



CUPID

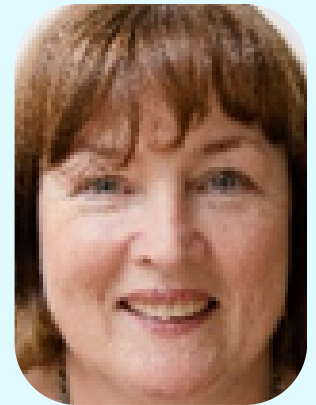
**Cancer- Understanding Prevention
in Intellectual Disabilities**



NEWSLETTER

Newsletter No3 - April 2025

As Chair of the COST Action CA21123 CUPID project, I am pleased to share with you the latest edition of our project newsletter. Now entering our third year, we are making excellent progress toward achieving our goals and deliverables. Our membership continues to grow — we now have 254 members from 38 countries — and we are proud to be building a strong, collaborative international network.



A key initiative is the creation of a database of experts in the field of cancer prevention and intellectual disability. All Action members have been invited via email to contribute to this by completing a short survey. Your input is highly valued, and we encourage you to take a few minutes to participate. For more information, please don't hesitate to contact us at info@cupidproject.eu.

We are establishing an Early Career Researcher (ECR) Network to support and connect emerging professionals within the CUPID community. The emailed survey includes a section to register your interest in joining or supporting this initiative.

This newsletter includes updates on our recent activities and highlights from our Management Committee meeting where we were honoured to welcome Her Excellency Dr. Marie-Louise Coleiro Preca, President Emeritus of Malta, who delivered an inspiring keynote address.

We are looking forward our second Training School, which will take place in Dublin in the next few days. More details are included within this issue . Additionally, we are planning a CUPID webinar in June "Towards Equity in Health Care: Updates from the COST Action CUPID Project".

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	254
• Countries Full COST	34
• Country partners	1
• International partner	2
• Near Neighbourhoods Countries	1
• Management Committee members	41
• Gender Balance	Female:190 Male: 64
• Young Researcher Innovators(YRI) Balance	YRI: 115 NON YRI:139
• Inclusiveness Target Countries (ITC) Balance	ITC:148 NON ITC:97

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)

SHORT-TERM SCIENTIFIC MISSIONS (STSMS)

Amina Banda from Radboud University in The Netherlands completed her STSM Enhancing Knowledge on Cancer Screening for People with Intellectual Disabilities with colleagues from at the Statens Institut for Folkesundhed in Copenhagen



As part of the COST CUPID Action, Amina carried out a Scientific Short-Term Mission (STSM) at the Statens Institut for Folkesundhed in Copenhagen, Denmark in September 2024. The focus of her visit was to exchange expertise on cancer screening among individuals with intellectual disabilities (ID), with special attention to participation rates of the cancer screening programs and healthcare system differences between the Netherlands and Denmark. Amina tells us about her experience:

“During my three-week stay, I collaborated with local researchers to review and compare cancer screening data from both countries, evaluating outcomes from the Dutch and Denmark for breast, cervical and colorectal screening programs. These insights laid the groundwork for a joint scientific commentary to highlight the similarities and differences between national approaches and to inform future health policy.

In addition to the data analysis, I presented my ongoing PhD research and participated in discussions around qualitative research approaches in the ID field. These exchanges strengthened mutual understanding and supported one of COST CUPID’s key objectives: fostering international collaboration and knowledge sharing in cancer and intellectual disability research.

In the final week, I attended the PhD course on Register-based Epidemiology, deepening my understanding of using health registries for research and addressing methodological challenges in register-based studies.

This mission supported collaboration and contributed to a comparative study of cancer screening outcomes for bowel and breast cancer among people with intellectual disabilities in the Netherlands and Denmark. ”

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.

MC & WG4 GROUPS MEETING IN MALTA



On 27 and 28 March 2025 the University of Malta hosted the MC members meeting in the beautiful city of Valletta. This hybrid meeting gave the opportunity to both groups to meet, network and review the work completed to date on the project and discussed the activities planned for Year 3 of the Action. As part of the MC meeting, updates were given on the activities of each working groups, the MC group reviewed the rapporteur comments on the Year 2 progress report to ensure that issues are highlighted and addressed for the successful completion of the project. WG4 meeting also focused on the activities being completed and the membership of that working group.

The members of the MC group were delighted to welcome Her Excellency Dr Marie-Louise Coleiro Preca, President Emeritus of Malta, who delivered a compelling keynote address, with emphasis on the critical importance of fostering inclusive cancer prevention strategies and ensuring that health communication is accessible to persons with IDD. In her presentation, she articulated the challenges faced by this population in accessing health information and services, advocating for tailored approaches that address their unique needs.

Good morning, Everyone

It is an honour to share some brief moments with you today at this important gathering of academics dedicated to addressing a challenge that has long been overlooked in our healthcare systems: cancer prevention for persons with intellectual disabilities.

Let me begin with a humble acknowledgment. I am not a medic, nor am I a healthcare provider or care giver. However, throughout my life and career, I have had the privilege of championing both disability rights, cancer awareness, and research. In the various roles I have held, I have seen firsthand how the intersection of these two critical areas, often results in profound disparities. I have met families who struggle to access even the most basic preventive screenings, caregivers who lack the guidance they need, and individuals whose voices remain unheard in medical spaces. But this issue is not just professional for me. It is deeply personal.



In fact, I have had a recent firsthand experience of a real-life story that continues to weigh on my heart. There was a person I knew — a vulnerable individual with an intellectual disability who was also deaf and non-speaking. For quite some time, he had been suffering from persistent pain, which worsened as the months went by. His caregivers did everything they could. They took him to his physician, they sought advice from specialists, they followed medical recommendations. But because he was unable to express his pain in conventional ways, his suffering remained a mystery to those around him. His condition continued to deteriorate, yet no one suspected a life-threatening illness. It was only in the final stages, when he began losing weight at an alarming rate, that the specialists decided to conduct further tests. And that was when the devastating truth came to light: he had advanced-stage cancer. By then, it was too late. Treatment was no longer an option, and his caregivers could do nothing but watch as he faded away. Heartbreakingly, he passed away very soon after. His story is not unique. It is the reality of many individuals with intellectual disabilities around the world — individuals who endure pain in silence, who miss out on early detection, who are diagnosed when it is too late.

The World Health Organization reminds us that “the highest attainable standard of health is a fundamental right of every human being” (WHO, 2022). And yet, for persons with intellectual disabilities, this right is often compromised, not due to medical limitations, but due to systemic barriers that prevent access to life-saving screenings, and early detection. Cancer does not discriminate, but access to prevention and treatment does. Today, we are here to create awareness and amplify the voices of these vulnerable individuals with the hope of changing the status quo.

Her Excellency full address is available on our project website

<https://cupidproject.eu/mc-wg4-meeting-malta/>

UPDATES FROM OUR WORKING GROUPS

WG1: The interdisciplinary co-production team



Working Group 1 (WG1) of the COST Action CA21123 CUPID project focuses on interdisciplinary co-production to enhance cancer prevention for persons with IDD. Led by Dr Margaret Denny and Dr Oliwia Kowalczyk, a central goal for 2025/6 is to develop a policy protocol to evaluate how inclusive cancer prevention programmes are, ensuring equitable access to screening across Europe. This process will involve a literature review, stake-holder engagement (including clinicians, persons with IDD, and families), data collection through online focus groups and surveys, and the formulation of recommendations to improve accessibility.

WG1 emphasises knowledge co-production, with achievements including the insights gained from the September 2024 Training School. Several publications are underway or planned, including an European survey analysis, reflections on lived experiences from persons with IDD, two book chapters on cancer literacy (accepted by Springer Nature), and a scoping review intended for submission in mid-2025. A Scoping Review Protocol is available as an OSR publication. Additionally, WG1 actively supports 'Early Career Researchers' (ECRs) through mentorship initiatives. In collaboration with WG3, they are planning a workshop and mentorship programme that includes networking, skills training in writing, grant applications, and communication. This is scheduled to occur in July/August 2025. WG1 also aims to expand dissemination through international conferences (e.g., accepted for 2025, Sorbonne, Maribor Universities conferences) and the development of a protocol policy via survey, focus groups, engagement activities, thereby, strengthening the CUPID project's impact and reach across Europe.

WG2: Cancer prevention policies: audit and evaluation

Working Group 2 (WG2) of the COST Action CA21123 "CUPID" (Cancer – Understanding Prevention in Intellectual Disabilities) focuses on auditing and evaluating cancer prevention policies across Europe, especially in terms of access for persons with IDD.

Led by Dr Martin McMahon and Dr Vladimir Vukovic, WG2 aims to exchange knowledge on national health systems, evaluate healthcare access, and identify areas for research and training to improve equity. Key activities include national policy audits, meetings and weekly subcommittee discussions.

A systematic policy search was completed across 44 European countries, with efforts made to include underrepresented regions. A significant achievement was the engagement of new countries and increased membership—114 participants from 26 countries, notably Türkiye and Ireland. WG2 is also organising a Training School in Trinity College Dublin (May 2025), with thorough preparation including agenda setting and presenter confirmations. Outputs include publications on cancer policy inequalities, a systematic policy review, and a survey on perceptions of national policies. The WG continues to lead efforts to highlight disparities in cancer prevention for persons with IDD, advocating for inclusive, evidence-based health policy across Europe.



UPDATES FROM OUR WORKING GROUPS

WG3: Universal EU Cancer prevention strategy methodology



Working Group 3 (WG3) of the COST Action CA21123 CUPID initiative focuses on creating a universal EU cancer prevention strategy for persons with IDD. Led by Dr Kate Sykes and Dr Vera Dimitrievska, its main objectives include developing a research agenda for EU-wide guidelines, establishing standards for equitable access to cancer prevention and screening, and defining necessary competencies for health professionals. WG3 also aims to implement evaluation designs to assess outcomes and have organised a Training School with WG2 addressing

targeted cancer prevention strategies. Progress on the research agenda includes initiating a literature review and developing a protocol to triangulate data across WG1, WG2, and WG3. Activities in development involve framing the agenda theoretically, producing accessible materials (e.g., infographics and easy-read formats), and planning for underrepresented groups such as persons with IDD in secure settings. Regarding the Training School preparation, six meetings have been held with a seventh planned. Responses from members were analysed, attendance confirmed, and programme planning is ongoing in collaboration with WG2. WG3 also organised events in Ireland and Turkey focusing on social determinants of health, culminating in a published article. A scientific meeting in Istanbul was held, along with participation in WG1's training school in Prague. Along with WG1, WG3 is working to establish a mentoring scheme and an Early Career Network to support emerging researchers.

WG4: Dissemination and Outreach

Working Group 4 (WG4) of the COST Action CA21123 CUPID project is dedicated to dissemination and outreach, ensuring that the initiative's goals and activities reach a broad audience. Led by Prof Dr Vladimir Trajkovski and Prof Dr Jean Calleja Aguis, WG4 promotes communication through various accessible platforms, including a dedicated website, social media (Facebook, Twitter/X), blogs, newsletters, infographics, YouTube videos, and open-access publications. WG4 targets diverse stakeholders—researchers, clinicians,

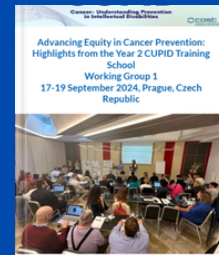


advocacy groups, policymakers, carers, and persons with IDD—by ensuring content is accessible and engaging. Key achievements include maintaining five active social media accounts, updating the project website, producing two infographics, one policy action paper, a booklet, over ten posters, and publishing six academic articles. Ongoing tasks include organising a scientific webinar in June and hosting an annual conference in October 2025. WG4 also actively supports dissemination needs for WG1, WG2 and WG3, contributing to the broader visibility and impact of the CUPID Action. Their work ensures research findings and resources are shared widely and inclusively across Europe.

RECENT PUBLICATIONS



[Women & Cancer: More than 12 million reasons for action](#)
[Date of publishing: November, 2024](#)



[Advancing Equity in Cancer Prevention: Highlights from the Year 2 CUPID Training School](#)
[Date of publishing: November, 2024](#)



[Breaking Barriers: A Commentary on Research Gaps in Cancer and Depression Among Individuals with Intellectual Disabilities](#)
[Date of publishing: January 6, 2025](#)



[Exploring Cancer Prevention Challenges for People with Intellectual Disabilities: Perspectives from Family Caregiver](#)
[Date of publishing: December 6, 2024](#)



["O profilaktyce chorób nowotworowych" and "O wyjeździe do Pragi opowiadają uczestniczki" Społeczeństwo dla Wszystkich](#)
[Date of publishing: December, 2024](#)



[Advancing a Universal European Cancer Prevention Methodology for People With Intellectual Disability: Findings From CUPID Workshops in Ireland and Türkiye](#)
[Date of publishing: January, 2025](#)



[Analysis of the European Union's National Cancer Control Programs: Meeting the Needs of People with Intellectual Disabilities](#)
[Date of publishing: 20 February, 2025](#)



[Gesundheitspolitische Strategien für eine barrierefreie Gesundheitsversorgung von Personen mit Störungen der Intelligenzentwicklung und Krebs](#)
[Date of publishing: 20 February, 2025](#)

CUPID

Working Group 2 and Working Group 3

TRAINING SCHOOL

Dublin, Ireland

12-14 May 2025



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

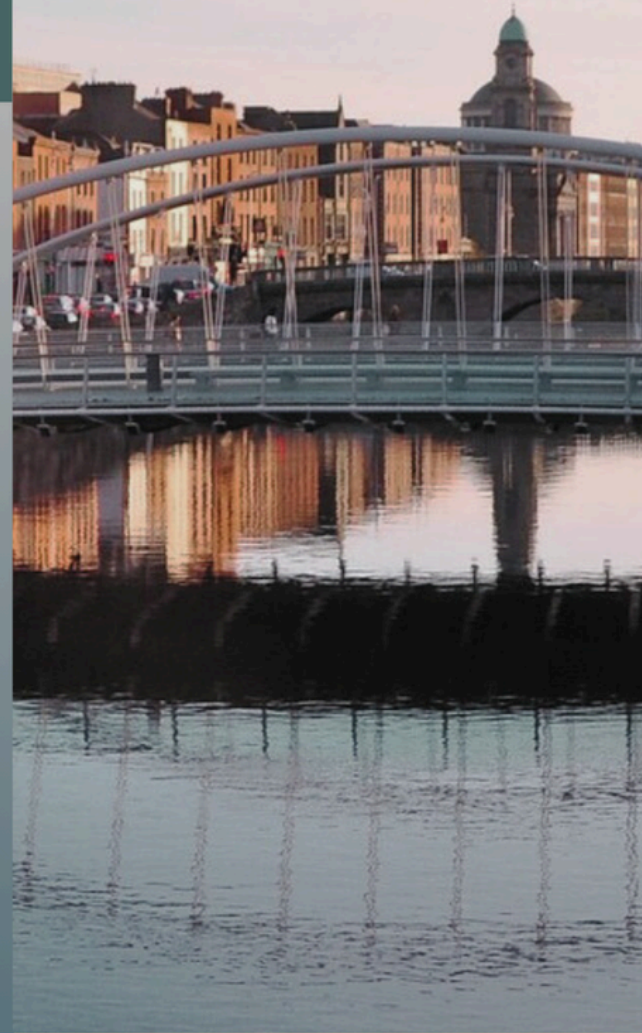
Objectives

To bring people together from different working groups within the CUPID COST action, to gain practical skills, and awareness of methods, and frameworks that they can use or apply in their work.

To equip participants with knowledge on the organisational context and strategies for implementing equitable cancer prevention and screening programmes.

To examine how different health systems approach cancer prevention and screening, including policy that can impact on access and equity for people with Intellectual Disabilities.

To develop recommendation from discussions to improve accessibility and participation in cancer screening programmes and cancer prevention initiatives for individuals with Intellectual Disabilities.



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.



CUPID COST Action, CA 21123
<https://cupidproject.eu>



The date of our next 2 days Training School is fast approaching !! Full Programme has been sent to all members with links to the Zoom sessions to give CUPID members the opportunity to participate online.

Just a reminder that this is a CUPID COST ONLY event !!

CURRENT ACTIVITIES



Towards Equity in Health Care — Updates from the CUPID COST Action

Scientific Webinar

19 June 2025
10:00 CEST



AGENDA

- 1 **Amina Banda**
Cancer screening participation among people with an intellectual disability in the Netherlands
- 2 **Anna de Wit**
Exergames to enhance physical activity for children attending special needs education
- 3 **Monika Chetchowska**
Communication Barriers in Cancer Prevention for Individuals with Intellectual Disabilities
- 4 **Genevieve Breau**
Working together to make a video about bowel screening: an inclusive research approach to video co-production
- 5 **Natalie Gil**
Cancer risk-factor and symptom awareness among people with learning disabilities, paid and unpaid carers, and healthcare practitioners

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Early Career

Researchers Network

As part of our commitment to fostering a collaborative and inclusive research environment, we are currently developing the **CUPID Early Career Researchers Network**

The ECR Network will serve as a platform for connecting early career professionals, sharing resources, and offering opportunities for networking, mentorship, and career advancement. It will also provide information about upcoming events, training opportunities, and initiatives designed to foster collaboration and knowledge exchange.

[Updates on this network will be provided on the newly created Early Career Researchers page of the CUPID website](#)

Database of Experts

A key new initiative in the project is the development of a database of experts in the field of cancer prevention and intellectual disability. Going forward the database will help CUPID members to link up and collaborate to drive future research and initiatives in the area of cancer prevention for people with intellectual disability.

We recently sent an email to all CUPID members encouraging them to complete a survey. The survey only takes a few minutes to complete and your input is highly valued

Our Project will be presented at the following

Conferences

Paris Conference on Education (PCE2025)

Paris - June 2025

Presentation Title

Equitable Access to Cancer Prevention Education for People with Intellectual and Developmental Disabilities: Insights from a Co-produced Training School

Presenters

Margaret Denny, Dragana Milutinović, Špela Golubović, Suzanne Denieffe

European congress on mental health in intellectual disability (EAMHID25)

Ghent - September 2025

Presentation Title

Cancer in People with Intellectual Disabilities: Barriers, Advances, and Future Directions

Presenters

Maarten Cuypers, Theresa Wagner, Tanja Sappok

FOR THE LATEST NEWS ON COST ACTION CUPID

CUPID

**Cancer - Understanding Prevention
in Intellectual Disabilities**

Your paragraph text

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