



CUPID

**Cancer- Understanding Prevention
in Intellectual Disabilities**



NEWSLETTER

Newsletter No5 - May 2026



As Chair of the COST Action CA21123 CUPID project, I am pleased to share the 5th edition of our project newsletter as we move into the final phase of our work. We continue to make strong progress across all activities, and it is particularly encouraging to see our membership growing steadily, further strengthening our international, collaborative network committed to improving cancer prevention for people with intellectual disabilities. Our project now have over 300 members.

As we approach the culmination of the project, preparations are well underway for our Final CUPID Conference, “Cancer – Understanding Prevention in Intellectual Disability: Partnering to Support Co-produced Change,” which will take place on 23–24 June 2026 in Brussels, Belgium

This important concluding event will bring together project partners, researchers, practitioners, policymakers, and key stakeholders to present the key outcomes of the CUPID project, share best practices, and explore future directions. The conference will provide a valuable platform for collaboration, knowledge exchange, and continued progress in addressing inequalities in cancer prevention.

We were also delighted to launch the CUPID Lunch & Learn Series, an engaging initiative focused on advancing knowledge and best practice in cancer screening and prevention for people with intellectual disabilities. This series will cover key topics including the importance of screening, cancer statistics and inequalities, augmentative communication, and ethical research practice. Further details will be shared via email and on the CUPID website.

This newsletter also highlights a range of ongoing activities, including member participation in cancer awareness initiatives, conference presentations, and continued dissemination of CUPID work across international platforms.

As always, we encourage you to share this newsletter widely within your networks and to stay connected through our website and social media channels for the latest 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	302
• Countries Full COST	34
• Country partners	1
• International partner	5
• Near Neighbourhoods Countries	1
• Management Committee members	41
• Gender Balance	Female:224 Male:78
• Young Researcher Innovators(YRI) Balance	YRI: 141 NON YRI:161
• Inclusiveness Target Countries (ITC) Balance	ITC:181 NON ITC:112

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)

FINAL PROJECT CONFERENCE BRUSSELS JUNE 2026



CUPID
Cancer- Understanding Prevention
in Intellectual Disabilities

**FINAL
CONFERENCE**

23 - 24 June 2026

**Cancer – Understanding Prevention
in Intellectual Disability:**

**Partnering to Support
Co-produced Change**

**BRUSSELS
Belgium**



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.



Funded by the
European Union

The Final CUPID Conference

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

will take place on 23–24 June 2026 in Brussels, Belgium. This concluding international event will bring together project partners, researchers, practitioners, policymakers, and key stakeholders to present the main outcomes of the CUPID project, share best practices, and explore future directions.

The conference will provide a platform for collaboration, knowledge exchange, and discussion, supporting continued progress in improving cancer prevention for people with intellectual disabilities.

Further information on the conference programme, speakers and details of online registration will be announced in due course.

***Follow updates on our project website
<https://cupidproject.eu/cupid-final-conference/>***

WORKING GROUP UPDATES

Working Group 1 has made strong progress on the co-produced Evaluation Protocol for inclusive cancer prevention for people with intellectual disabilities.



The protocol was further refined during a recent meeting in Warsaw (28 January 2026 | In-person and Hybrid), where members reviewed its scope, structure, and methodological approach and the WG leads Dr Margeret Denny and Dr Oliwia Kowalczyk would like to thank all the attendees for this great work.

The focus of the protocol is on ensuring it supports services to evaluate the inclusivity of their cancer prevention, education, and screening practices, while remaining adaptable across different national contexts.

Key domains include workforce capability, reasonable adjustments, governance, co-production, consent, organisational readiness, and quality assurance. The protocol is designed as a reflective, service-level tool to support continuous improvement rather than prescribe specific actions.

The protocol has now entered the pilot phase with the wider CUPID membership, alongside engagement with networks such as IASSID and EASPD. Thank you to everyone who has responded to date. This stage will assess clarity, feasibility, and usability across diverse service settings, with findings informing final revisions ahead of wider dissemination across Europe.

An easy-read version is also being developed to support accessibility and meaningful inclusion, thanks to Professor Agnieszka Zyta and Dr Kate Sykes for their work on this important resource.

We were delighted to open our
Lunch and Lean webinar series
with a presentation from Kate and Simon.



Kate is based at Northumbria University, and Simon lives and works at Botton Village Community, part of Camphill Village Trust.

Together, they explored what cancer screening and prevention involve, and why these matter so much for people with intellectual disabilities. Kate and Simon closed by reminding everyone that access to cancer screening and prevention is a right, not a privilege.

Reflecting on the webinar, Simon said: "I thought it was excellent, the thing that we did. Yeah, I enjoyed it." Kate echoed this: "I really enjoyed working with Simon to deliver the webinar. I hope everyone learnt something new".

In preparing for the webinar materials Kate designed the slides in an Easy Read-inspired format (images on the left, text on the right) to make the content accessible. She and Simon met online to work through the slides together, with Kate asking Simon about each topic and turning his responses into speech bubbles. This approach both captured Simon's perspective authentically and helped support him during the live session.

Simon reflected: "It was good to talk about what we were looking at, and sharing it with Françoise and with the other colleagues... I've done talks and stuff like this before, but not medical-related stuff."

Kate also spoke about the importance of meaningful involvement: "It is really important we involve people with intellectual disabilities in research and throughout projects. Working with Simon over several years, I have seen his confidence grow and his knowledge increase. It's amazing to see. Simon is a great person to work with, and I want to thank him for supporting the CUPID project and for being willing to share his own cancer journey and experiences."

Simon described his understanding of cancer as coming largely from personal experience. When asked what advice he would give someone who noticed a lump or an unexpected change in their body, Simon offered clear, step-by-step guidance: "you need to go see a doctor and get that checked up on. If they needed support, speak to a support staff member and see if you can get a GP appointment. The GP checks it out, and if you need more analysis, you would go to the hospital — you might need a biopsy appointment if it's a lump. You can get an MRI scan, and they put a dye in the body to check if you have cancer."

All webinars will take place from 13.00 to 13.45 (GMT), 14.00 to 14.45 (CEST)

25 March 2026

Dr. Kate Sykes

WHY IT MATTERS: THE CASE FOR CANCER SCREENING & PREVENTION

29 April 2026

Dr. Martin McMahon & Dr. Kálya Yasmine Lima

THE NUMBERS BEHIND THE NEEDS: CANCER STATISTICS, SCREENING UPTAKES AND CANCER INEQUALITIES

06 May 2026

Dr. Oliwia Kowalczyk & Dr. Margaret Denny

BEYOND WORDS: A FOCUS ON AUGMENTATIVE COMMUNICATION

27 May 2026

Dr. Vera Dimitrievska

DOING RESEARCH RIGHT: ETHICAL STANDARDS IN PRACTICE

The slides and recordings of all the webinars in the series are available on the CUPID website and the YouTube Channel.

The final webinar will take place on Wednesday 27 May 2026

Comparative Analysis of Cancer Prevention in Intellectual Disability Services

A Short-Term Scientific Mission (STSMs)
completed by Dr Suzanne Denieffe, Chair of CUPID Project



As part of the COST Action CA21123 (CUPID), I conducted a Short-Term Scientific Mission at Nicolaus Copernicus University, Bydgoszcz, Poland, under the guidance of Dr Oliwia Kowalczyk (WG1 Leader), from 3rd–10th August 2025. The focus of the mission was a comparative analysis of intellectual disability (ID) service provision in Ireland and Poland, with particular emphasis on cancer prevention.

During the visit, I engaged with national healthcare structures and policy frameworks, gaining insight into how cancer prevention is approached within Polish ID services. I worked with CUPID Working Group 1 (WG1) cross-European survey data, focusing on Irish and Polish responses, and explored key areas such as screening uptake, service accessibility, and the availability of policies and guidelines.

Although planned service visits were not possible due to summer closures, this provided an opportunity to undertake more in-depth desk-based analysis. I reviewed qualitative survey responses alongside national policy documents and research literature, which allowed for a deeper understanding of the similarities and differences between the two systems.

I observed that Ireland has a more structured, policy-led approach to cancer screening, while Poland demonstrates strong community-based services, with some regional variation in prevention practices. In both countries, gaps were evident in staff training related to the cancer risk profile of people with intellectual disabilities.

A key outcome of the mission was the initiation of a comparative academic paper examining the historical development, policy priorities, and service contexts in both countries. This work contributes to the CUPID Action by strengthening the comparative evidence base, supporting knowledge exchange, and informing future research, policy, and practice

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.

CUPID at Dáil Éireann: Advocating for Inclusive Cancer Prevention Dublin March 2026



Dr Margaret Denny with Irish Government Minister Mary Butler

Irish Cancer Society Coffee Morning at Dáil Éireann. Government of Ireland, following an invitation from the Irish Cancer Society through Krista Costello, Grassroots Advocacy Coordinator. This an important annual event bringing together policymakers, advocates, and key stakeholders

The event provided a valuable opportunity to showcase the CUPID project. Dr Denny engaged in meaningful discussions about the CUPID project with key stakeholders including Mary Butler TD, Minister for Mental Health and Older People, Nikki Gallagher, CEO of the Irish Cancer Society, and Amy Nolan, Head of Clinical Affairs.

These conversations reinforced the urgent need to tackle inequalities in cancer prevention and screening for people with intellectual disabilities. In particular, they highlighted ongoing barriers to accessing services and the critical need for more accessible, inclusive health information.



Margaret with Irish Cancer Society CEO Nikki Gallagher

Trinity Health and Education International Research Conference (THEconf2026)

Dublin March 2026



Dr Oliwia Kowalczyk with Dr Martin Mc Mahon

Dr Oliwia Kowalczyk was given the opportunity to present her research titled “Beyond Universal Care: Cancer Prevention Accessibility for People with Intellectual Disabilities in Europe. at the THEconf2026, held on 3–5 March 2026.

The presentation addressed disparities in access to cancer prevention and screening services for people with intellectual disabilities within European healthcare systems, with particular emphasis on structural, communication, and systemic barriers affecting participation in preventive programmes. The presentation generated a constructive discussion among conference participants , which highlighted common challenges across healthcare systems.

Attending the conference facilitated international academic networking, and created a basis for potential future collaborations aimed at advancing research and policy development related to equitable access to cancer prevention services for people with intellectual disabilities .

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