identify reviews published from October 2025. The updated search has not been completed. It is anticipated that KS will undertake this task in December 2026. Any new reviews that meet the inclusion criteria will be screened and extracted using the same methods as the original review, coded to the SEM, and merged with the existing analysis. The updated findings will then be triangulated with the other data sources (the conference contributions, the CUPID website documents, and the policy review) to produce a comprehensive research agenda covering cancer screening and prevention initiatives for people with an intellectual disability.

Following the synthesis of four triangulated data sources, a stakeholder prioritisation exercise will gather wider input before the research agenda is finalised. The synthesis produces recommendations, reasonable adjustments (changes to how a screening service could be delivered, each offered at more than one level of intensity) and research priorities. Stakeholders will assess the recommendations and adjustments as two separate item sets, developed through a documented process of identification, merging, shortlisting and wording.

Parallel activities will make the exercise accessible to each group. People with an ID will take part in an adapted Q methodology study, facilitated in person with easy-read materials, aiming for at least 40 participants across several European countries. Family carers, healthcare professionals and academics/researchers will complete two online surveys: best-worst scaling for the recommendations, and a discrete choice experiment (DCE) on cervical screening services for the adjustments, building on a June 2026 pilot. Recruitment will use the CUPID network and snowball sampling across the 27 EU member states and the UK, targeting up to 420 people for best-worst scaling and at least 150 for the DCE.

Results will be presented side by side, without an agreement threshold, so that shared and group-specific priorities are reported as findings. Research priorities will not be assessed directly. Each will be linked to the recommendations and adjustments they would inform, and existing evidence will be rated as established, limited or absent, and combined with stakeholder priority. High-priority items with limited evidence will be treated as top research priorities, and those with established evidence will become implementation priorities. Ethical approval will be obtained from Northumbria University, prior to any data collection starting. The findings will finalise the research agenda and be shared as academic papers and an accessible infographic. An infographic summarising this activity is presented below (Figure 4).

Figure 4: Protocol infographic (made by Gemini Notebook (an AI tool))



Deliverable 2: Training school

A two-day CUPID training school, held on 12 and 13 May 2025, brought together presentations and group discussions on equitable cancer prevention and screening for people with an ID. In total, 48 individuals attended in person, and 20 joined selected sessions online.

Day one centred on screening, inequity and policy, and was aligned to WG2 deliverables. Day two, aligned to WG3 deliverables, focused on awareness, accessibility and the voices of people with intellectual disabilities. Sessions outlined the stages of prevention and a scoping review of cancer risk-factor and symptom awareness, and discussed accessible information, which was described as the right resource combined with the right support, using formats such as easy-read, Makaton, sign language, audio and video. A person's cancer journey was used to illustrate the importance of early diagnosis, empathetic communication and proactive care, and a world café identified five priorities: education, the involvement of carers and organisations, empowering people with intellectual disabilities to understand cancer prevention and screening, inclusive health systems, and inclusive screening and prevention policy. Taken together, the messages from the training school emphasised that accessible information, trained and empathetic providers, involvement of carers, and policy that explicitly includes people with intellectual disabilities are needed to achieve equity.

The slides from the second day can be accessed here: https://cupidproject.eu/wp-content/uploads/2025/06/trainingschooltuesday.pdf



Other WG3 activities

In this section, other WG3 activities are described.

Short Term Scientific Missions

WG3 supported two Short Term Scientific Missions (STSMs):

- Dalia Ibrahim (WG3 member) from the Ministry of Health and Population in Egypt completed her STSM, under the guidance of Dr Oliwia Kowalczyk, WG1 Leader in Poland. The focus of the mission was adapting accessible cancer prevention messages for people with ID, aligning with the CUPID Action's goals of improving accessibility, communication, and equity in cancer care.
- Professor Jean Calleja-Agius from Malta joined Dr Kate Sykes, WG3 Leader in England. The visit included taking part in an Easy Read research document project (a team meeting and data analysis workshop), visiting day services for people with a learning disability with the potential to co-host an education workshop with Dr Sykes, and giving a guest lecture in the School Research Conversations series to engage a wider group of colleagues.

Lunch and Learn Series

As part of the Cancer – Screening and Prevention for People with Intellectual Disability – Lunch & Learn – Webinar Series, members of WG3 contributed to the delivery. This included Dr Kate Sykes and Dr Vera Dimitrievska, who each delivered a presentation. Details and viewing figures are given below:

The first webinar was from Dr Kate Sykes, on 25th March 2026. This session was also produced and delivered by Simon, a person with an intellectual disability. During the session, participants explored what cancer screening means, what cancer prevention involves, and why these are important for the health of people with intellectual disabilities, who face significant inequalities in health and cancer outcomes. Crucially, the session also centred the voices and lived experiences of people with intellectual disabilities themselves — their perspectives on cancer, screening, and prevention, and why equitable access to these services matters to them. Their insights remind us that this is not just a clinical issue, but a matter of rights, dignity, and fairness. The link to the video is: https://www.youtube.com/watch?v=j999bgTBqAU&t=1770s. To date, the video has had 88 views on YouTube.

The second webinar was by Dr Vera Dimitrievska, on Doing Research Right: Ethical Standards in Practice, on 27th May 2026. The session focused on ethical considerations in research involving people with intellectual disabilities, emphasising inclusive methodologies, informed consent, and responsible research practices.

The link to the video is: https://www.youtube.com/watch?v=sgwDIBlq3ZI. To date, the video has had 19 views on YouTube.

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