



# CUPID

**Cancer- Understanding Prevention  
in Intellectual Disabilities**



## NEWSLETTER

Newsletter No2 - November 2024

***As Chair of the COST Action CA21123 CUPID project, I am happy to share with you our second project newsletter. We have now completed the 2nd year and the project is progressing well. Our membership has now expanded to 221 members coming from 38 countries.***

***This newsletter includes accounts of the project activities since our last newsletter, including a description of a short term scientific mission and networking and dissemination activities on which the CUPID project members have been leading. A major highlight during the period has been the success of the 3 day Training School organised by WG1 members which took place in Prague in September 2024. Another highlight, held to mark the end of year 2 on the project, was the 2nd Annual Conference held in October 2024 and organised by Prof Dr Vladimir Trajkovski and other WG4 members.***

***Please feel free to circulate this newsletter widely and I encourage you to follow us on social media and to check our project website regularly for updates on the project.***



# CUPID

**Cancer- Understanding Prevention  
in Intellectual Disabilities**

## ABOUT THE CUPID PROJECT

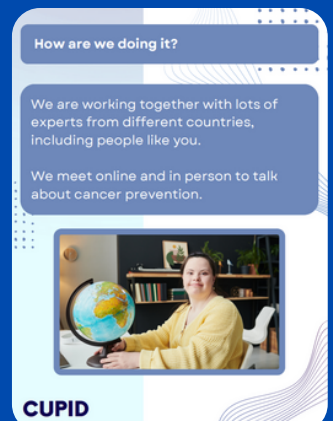
- There is poor understanding of cancer prevention among people with intellectual disabilities.
- The COST Action CUPID project aims to establish a research agenda and knowledge base to improve this in the European Union and beyond.
- The project is developing collaborative links with the EU research and service provider communities to reach consensus on addressing the many challenges around cancer prevention in the intellectual disability population.
- To find out more about the CUPID project and its objectives, please visit <https://cupidproject.eu/>

The activities on the project are organised around four interconnected Working Groups(WG)

- **WG1: THE INTERDISCIPLINARY CO-PRODUCTION TEAM** is working with people with intellectual disabilities and relevant stakeholders to focus on the co-production of a knowledge base about cancer prevention strategies for people with intellectual disabilities across the EU. This process uses peer learning to constitute the exchange of information between people with intellectual disabilities, carers and healthcare professionals.
- **WG2 CANCER PREVENTION POLICIES: AUDIT AND EVALUATION** is focusing on EU policy in the area of cancer prevention and unique challenges people with intellectual disability may face related to access to cancer screening and prevention programmes across the partner countries.
- **WG3 UNIVERSAL EU CANCER PREVENTION STRATEGY METHODOLOGY** is focusing on combining the outcomes from WG's 1 and 2 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 intellectual disabilities
- **WG4 DISSEMINATION AND OUTREACH** focuses on the dissemination of the Action and its activities and deliverables through a purpose designed accessible website, social media platforms such as Facebook and Twitter, blogs, open access journals, newsletters, accessible information reports and infographics, and Youtube Videos.

## CUPID Easy-to-Read Brochure

An easy-to- and generic CUPID brochure is available to view and download on the CUPID Project website  
(<https://cupidproject.eu/wp-content/uploads/2024/03/Easy-to-read-CUPID-brochure.pdf>).



# 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	221
• Countries Full cost	34
• Country partners	1
• International partner	2
• Near Neighbourhoods Countries	1
• Management Committee members	38
• Gender Balance	Female:165 Male: 56
• Young Researcher Innovators(YRI) Balance	YRI: 99 NON YRI:122
• Inclusiveness Target Countries (ITC) Balance	ITC:135 NON ITC:82

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/>

# SHORT-TERM SCIENTIFIC MISSIONS (STSMS)



***Bahar Aksoy from Akdeniz University in Turkey completed her STSM in Trinity College Dublin under the guidance of Dr Martin McMahon, WG2 Leader***

At the start of the STSM, I learned from Dr Martin McMahon about the development and operation of both the Trinity Centre for Ageing and Intellectual Disability and School of Nursing & Midwifery. I learned a lot about nurse training and in particular intellectual disability nurse training in Ireland which is not available in Türkiye, and learning how these nurses support cancer prevention in people with Intellectual disability. Ireland is unique in that it is one of the few countries that offer undergraduate registration with the Nursing and Midwifery Board of Ireland as an 'Intellectual Disability Nurse'. Intellectual Disability Nursing is the cornerstone of health services and plays a critical role in early diagnosis of cancer, management of risk factors and promotion of healthy lifestyles. The training focuses on learning about cancer risk factors, recognizing early signs and symptoms, the screening methods available and how screening should be performed and results interpreted. The training of these nurses also includes prevention strategies available through encouraging healthy lifestyle habits and raising public awareness about cancer prevention by receiving training in public health education and advocacy. Once student nurses have received this essential training they are then better equipped to fulfil their roles effectively, applying their knowledge to society, to inform individuals, families and communities about cancer prevention and to be more competent professionally in early diagnosis and timely intervention.

Nursing students learn not only their own roles in cancer prevention, but also the importance of collaborating with other health professionals. This enables for a multidisciplinary approach to be adopted and thus a more effective cancer prevention strategy to be implemented. As a result, the education of nursing students on cancer prevention in people with intellectual disabilities is of great importance in terms of both individual and social health.

The academics in Trinity College Dublin, and in Intellectual Disability Nursing section of the School have undertaken important research in determining cancer risk factors in individuals with intellectual disability, these risks factors are also included in the cancer screening protocol for mentally disabled individuals in Türkiye, in creating cancer prevention and prevention strategies, and in monitoring the screening control protocol and its success.

During this STSM, I also visited Stewarts Care, which was established in Dublin in 1869 as an institution for the education, training and care of children with intellectual disability from all over the island of Ireland. Stewarts Care is dedicated to providing the services that children and adults with intellectual disability need and to providing optimum services that promote the education, well-being, dignity, health and happiness of individuals. During my time at Stewarts Care, I observed the playrooms, individual study rooms, painting rooms, bathrooms, individual rooms, gardens and other occupational areas offered to children and adults with cancer. The clinical services offered to include occupational therapy, physiotherapy, speech and language therapy, dietetics, psychology, psychiatry, social work, medical and nursing care.

With this STSM, I also learned about research on individuals with cancer at the Trinity Center for Ageing and Intellectual Disability, and the functioning of this process at Stewarts Care. Trinity Center for Ageing and Intellectual Disability conducts meticulous and participatory research on the physical and social determinants of health and well-being, addressing the inequalities and health disparities that occur in individuals with intellectual disability as they age, and transferring the findings to policy and practice models, and identifying and monitoring individuals with intellectual disabilities and potential patients. The process followed by this research center was taken as a reference in the creation of a cancer prevention and screening protocol for individuals with intellectual disabilities.

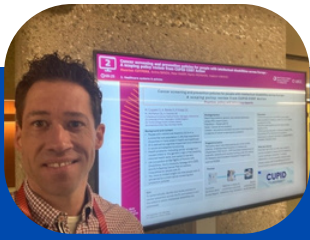
## STSMS

**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 PRESENTATIONS AT CONFERENCES

## *World Cancer Congress Geneva September 2024*



Maarten Cuypers presented on the policy review currently underway within WG2. This review assesses the extent to which national cancer screening and prevention policies in Europe address the needs of people with intellectual disabilities (ID).

The conference session focused around the CUPID project, introduced the audience to the unique relationship between intellectual disability and cancer. The insights shared on how WG2 has reviewed national policies and other documents for guidance on supporting individuals with ID enriched the session's discussions.

A key outcome from the conference was the connection made with representatives from The International Cancer Control Partnership (ICCP), a coalition of organizations dedicated to cancer control planning. ICCP provides resources, such as national cancer control plans and country-specific profiles, that are directly relevant to WG2's work.

In addition to CUPID's work, Maarten also shared findings from his own research group on cancer incidence among individuals with ID in the Netherlands. This data further highlighted the importance of inclusive cancer prevention and screening policies.

## *WONCA EUROPE 2024 - Dublin - September 2024*



With 2,600 participants from 77 represented countries, 10 keynote speakers and 1,357 submitted abstracts, this major Conference was an exceptional opportunity to share expertise, experiences, and enthusiasm about general practice/family medicine/multidisciplinary work in various fields and provided a valuable platform for discussing key issues in the session Measuring and Improving Quality. Špela Golubović presented on Enhancing cancer prevention strategies for individuals with intellectual and developmental disabilities. The presentation had a particular emphasis on the family aspect, aligning with the broader theme of the conference. The audience demonstrated strong interest in the topic, particularly in respect to the parents involvement in the prevention process as well as support and preventive strategies most critical for families. The presentation followed another discussion on caring for individuals affected by cancer and was followed by a session on anxiety related to such situations, creating a coherent flow of topics. Participants were particularly curious about the reasons why mothers are more often engaged in caregiving for individuals with intellectual disabilities, which sparked an engaging discussion. Further questions, Questions around the role of general practitioners in recognizing the importance of family involvement in cancer prevention were raised with the discussion also highlighting the value of participatory practices among professionals working with these populations. The interest opens the door to potential future collaborations,

## *Multidisciplinary Approaches in Education & Rehabilitation, Sarajevo, May 2024*

At the conference CUPID members Jovana Uzelac and Sandra Glamočak presented their work on the following topics

- Medical and Nursing Students' Attitudes Toward People with Intellectual Disabilities
- The Perception of Physiotherapy Students About the Rights of Patients with Intellectual Disabilities in Healthcare

Through the conversations which followed, it was concluded that if we aim to achieve an inclusive society, inclusion should be embedded not only in the educational system but also within the healthcare and social security systems. The conference was truly inspiring, and the topics we presented definitely encourage further research in this field.

# WG1 TRAINING SCHOOL PRAGUE SEPTEMBER 2024



**3 Day Training School**  
**43 in person attendees including People with Intellectual Disability**  
**Presentations and Workshops**  
**Hybrid basis with 51 participants online**

	Tuesday 17	Wednesday 18	Thursday 19
09:00-09:30	<b>09:00-09:15</b> Welcome: Dr Suzanne Denieffe (CUPID CHAIR) & Professor Dr Vladimir Talyzavski (CUPID Vice Chair)	<b>Day 1: RECAP</b> Dr Margaret Denny & Dr Oliwia Kowalczyk	<b>Day 2: RECAP &amp; Group Photograph</b>
09:30-10:00	<b>09:15-09:30</b> Opening: Paula Baxa (CEO Rytmus)	<b>Exercise &amp; Cancer</b> Dr Evan Mathews & Dr Frantisek Dolak	<b>Breast Self Examination &amp; Screening Interventions</b> Dr Oliwia Kowalczyk & Dr Margaret Denny
10:00-10:30	<b>09:30-10:30</b> Overview of CUPID & Training School, Welcome and Icebreakers Dr Margaret Denny & Dr Oliwia Kowalczyk (CUPID WG1 Co-leads)		<b>Best Practice in Designing Education Sessions for Cancer Prevention &amp; PWIDD</b> Dr Ilana Folsi & Professor Dr Silvia Maggolini
10:30-11:00	Light Refreshments		
11:00-11:45	<b>Cancer Prevention &amp; PWIDD Across Europe: Survey Results &amp; Discussions (VIRTUAL)</b> Panel: Dr Suzanne Denieffe, Dr Margaret Denny, Dr Oliwia Kowalczyk	<b>Navigating Cancer Prevention with Vulnerable Communities (VIRTUAL)</b> Dr Igor Grabovac	<b>Listening to the Voices of PWIDD and their Carers about Cancer and Cancer Prevention (VIRTUAL)</b> Dr Siméad Foran & Dr Suzanne Denieffe
11:45-12:00	Break		
12:00-13:00	<b>Body &amp; Health Cancer Prevention &amp; Screening</b> Dr Gabriela Stefková	<b>Alcohol, Smoking &amp; Cancer Prevention</b> Mag Florian Scheibeln	<b>Bowel Screening &amp; Cancer Prevention</b> Dr Siméad Foran
13:00-14:00	Light Refreshments		
14:00-14:45	<b>Inclusive Innovation: Raising Awareness for People with Intellectual &amp; Developmental Disabilities Through New Technologies (VIRTUAL)</b> Dr Tim Coughlan	<b>Italian Perspective on IDD &amp; Cancer (VIRTUAL)</b> Dr Fabrizio Foa	<b>14:00-14:15</b> Association between Autism Spectrum Disorder & Cancer Professor Dr Vladimir Talyzavski <b>14:15-14:45</b> Questions, Answers & Discussion
14:45-15:00	Break		
15:00-15:30	<b>Diet &amp; Weight</b> Presenters: Dr Eda Sahin, Dr Katarzyna Cwirynka & Dr Agnieszka Zyta	<b>Sun Protection &amp; Cancer Prevention</b> Professor Dr Spela Golubović & Professor Dr Dragana Miliutinović	<b>Extended Discussion - Evaluation of Training</b> Minutes: Professor Dr Spela Golubović, Professor Dr Dragana Miliutinović & Dr Gabriela Stefková
15:00-16:00	<b>Closing Comments</b> Dr Suzanne Denieffe (CUPID Chair), Dr Margaret Denny & Dr Oliwia Kowalczyk (CUPID WG1 Co-leads)		
16:00-16:45	<b>Evaluation (Day 1)</b> For all Team Members Minutes: Dr Siméad Foran, Dr Ilana Folsi & Professor Dr Silvia Maggolini	<b>Evaluation (Day 2)</b> For all Team Members Minutes: Dr Eda Sahin, Dr Katarzyna Cwirynka & Dr Agnieszka Zyta	

*Working Group 1 (WG1) members held a 'Training School' (TS) in Prague for 17th- 19th September 2024, as part of the CUPID COST Action.*

*The Training School aimed to develop a knowledge base on cancer prevention strategies across the EU, in collaboration with individuals who have intellectual and developmental disabilities, as well as other relevant stakeholders.*

*It was not just a three-day event, but a crucial initiative aimed at addressing the issues highlighted in the CUPID project using a co-production approach. This significant gathering of people with intellectual and developmental disabilities, healthcare professionals, researchers, oncology experts, support workers, and other relevant stakeholders focused on discussing cancer prevention approaches and training intervention modalities for persons with intellectual and developmental disabilities. The objective of this TS was to highlight effective cancer prevention approaches.*

*The Training School programme was finalised with people with intellectual and developmental disabilities in mind ensuring that presentations and documentations were prepared in Easy Read format and that breakout sessions were facilitated throughout the 3 days of the event.*

*For more information, please contact Margaret Denny or Oliwia Kowalczyk (Working Group 1 Lead and Deputy Lead)*

# WG1 TRAINING SCHOOL IN PHOTOS



# SECOND ANNUAL CUPID CONFERENCE

## 29 OCTOBER 2024

Held online and moderated by Prof Dr Vladimir Trajkovski, Vice Chair of the CUPID project, the conference presented the results of Year 2 of the Project. Prof Jean Calleja Agius, the Science Communicator for the project also presented on Cervical Screening for PWIDD



### AGENDA

- **13:00**  
**Prof. Dr. Vladimir Trajkovski (moderator)**  
Opening the conference
- **13:05 - 13:15**  
**Dr. Margaret Denny, Dr. Oliwia Kowalczyk, Dr. Suzanne Denieffe Barry**  
Reflections on the CUPID WG1 training school in Prague, September 2024
- **13:15 - 13:25**  
**Dr. Martin Mc Mahon**  
Systematic review and meta-analysis on cancer prevalence and incidence in adults with intellectual disability
- **13:25 - 13:35**  
**Prof. Dr. Peter Knapp**  
Influences on the uptake of colorectal cancer screening in people with learning disabilities: a systematic review
- **13:35 - 13:45**  
**Prof. Dr. Vladimir Trajkovski**  
Annual report WG4
- **13:45 - 13:55**  
**Prof Jean Calleja Agius**  
Cervical Cancer Screening among Persons with Intellectual Disability
- **13:55 - 14:10**  
Questions, discussion, closing remarks



### REGISTRATION <<<

here:  
<https://forms.gle/KwAuNVqfgCbHb7nA7>

or  
scan the QR code:





# RECENT UPDATES



## Warsaw 3 & 4 October 2024

The Chair and the WG leaders met in Warsaw to review Year 2 of the Action in preparation for Year end reporting

They also discussed financial planning and the range of project activities for year 3 to ensure the project is on track and progressing well

We have much in look forward to in Year 3!

## STSMs 2025

Applications for STSMs will reopen soon. We are currently putting together a register of topics, host organisations and interested young researchers and would be delighted to hear from you on this.

Updates are posted on a regular basis on our Website and Social Media.

[wordpress@cupidproject.eu](mailto:wordpress@cupidproject.eu)



## Training School 2025

A Training School is being jointly organised by WG2 & WG3 and will take place in Dublin in May 2025.

More details will follow as arrangements are confirmed



As part of [ECO's](#) Inequalities Network, the Women and Cancer workstream looks to address the unique inequities faced by women who experience a cancer diagnosis, women working in the cancer sector, and women who provide care to persons with cancer. Dr Margaret Denny and Dr Suzanne Denieffe, on behalf of the COST Action CUPID project, contributed to the recent policy action paper published during European Gender Equality week to highlight the particular challenges faced by women with intellectual disability in relation to cancer screening and prevention.

The policy paper can be accessed from

[Women-and-cancer-more-than-12-million-reasons-for-action](#)

# FOR THE LATEST NEWS ON COST ACTION CUPID

# CUPID

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Your paragraph text

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