CUPID

Cancer- Understanding Prevention in Intellectual Disabilities

cost EUROPEAN COOPERATION IN SCIENCE AND TECHNOLOGY

NEWSLETTER

Newsletter No6 - October 2026



As our Action draws to a close, this edition provides an opportunity to celebrate our achievements, reflect on what we have learned and consider how the work of CUPID can continue to make a difference.

Over the past four years, CUPID has grown into a vibrant international network of over 300 members, bringing together researchers, practitioners, policymakers, advocates and people with intellectual disabilities, united by a commitment to addressing inequalities in cancer prevention and screening.

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Through our Working Groups, Training Schools, Short-Term Scientific Missions, Webinars, Conferences, Publications and dissemination activities, we have strengthened international collaboration, advanced research and developed resources to support more inclusive cancer prevention. Importantly, we have sought to ensure that the voices and experiences of people with intellectual disabilities remain central to our work.

Our Final Conference in Brussels in June 2026 was a fitting culmination of these efforts, providing an opportunity to share our achievements, celebrate collaborations and explore future directions.

While the formal Action is ending, the challenges we set out to address remain. Our priority now is to build on the relationships, knowledge and resources developed through CUPID, ensuring they continue to influence research, policy and practice.

I extend my sincere thanks to our Management Committee, Working Group leaders, Grant Holder team, members, partner organisations and COST for their commitment and support. In particular, I thank the people with intellectual disabilities who shared their experiences and expertise, reminding us continually why this work matters.

It has been a privilege to Chair CUPID. I hope the collaborations and friendships established will endure and that together we will continue working towards equitable cancer prevention for all.

Dr Suzanne Denieffe
Chair, COST Action CA21123 CUPID

cost EUROPEAN COOPERATION IN SCIENCE & TECHNOLOGY

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 Final Project Membership

Total number of members	310	
Countries Full COST	34	
Country partners	1	
International partner	5	
Near Neighbourhoods Countries	1	
Management Committee members	41	
Gender Balance	Female:230	Male:1
Young Researcher Innovators(YRI) Balance	YRI: 118	NON YRI:192
Inclusiveness Target Countries (ITC) Balance	ITC:190	NON ITC:120

More information on the CUPID membership can be found on our project website.
The project contributed to creating an enthusiastic network of researchers, clinicians, healthcare professionals, educators, policymakers, advocacy organisations, Persons with Intellectual and physical disabilities and their support persons....
We would like to thanks all of them for their involvement in the project which contributed to the project success and achievements of goals.

FINAL PROJECT CONFERENCE BRUSSELS JUNE 2026



CUPID FINAL CONFERENCE – BRUSSELS 2026

Cancer – Understanding Prevention in Intellectual Disability: Partnering to Support Co-produced Change

23–24 June 2026 | Brussels, Belgium

The CUPID Final Conference brought together researchers, healthcare professionals, educators, policymakers, advocates and people with intellectual disabilities from across Europe and beyond to celebrate four years of international collaboration



FINAL PROJECT CONFERENCE BRUSSELS JUNE 2026

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Held over two days in Brussels and attended by over 70 members including 7 People with Physical and Intellectual dissabilities, the conference provided an opportunity to reflect on CUPID's journey, showcase the work of its four Working Groups and explore how research, education, policy and practice can contribute to more inclusive cancer prevention and screening.

Sharing Knowledge and Celebrating Achievements

The programme featured an opening address by MEP Cynthia Ní Mhurchú , keynote presentations from Dr Suzanne Denieffe, Dr Katarzyna Świeczkowska and Dr Fabrizio Fea, alongside presentations from CUPID Working Group leaders, researchers and practitioners. Topics included accessible cancer screening, health communication, reasonable adjustments, professional education and the importance of translating research into meaningful improvements in healthcare.

Interactive sessions highlighted the innovative work undertaken through CUPID Training Schools, while oral and poster presentations demonstrated the breadth of research and international collaboration developed through the Action.

Putting Lived Experiences at the Centre

One of the most important aspects of the conference was the inclusion of lived experience. Daniela Bell shared her personal experiences of cancer and healthcare, while Raymond's story, presented by Dr Sinéad Foran, highlighted the challenges people with intellectual disabilities can encounter along the cancer care pathway.

These powerful contributions reinforced a central message of CUPID: people with intellectual disabilities must be actively involved in shaping the research, policies and services that affect their lives.









FINAL PROJECT CONFERENCE BRUSSELS JUNE 2026

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Looking Beyond CUPID

The conference concluded with discussions on future priorities and opportunities to build on the relationships, knowledge and resources developed through CUPID.

Although the COST Action is coming to an end, the conference demonstrated the strength of the international network established and the shared commitment to continuing efforts to reduce inequalities in cancer prevention and care.

The CUPID legacy is not simply what we have achieved together, but what we can continue to change together.

Explore the Conference Proceedings

The full conference proceedings, including keynote contributions, research abstracts, Working Group achievements and presentations, are available on the project website

DOI: https://doi.org/10.5281/zenodo.21647799











WORKING GROUP UPDATES

Working Group 1: The interdisciplinary co-production team

WG1 adopted a collaborative and participatory approach throughout the four-year COST Action. Activities focused on establishing an interdisciplinary European network, engaging stakeholders through co-production methodologies, developing accessible resources, implementing an international Training School, supporting Short-Term Scientific Missions (STSMs), and fostering early-career researcher development. Knowledge exchange was facilitated through stakeholder engagement initiatives, pilot implementation activities, conference presentations, scholarly publications, and collaborative dissemination. A rights-based framework underpinned all activities, ensuring that the voices of people with intellectual disabilities informed the design, implementation, and evaluation of project outputs. Results: WG1 successfully achieved the objectives and deliverables assigned within the CUPID COST Action. Key achievements included establishing a strong interdisciplinary European network and developing accessible educational and research resources. The group co-produced a rightsbased Evaluation Protocol, accompanied by an Easy-Read version, to support inclusive cancer prevention and screening practices. Extensive stakeholder engagement activities were conducted across Europe, alongside pilot implementation initiatives and STSMs that strengthened international collaboration and knowledge exchange. WG1 also delivered Programmes supporting early-career researchers, contributed substantially to conference presentations, peer-reviewed publications, and the CUPID Training School book, and generated empirical evidence to inform policy and practice. These activities strengthened international partnerships and promoted inclusive research methodologies across participating countries. Conclusions: WG1 made a substantial contribution to the successful delivery of the CUPID COST Action by advancing collaborative research, capacity building, and inclusive practice in cancer prevention and screening for people with intellectual disabilities. The outputs generated provide a sustainable foundation for future research, education, policy development, and service delivery. Through co-production, international collaboration, and stakeholder engagement, WG1 has helped establish an enduring framework that supports equitable access to cancer prevention and screening for people with intellectual disabilities across Europe



WG group leaders

- Dr Margaret Denny
- Dr Oliwia Kowalczyk

Number of members 181

In person meetings

- Year 1 – March 2023 Warsaw- Poland & October 2023 Gdansk- Poland
- Year 2 March 2024 Roma- Italy
- Year 3 January 2025 Vienna- Austria
- Year 4 January 2026 Warsaw- Poland

Training school

- Prague September 2024

Lunch & learn Webinars

- May 2026 – Beyond Words: A focus on Augmentative Communication

Final report

https://cupidproject.eu/wp-content/uploads/2026/11/Final-Report-27-septWG1.pdf

WORKING GROUP UPDATES

Working Group 2: Cancer prevention policies: audit and evaluation

WG2 developed a standardised protocol for searching academic databases, grey literature and relevant organisations across participating countries. The review identified 16 policy, guideline, recommendation and information documents. Most focused on breast, cervical and colorectal cancer screening, while prevention, clinical monitoring and treatment received substantially less attention.

Results: The review identified a range of recommended reasonable adjustments, including accessible invitations and information, flexible appointments, pre-visit preparation, involvement of support persons, and supported decision-making that respects autonomy and the right to refuse. To date, WG2 has brought together more than 125 members, with 40 contributors from 25 organisations across 18 countries participating in the review. Activities have included a joint WG2 and WG3 Training School at Trinity College Dublin, webinars, workshops, knowledge exchange initiatives and a Short-Term Scientific Mission. At the final conference, the group explored the potential use of a discrete choice experiment to rank reasonable adjustments according to their importance and feasibility within cancer screening services.

Conclusions: Next steps include publishing the policy review, developing a European report with evidence-informed recommendations, and refining methods to prioritise reasonable adjustments in partnership with people with intellectual disabilities, supporters, healthcare professionals and policymakers. Collectively, this work provides a strong foundation for more consistent, inclusive and equitable cancer prevention and screening policy across Europe.



WG Leaders

- Professor Martin McMahon
- Dr Vladimir Vokovic

Number of members 144

In person meetings

- Year 1 – June 2023 – Nijmegen , Netherlands
- Year 2 – April 2024 – Prague, Czech Republic
- Year 3 – July 2025 – Athens, Greece
- Year 4 – May 2026 – Barcelona, Spain

Training school

- Joint WG2/WG3 training school - Dublin - May 2025

Lunch & learn Webinars

- April 2026 The numbers behind the needs

Final report

https://cupidproject.eu/wp-content/uploads/2026/11/CUPID-Working-Group-2-FINAL-DELIVERABLE.pdf

WORKING GROUP UPDATES

Working Group 3: Universal EU Cancer prevention strategy methodology

Working Group 3's main deliverable is to develop a Europe-wide cancer prevention and screening strategy for people with intellectual disabilities, led by Dr Kate Sykes (Northumbria University). Its core aim is to build a research agenda for EU-wide cancer prevention guidelines, drawing on findings from WG1 and WG2 to ensure fair, lasting access to prevention and screening Programmes, alongside guidance on the knowledge and skills healthcare workers need and how to measure whether their care is effective. To date, WG3 has completed a Training School at Trinity College Dublin (May 2025, attended by 48 people in person and 20 online) on health system approaches to screening and prevention, run cancer prevention workshops in Ireland and Turkey (paper published on this work), and currently carrying out a systematic review of reviews to identify barriers and facilitators to prevention and screening for this population. These sources, combined with CUPID publication, and WG2 policy review, are being used to structure a research agenda covering recommendations, workforce skills/competencies, and research questions on uptake, acceptability and interventions. Next steps involve finishing the systematic review and agenda analysis for publication, and consulting carers, healthcare professionals, and people with intellectual disabilities themselves to prioritise and validate the final agenda.



Working Group Leaders

- Dr Kate Syles
- Ms Vera Dimitrievska

Number of members 152

In person meetings

- Year 1 – May 2023 – Ankara, Turkiye
- Year 2 – May 2024 – Istanbul, Turkiye
- Year 4 – May 2026 – Newcastle-Upon-Tyne, United Kingdom

Training school

- Joint WG2/WG3 training school May 2025 Dublin

Lunch & learn Webinars

- March 2026 Why it matters: The case for cancer screening & prevention -
- May 2026 Doing Research Right: Ethical standards in Practice

Final report
https://cupidproject.eu/wp-content/uploads/2026/11/WG3_Report_Final.pdf

WORKING GROUP UPDATES

Working Group 4: Dissemination and Outreach

WG4 developed and implemented a comprehensive dissemination and communication strategy targeting researchers, healthcare professionals, policymakers, advocacy organisations, people with intellectual disabilities, and their carers. Activities included the development of an accessible project website, dissemination through social media platforms, newsletters, webinars, scientific conferences, training schools, open-access publications, Easy Read materials, promotional resources, and policy-oriented communication.

Results: WG4 successfully established a sustainable dissemination infrastructure, including an accessible project website, annual newsletters, open-access educational resources, promotional materials, and multimedia content. The group organized webinars and contributed to scientific meetings, supporting collaboration among Working Groups and increasing stakeholder engagement across Europe. Dissemination activities enhanced awareness of cancer prevention inequalities affecting people with intellectual disabilities, promoted inclusive health communication, and strengthened international networking. The Action also contributed to the development of policy roadmaps and supported the dissemination of scientific outputs produced across the CUPID network.

Conclusions: WG4 played a central role in increasing the visibility, accessibility, and societal impact of the COST Action CUPID. Through coordinated dissemination, accessible communication, and stakeholder engagement, the group contributed to sustainable knowledge translation, promoted equitable cancer prevention, and established a foundation for future international collaborations and policy development beyond the lifetime of the Action.



Working Group Leaders

- Prof. Dr. Vladimir Trajkoski
- Prof. Dr. Jean Calleja-Agius

Number of members 120

In person meetings

- Year 1 – March 2023 – Brussels, Belgium
- Year 2 – March 2024 – Copenhagen, Denmark
- Year 3 – March 2025 – Valetta, Malta
- Year 4 – March 2026 – Vienna, Austria

Annual Conferences

- Year 1 October 2023
- Year 2 November 2024
- Year 3 October 2025

Scientific Webinars

- May 2024
- June 2025

Final report

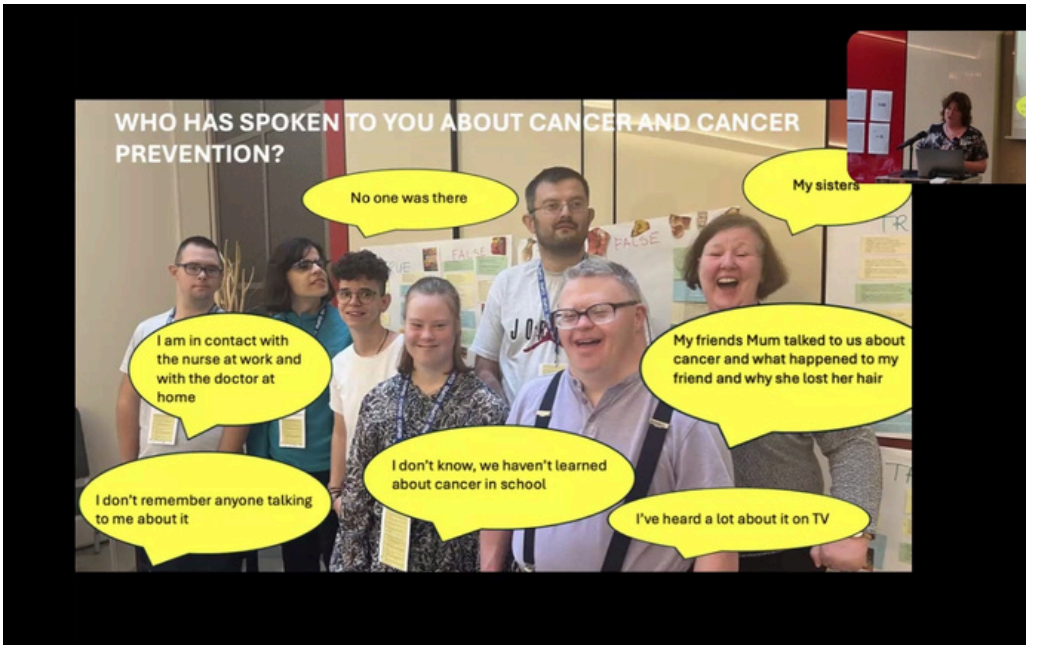
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CUPID IN PICTURES











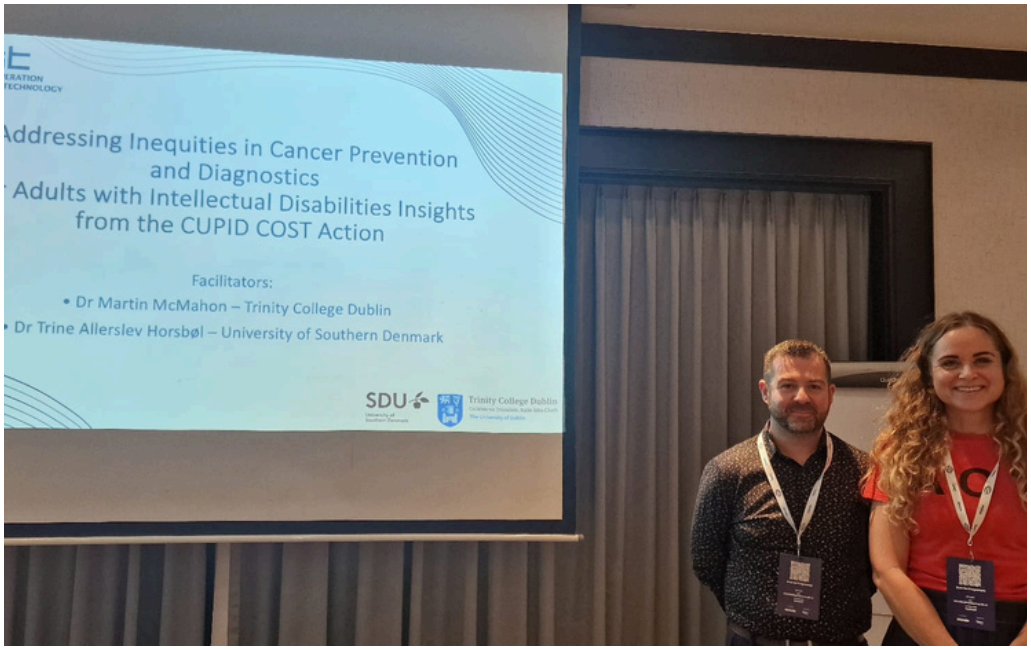


CUPID IN PICTURES













FOR MORE INFORMATION ON COST ACTION CUPID

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