



CUPID

**Cancer- Understanding Prevention
in Intellectual Disabilities**



NEWSLETTER

Newsletter No4 - November 2025



As Chair of the COST Action CA21123 CUPID project, I am pleased to share the latest edition of our project newsletter. Now entering our fourth year, we continue to make excellent progress toward achieving our goals and deliverables. Our membership is growing steadily — we now have 271 members from 41 countries — and we are proud to be building a strong, collaborative international network.

The third year of our project was highly successful, and you can read about many of our recent activities in this newsletter. Highlights include the Working Groups 2 and 3 Training School held in Dublin in May 2025, followed by our 3rd Annual Conference in October 2025. We also supported several Short Term Scientific Missions, including Dr Dalia Ibrahim's visit to Nicolaus Copernicus University in Bydgoszcz, Poland, in August 2025. Development of our Early Career Researcher network is also well underway, with a very successful launch event in Amsterdam in September. We will soon be circulating further information and opportunities to engage. We encourage you to share this newsletter widely within your networks. Be sure to follow us on social media and visit our project website regularly for the latest news and updates.



**Funded by
the European Union**

MEMBERSHIP OF CA21123

CUPID PROJECT

COST is an EU funded programme that supports the establishment of international researcher networks.

COST is committed to bringing out excellence and inclusiveness in science Europe-wide and clearing away obstacles by offering low-barrier entry research networks and creating interdisciplinary research cooperation opportunities for researchers.

The COST inclusiveness policy is developed around three main elements:

1. Geographical spread
2. Career stage: involving young researchers
3. Gender balance



Our current project membership

• Total number of members	271
• Countries Full COST	34
• Country partners	1
• International partner	5
• Near Neighbourhoods Countries	1
• Management Committee members	41
• Gender Balance	Female:203 Male: 68
• Young Researcher Innovators(YRI) Balance	YRI: 129 NON YRI:142
• Inclusiveness Target Countries (ITC) Balance	ITC:156 NON ITC:106

We are always keen to increase our membership for the project and to welcome new members across all working groups.

If interested in joining the project, we would love to hear from you.

See <https://www.cost.eu/actions/CA21123/>

COST Action CA21123

Cancer- Understanding Prevention in Intellectual Disabilities (CUPID)

Dalia Ibrahim
from the Ministry of Health and
Population in Egypt completes her
STSM, under the guidance of
Dr. Oliwia Kowalczyk WG1 Leader

As part of the COST CUPID Action, I conducted a Short-Term Scientific Mission at Ludwik Rydygier Collegium Medicum, Nicolaus Copernicus University in Bydgoszcz, Poland, under the guidance of Dr. Oliwia Kowalczyk WG1 Leader. The focus of the mission is Adapting accessible cancer prevention messages for people with intellectual disabilities, aligning with the CUPID Action's goals of improving accessibility, communication, and equity in cancer care.

Through in-depth discussions with Dr. Oliwia, I reviewed the ongoing project on Cross-National Analysis of Adapted Cancer Prevention Materials, focusing on communication accessibility standards for populations with Intellectual Disabilities (ID) and recommendations for healthcare professionals, including the design of self-examination questionnaire for patients and careers as well as educational leaflets. Awareness and educational materials were demonstrated, and I learned how their accessibility can be tested using tools such as the Automated Readability Test Flesch-Kincaid Test. A major part of the visit centered on simulation and awareness. At the Central Simulation Center in Collegium Medicum, I observed how medical students are trained to communicate with different patient groups, including individuals with ID. I was introduced to simulator resources for self-examination in cancer screening, tangible models for identifying breast lumps, and simulators replicating challenges faced by older adults.

I met with Dr. Oliwia's team across the oncology department, research laboratories, and the university mental health hospital. A tour of the mental health hospital provided insight into admissions, referral processes, and therapeutic approaches for populations, including vulnerable groups. Dr. Oliwia also shared her work with the Kochasz Dopilnuj Foundation, highlighting the value of sharing women's stories with cancer to validate pain and build empathy. By the end of the mission, I had practiced the evaluation of educational and awareness materials from different countries applying the assessment tools learned.

Key achievements of this STSM included learning how to evaluate health materials for clarity and inclusivity, understanding the design of patient and caregiver education tools, and observing effective training methods. The mission also strengthened knowledge sharing, fostering potential partnerships within the CUPID network. I am able to connect practical learning with the Action's objectives, such as promoting equitable access to health information, supporting capacity building among professionals, and enhancing communication with underserved populations.

SHORT-TERM SCIENTIFIC MISSIONS (STSMS)



STSMS

**ENHANCING RESEARCH
COLLABORATIONS AND
KNOWLEDGE EXCHANGE**

Short-term scientific missions (STSM) are exchange visits between researchers involved in a COST Action, allowing scientists to visit an institution or laboratory in another COST Member state participating to CUPID. These scientific missions may last up to six months. Their aim is to foster collaboration in excellent research infrastructures and share new techniques that may not be available in a participant's home institution or laboratory.

WG2 /WG3 TRAINING SCHOOL DUBLIN MAY 2025



2 Day Training School **48 in person attendees** **Presentations and Workshops** **Hybrid basis with 20 participants online**

On 12th and 13th May 2025, Working Groups (WG) 2 and 3 held a joint training school (TS), hosted by Dr Martin McMahon at Trinity College Dublin. Dr Vladimir Vuković, Dr Kate Sykes, and Prof Peter Knapp played an integral part, along with the Training School organising committee, in making this such a success. The TS was formally opened by Senator Dr Tom Clonan widely known for his work on human rights, equality, and disability advocacy.

The training school was titled “Equitable Cancer Prevention & Screening: Advancing Inclusion for People with Intellectual Disabilities.” The TS brought together members across Europe and beyond who shared a commitment to promoting equitable access to cancer prevention and screening for people with intellectual disabilities. Through a programme of expert presentations, interactive workshops, and collaborative discussions, we aimed to build capacity, share knowledge, and foster innovation to address longstanding barriers to inclusion.

Across the two-day event, 48 members from the CUPID COST network met in person. Attendees represented 15 different countries. In addition, 20 people joined some of the sessions online. The training school overall evaluated very well.

Discussions covered a range of topics related to cancer screening and prevention, with a particular focus on people with intellectual disabilities. Key areas included novel technologies in cancer screening, existing screening frameworks, and barriers to access. The conversation also addressed cancer prevention through awareness of risk factors and symptoms, relevant policy developments, and the importance of accessible information. Emphasis was placed on incorporating the voices of people with intellectual disabilities in shaping screening and prevention strategies, and on the role of health systems in ensuring equitable and inclusive approaches.

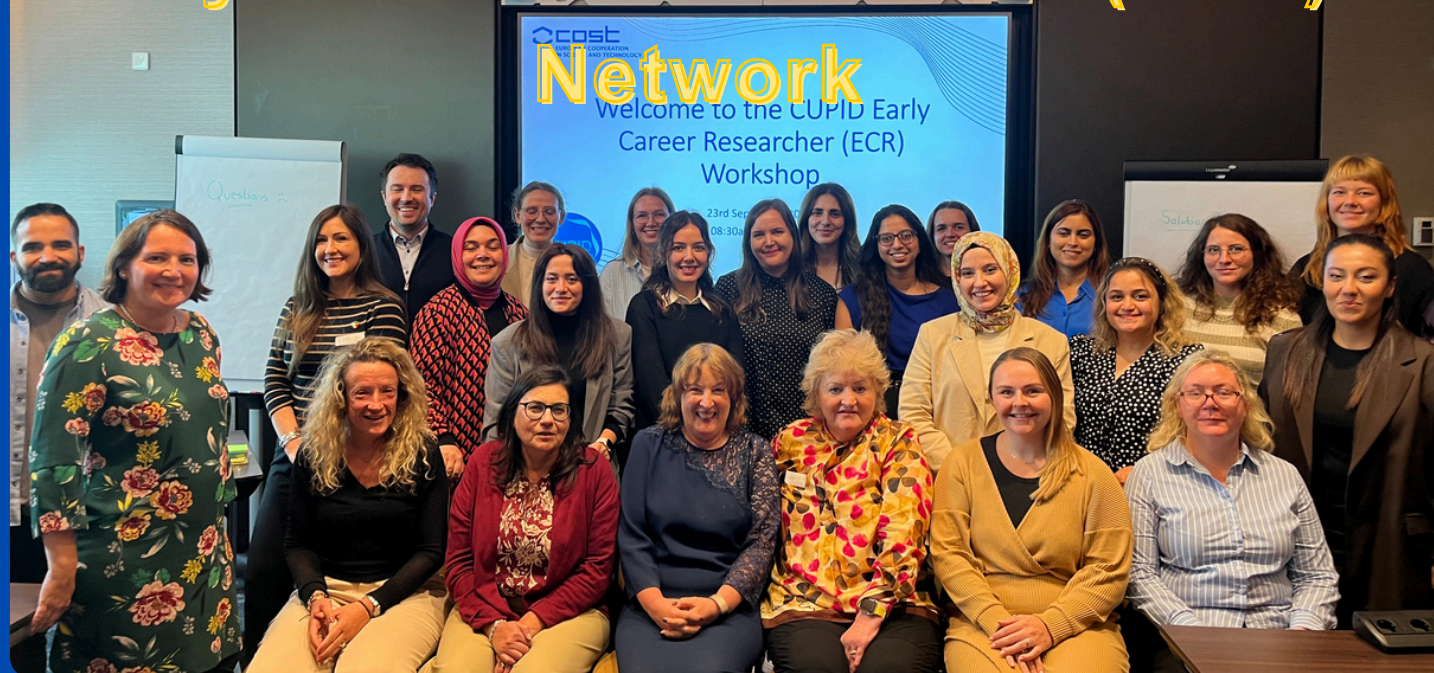
During the training school, members were encouraged to network outside of the formal agenda by attending social events. We would like to thank Dr McMahon, Gavin Dann, Kieva Leslie and Francoise Hickey for arranging a welcome reception and a range of social activities for attendees.

Slides from the two days can be accessed at the following link
<https://www.tcd.ie/tcaid/assets/pdf/breakingbarriers2025/trainingschooltakeawaymessages.pdf>

WG2/WG3 TRAINING SCHOOL IN PHOTOS



Early Career Researchers (ECR)



ECR Network Meeting - Amsterdam 23 September 2025

On the 23rd September we held a workshop for Young Researchers. A total of 23 young researchers attended, from 9 countries. The meeting specifically targeted early career researchers working on cancer prevention and intellectual disabilities, as part of the CUPID COST action. During the morning sessions topics focused on:

1. Scientific writing best practices for ECRs in this specialized field;
2. Strategies for increasing research impact and reach, including journal selection and citation maximization;
3. Case studies consent and research ethics when working with people who have intellectual disabilities, and
4. Issues young researchers are experiencing in terms of writing and publishing, generating solutions.

Following a break, there were presentations on:

- 1) Career development and collaboration opportunities within the CUPID network; and
- 2) Funding pathways and career progression guidance.

The day ended with four young researchers presenting research pitches obtaining constructive peer feedback. The resources presented on the day were shared with the attendees following the workshop.

An evaluation link was shared with participants and all respondents (n=10) reported high relevance, useful insights or connections, largely useful networking, strong logistics, inclusive participation, and appropriate timing. Value was attributed to case examples, networking, and support in clarifying research problems, while suggested improvements focused on depth and structure (e.g., a less basic introduction, a longer break, and more structured networking). Looking ahead, respondents requested topics such as co-production, grant-seeking and collaboration, methods, publication strategies, and leadership, with a minority specifically asking for structured or pair-based networking.

A survey will shortly circulated to co-design the CUPID Early Career Researcher Network, exploring what support/topics young researchers need and how they want it to be ran.

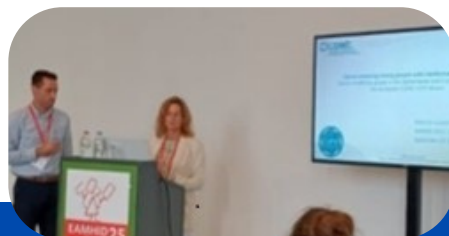
CUPID PRESENTATIONS AT CONFERENCES



Paris Conference on Education 2025 France June 2025

The 4th Paris Conference on Education (PCE2025) hosted at the Sorbonne University International Conference Center, welcomed some 500 participants from 80 countries and over 400 institutions worldwide. Professor Dragana Milutinović, and Professor Špela Golubović (University of Novi Sad, Serbia), Dr Margaret Denny (University of Maribor, Slovenia) and Dr Suzanne Denieffe (South East Technological University, Ireland) presented a workshop entitled: Equitable Access to Cancer Prevention Education for People with Intellectual and Developmental Disabilities: Insights from a Co-produced Training School. The panel presentations and discussion generated strong interest from international researchers, educators, and practitioners in disability and inclusive education. It introduced the 2024 CUPID Training School — a co-produced pan-European initiative involving people with IDD, supporters, clinicians, researchers, and academics — and showed how it integrates co-design, advocacy, and inclusive pedagogies to build knowledge and agency in cancer prevention. Delegates praised the model's person-centred, replicable structure and requested further details on curriculum and evaluation. Productive contacts were made with colleagues across multiple countries exploring inclusive health literacy, opening opportunities for knowledge exchange, joint research, publications, and collaborations.

EAMHID 2025 Ghent, Belgium September 2025



During the European congress on mental health in intellectual disability (EAMHID) in Ghent, CUPID members populated a symposium session on Cancer in People with Intellectual Disabilities: Barriers, Advances, and Future Directions. With representation from all four CUPID working groups, perspectives from different European countries were shared. Tanja Sappok chaired the session and presented a German study on cancer Incidence in adults with Down Syndrome. Maarten Cuypers presented on the participation in cancer screening by people with ID in the Netherlands, and explained how CUPID's WG2 is currently working on reviewing cancer policies in European countries on their attention for people with ID. Theresa Wagner presented findings from an Austrian study on factors affecting breast cancer screening participation from the perspectives of women with ID and caregivers. Final presentation in this symposium was delivered by Nora Sibert and Carmen Koko, who presented on an other pan-European project EUcanScreen, which is complementary to CUPID, and also has attention for the many challenges the ID population is facing around cancer prevention.



5th Asia Pacific Congress of the IASSIDD Singapore October 2025

Martin McMahon and Trine Allerslev Horsbøl chaired a roundtable discussion entitled Addressing Inequities in Cancer prevention and diagnostics for Adults with Intellectual Disabilities: Insights from the CUPID COST Action. The session opened with a brief presentation on CUPID's objectives and progress, followed by three structured discussion rounds addressing: (1) challenges across the cancer care continuum, (2) innovative practices and programs, and (3) priorities for future international collaboration. Participants representing multiple European countries contributed insights from diverse healthcare contexts. The discussion was highly engaged and highlighted persistent inequality and barriers in cancer prevention, diagnostics, and treatment timeliness, alongside examples of good practice. The session concluded with agreement on the importance of strengthening cross-national collaboration and developing joint research and funding proposals to improve cancer care for people with intellectual disabilities.

In addition to CUPID's work, Martin and Trine also shared findings within the intellectual disability field from their own research groups

3RD ANNUAL CUPID CONFERENCE

6 OCTOBER 2025



The Third CUPID Annual Conference was held via the Zoom platform on October 6th, 2025, bringing together participants from across Europe and beyond.

People with intellectual disabilities—estimated to number nearly 200 million globally—continue to face marked disparities in cancer prevention, diagnosis, and treatment. Given that cancer remains one of the leading causes of mortality worldwide, the intersection of oncology and intellectual disability constitutes a crucial yet frequently underexplored domain within global public health. Addressing these inequities requires tailored, evidence-based strategies and inclusive healthcare policies.

Over the past three years, the CUPID network has developed into a vibrant, interdisciplinary community of researchers, clinicians, policymakers, families, and self-advocates. Guided by a shared vision of health equity, the network strives to eliminate systemic barriers, close existing service gaps, and advance inclusive and person-centered approaches to healthcare. The 2025 conference provided a significant platform to:

- Present cutting-edge research and discuss emerging challenges in cancer prevention among individuals with intellectual disabilities;*
- Strengthen international and cross-sectoral collaborations that connect research, policy, and practice; and*
- Promote capacity building among early-career researchers, particularly those from less research-intensive countries.*



Cancer - Understanding Prevention in Intellectual Disabilities

Monday, 6 October 2025
10:00 CET - online 



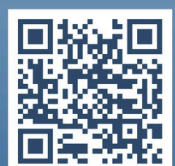
Uniting Knowledge and Practice: Third Annual CUPID Conference

AGENDA

- | | |
|---------------|--|
| 10:00 | Prof. Dr. Vladimir Trajkovski (moderator)
Opening the conference |
| 10:05 - 10:15 | Dr. Margaret Denny, Dr. Oliwia Kowalczyk
Enhancing Inclusion in Cancer Prevention: a Scoping Review to Guide Co-Production and People with Intellectual Disabilities |
| 10:15 - 10:25 | Dr. Vladimir Vuković
An Overview of WG2 CUPID COST Action Activities during 2024/2025 |
| 10:25 - 10:35 | Dr. Vera Dimitrievska, Dr. Kate Sykes
Understanding Cancer Prevention and Screening in People with Intellectual Disabilities: A Systematic Review of Reviews |
| 10:35 - 10:45 | Prof. Dr. Vladimir Trajkovski
Annual report on activities of WG4 |
| 10:45 - 10:55 | Natalie Gil
Understanding the Cancer Diagnosis Pathway: Experiences of Adults with Intellectual Disability and those who Support them |
| 10:55 - 11:15 | Questions, discussion, closing remarks |

Join the Conference

here: <https://setu-je.zoom.us/j/94497084880>
or scan the QR code:



Based upon work from COST Action CUPID, CA 21123, supported by COST (European Cooperation in Science and Technology)

COST (European Cooperation in Science and Technology) is a funding agency for research and innovation networks. Our Actions help connect research initiatives across Europe and enable scientists to grow their ideas by sharing them with their peers. This boosts their research, career and innovation.



<https://cupidproject.eu>

CURRENT ACTIVITIES



CUPID

TASK & FINISH GROUP

As part of the IASSIDD Health Issues SIRG conference in September 2025, an online CUPID Task and Finish group was convened on September 3, 2025.

During this meeting, we decided on three main initiatives related to the CUPID group:

- enhanced written dissemination about CUPID outputs;
- applying for external funding to develop in-person knowledge dissemination events for health professionals, focusing on the interventions that CUPID members have developed; and
- applying for further funding to implement some of these interventions developed by CUPID members into routine clinical practice.

Over 15 CUPID members are part of this project, and the Task and Finish Group held a further meeting on Nov. 3, 2025. For those who were able to attend this meeting, we have decided to focus on developing external funding applications to support hosting in-person knowledge dissemination events for health professionals in multiple EU and affiliate countries. We will have a further meeting in the coming months to continue developing this project idea.

If you would like to be included in further online meetings/emails about the Task and Finish Group, or would like more information, please email Dr. Genevieve Breau at G.Breau@greenwich.ac.uk

PLANNING FOR THE FINAL YEAR OF CUPID

We are currently planning the final year of the project

End of project conference June 2026 - Brussels

We are hoping for a 2 days event next year to showcase the achievements of the project.

If you are interesting in helping us planning this event we would love to hear from you !

STSMs 2026

Applications for STSMs will reopen soon. In the final year of the project we would hope to be able to offer up to 4 STS, topics retained and details of the proposed STSM. If you interested in either completing an STSM or hosting a STSM , please share your ideas as soon as possible!

Publications

We need to hear from anyone who is working on or planning a publication related to the CUPID themes so that we can ensure that the details are posted on the project website.

Dissemination Grants for Conferences

These grants will also be available in the final year of the project .If you have plans to present the project at a conference , please let us know

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CUPID

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