



Science Communication Plan

COST Action: CUPID (CA21123)

Versions and history of changes

Version	Date of adoption by MC	Notes (e.g. changes from previous versions)	Lead author(s)*
1	9 th October 2023		Suzanne Denieffe: Vladimir Trajkowski: John Wells

1. INTRODUCTION

This document details the Science Communication Plan for the COST Action “Cancer: Understanding Prevention in Intellectual Disabilities” (CUPID) CA21123). This project is 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. Cost Actions help connect research initiatives across Europe and enable scientists to grow their ideas by sharing them with their peers, boosting their research, careers and innovation.

The CUPID (CA 21123) Management Committee (MC) adopted this communication, dissemination, and valorisation strategy, as well as the plan to implement this strategy in year 2 of the COST ACTION.

The Science Communication Plan reflects the CUPID MoU, in particular, connecting to the aims and objectives of the Action. The Science Communication plan has been developed, and its implementation will be monitored under the overall supervision of the Science Communication Coordinator, and in close collaboration with other relevant contributors, the MC and Working Group leads. The Science Communication Plan, including progress on implementation, is an agenda item on MC meeting and is reviewed or amended where necessary.

The Science Communication Plan was approved by the MC 9th October 2023.

The overall aim of the Communication Plan is ensure that communication dissemination and valorisation activities will take place at all levels across the lifespan of the CUPID COST Action. The Action will make use of a multimodal and hybrid dissemination plan.

2. Background and Aim of CUPID- CA21123

There is poor understanding of cancer prevention among people with intellectual disabilities. CUPID will establish a research agenda and knowledge base to improve this in the European Union and beyond. Among the European intellectual disabilities population, many cancer diagnoses are symptomatic presentations following on from behavioural distress or physical changes. Cancer deaths among this population occur up to 20 years earlier than the general population. Factors influencing unequal health status and premature death amongst people with intellectual disabilities warrant further investigation. Article 25 of the United Nations Convention on the Rights of People with Disabilities acknowledges their right to healthcare. The Council of Europe Disability Strategy 2017-2023 recognises health systems failure to engage with and include people with disabilities.

Many external and internal factors influence healthcare engagement among this population resulting in long- term health consequences. External factors include diagnostic overshadowing, paternalism and cancer screening delays during the COVID-19 pandemic. For the person challenges with communication, cognitive ability and decision-making capacity influence healthcare engagement. It is timely to develop collaborative links with the EU research and service provider communities to reach consensus on addressing these challenges. CUPID will establish active working partnerships with academics, researchers, non-governmental organisations, carers, people with intellectual disabilities and policy makers. CUPID will establish a research agenda and exchange information regarding cancer prevention in the intellectual disability population. Short term scientific exchanges, training schools, conferences and seminars using a hybrid approach will explore highlighted issues.

3. Structures to Support Communication Activities

A Science Communications co-ordinator has been appointed to CUPID- CA21123 (Dr Suzanne Denieffe, Ireland). This co-ordinator will be responsible for communication activities.

The Science Communications Co-ordinator will work closely with Working Group (WG) 4 within the Action and WG group 4 leads (Dr Vladimir Trajowski, and Professor John Wells, Ireland). WG4 focuses on the dissemination of the Action and its activities and deliverables.

The Science Communications Co- Ordinator is also a member of the management committee (MC) and will work closely with the MC to ensure that the Communication Strategy and Plan is developed, agreed, implemented, reviewed and monitored.

With each of the working groups 1-3, a named person will be in place to ensure that the groups activities are communicated in line with the Communication strategy and plan. These people are as follows

WG1: Dr Oliwia Kowalczyk and Dr Margaret Denny

WG2: Dr Maaten Cuypers and Dr Vladimir Vukovic

WG3: Dr Peter Knapp and Dr Vera Dimitrievska

A yearly plan is proposed by each working group (1-3) on the key communication, dissemination and valorisation activities which will be undertaken by the group.

WG4 will co-ordinate these WG 1-3 activities and will also prepare their own plan for key communication, dissemination and valorisation activities.

4. General Aim and Target Audiences

The CUPID- CA21123 Research Coordination Objectives are as follows

1. To create a sustainable network of researchers involved in intellectual disabilities, cancer prevention, epidemiology, health sciences, social sciences, education and other adjacent fields, engaged in knowledge exchange.
2. To establish the 'state of the art' in terms of national and cross-national co-produced knowledge base, and explore how this could be of benefit in the lives of people with intellectual disabilities
3. To develop of a research agenda exploring where the current challenges lie and what targeted research projects and initiatives would be of most benefit to tackle them while being responsive to the unique needs of people with intellectual disabilities
4. To promote new collaborative funding applications from network members including national and EU funding opportunities in the area of cancer prevention strategies.

Key beneficiaries of these dissemination activities of this COST Action include people with intellectual disabilities; healthcare professionals, carers (professional and family), health care academics and members of the CUPID network. In addition, other key beneficiaries include policy makers, such as advisors to the Ministries of Health and strategic directors of Disability Services, while from a research perspective collaborations will be forged with agencies such as National Cancer Control Programmes.

Key messages for each target audiences will be included in the annual plan considered in the first instance by each WG and then collated by WG4. The plan describes how to reach and, whenever necessary,

engage these audiences online or in physical or hybrid events. The comprehensive communication plan defines clear objectives with key messages addressed to relevant target audiences and set out a description and timing for each activity.

1. COMMUNICATION PLAN

Communication deals with raising awareness and promoting the Action and its results towards the general public and end-users, civil society and mass media. Hence, information will be conveyed in a language that is widely accessible to ensure that the key messages associated to the Action aim, approach, (expected) results and impact are disseminated to those who can benefit from these. The Cupid Cost Action logo will be used in all messages to clearly identify/ brand Actions activities and results/ impacts.

Communication tools/channels will be used as appropriate to the message and the audience, through use of the Cupid website, social media, press releases and infographics.

Communication Objectives and Deliverables

Objective 1: To ensure that there is awareness and promotion of the Action and its results towards the general public and end-users, civil society and mass media

Rationale: The visibility of the Action and its results can be amplified and can be understood by non-specialists.

Methodology: These communication activities will be built into each WG plan for their communication, dissemination and valorisation of project.

Timeline: Duration of project.

Evaluation- Tracking of activities and measures such as comments/ posts/ tweets and re-tweets.

Objective 2: to ensure all ‘communications’ are appropriate to the objective of the ‘message’, be that for communication, dissemination or valorisation purposes.

Rationale: Key to the Cupid Project is clear appropriate communication with all target audiences. *Timeline:* Duration of project.

Methodology- Exact methods of communication will be built into each WG plan for their communication, dissemination and valorisation activities.

Communication will be a standing item on all working group and management committee meetings

Evaluation: Report on all communication activities compiled by WG 4 and reviewed annually by Management committee of Cost Action.

Objective 3: To ensure all communication activities adhere to COST action branding guidelines

Rationale: Required under COST Action rules

Timeline; For duration of Action.

Methodology; the branding guidelines will be circulated to all MC members by WG leads.

This includes the [visual identity page](#) with a downloadable zip file of the COST animated logo.
Accessed here:

https://www.cost.eu/uploads/2023/05/COST_logo_animation_for_COST_Action_videos.zip

Evaluation: Assessed on degree of adherence to use of the branding guidelines in all communication materials.

Objective 4: To develop and maintain the CUPID CA Website and Social Media Presence.

Rationale: A Website will provide a platform for external facing and internal communication purposes. The social media platforms can be used to publicise the COST Action communication, dissemination and valorisation activities

Timeline: Developed within 3 months of project commencement and maintained for duration of project.

Methodology Lead Person: WG 4, led for this task by Dr Vladimir Trajowski will make arrangements for development of this website. This person will link monthly with the WG leads to ensure that the content on both the webpage and social media sites is up to date and reflects the Actions Activities.

Evaluation: Reviewed by Management Committee annually

Objective 5: To ensure good cross working group communications

Rationale: The activities of the working groups are interlinked and to ensure the coherency and smooth flow of the COST Action Cupid project, clear communication channels are important between the working groups and management committee

Timeline: Developed with 1 month of project commencement and maintained for duration of the project

Methodology: The management committee will be formed and will include representation from across the working groups. Working groups will publish reports from working group meetings which will be shared across the Action.

Evaluation: Reviewed by Management Committee annually

Objective 6: To ensure that all CUPID Cost Activities adhere to all relevant data protection legislation

Rationale: Required under National and/or EU law

Timeline: Duration of Project

Methodology: The CUPID Cost action members will ensure that all data protection legislation is adhered to in any of their activities. Training on general data protection regulations can be provided where required.

Evaluation: Oversight by the MC and reviewed annually.

Objective 7: To ensure CUPID COST Action activities, including meetings utilises virtual and hybrid communication effectively

Rationale: Online communication mechanisms can be very useful to the CUPID Cost Activities but need to be used to best effectiveness

Timeline: Duration of Project

Methodology: The guidance document as developed by Working Group 4 will be utilised by working group leaders when planning any online activities

Evaluation: Oversight by the MC and reviewed annually.

2. PLAN FOR THE DISSEMINATION OF ACTION RESULTS

Dissemination deals with making Action knowledge and results public towards its target audiences, who could benefit and use them. The information will be conveyed in a language that is customised to the specific target audience, in particular ensuring that those with an intellectual disability are considered.

The CUPID COST Action is committed to Open Science and Open Access (e.g., openness, accessibility, adherence to FAIR principles, IPR) and will seek to ensure that this commitment is adhered to in the dissemination activities.

Each year, the working groups will identify the planned dissemination products to be developed, their tentative timeline and the expected contribution from Working Group Action participants. Relevant target events or conferences, scientific journals or other forums to disseminate the Action results will be identified and described. This information will form the annual Dissemination Plan for the CUPID project

3. PLAN FOR THE VALORISATION OF ACTION RESULTS

Valorisation deals with the exploitation of Action results by specific target audiences, creating potential significant societal, economic or policy impact. It is envisaged that these activities will take place primarily in years 3 and 4 of the project

Each working group has identified deliverables which will be used for valorisation of the Action results.

Working Group 1

In Year 1, a scoping review of best practices in co-production with people with ID will be undertaken. This will lead to the publication of an academic paper.

In Year 2- the focus will move to establish how people with intellectual disabilities and their relatives perceive cancer prevention and access to screening programmes; and how involved are people with intellectual disabilities in the decision making process to participate in such programmes.

Year 3 will build on the work of Years 1 and 2, leading to the development of the protocol on how to evaluate the inclusiveness of cancer prevention programmes. This will include linking with key stakeholders to ascertain their views on this, leading to refinement and final agreement of the protocol.

In addition, a training school about cancer prevention programmes and factors impacting on equality of access for and with people with intellectual disabilities will be organised

Year 4 activities will focus on raising awareness of the protocol among key stakeholder groups so as to obtain health care policy impacts. The protocol will be presented at the final Action Conference.

Working Group 2

In year 1, the knowledge base to identify the minimum EU policy standard for cancer prevention for people with intellectual disabilities across the pan-European area will be explored.

In years 2 and 3, a training school will be organised about organisational context and implementation of equitable cancer prevention strategies including access to screening programmes.

Working Group 2 will also contribute to the Action Conference around the knowledge based on ERU policy standards and implementation of equitable cancer prevention strategies.

Working Group 3

In Year 1 the focus will be on establishing the extent of current relevant research and its relationship to national policies and practice. This will involve in-person workshops including, when possible, early career researchers and participants from Inclusiveness Target Countries; the findings will be written for publication.

In Years 2 and 3 several valorisation activities will be undertaken:

- A protocol will be developed for triangulating data from WG1 and WG2 to develop a research agenda.
- There will be a focus on PPI (Patient and Public Involvement) meetings with people with intellectual disabilities (and families and carers, as relevant) to inform WG3's work on prioritizing research studies.
- A Training School will be organized in collaboration with WG2 to develop a research agenda for equitable cancer prevention and screening policies and practice across Europe; as far as possible, this activity will involve early career researchers and participants from Inclusiveness Target Countries.
- A journal paper will be written on ovarian cancers and people with disabilities.

In Year 4 activities will focus on the development of research grant applications, both internationally and within member states, and when possible, will recommend the development of teaching modules

Working Group 4

Across all years of the project, working group 4 will support the valorisation of the results emerging from the Working groups through the website/ social media/ newsletter/ supporting academic and non academic papers and delivering on the final conference.

Summary of Communication Plan.

<p>WHY It is relevant to communicate about the Action?</p>	<p>Cancer is a leading cause of mortality and morbidity across Europe</p> <ul style="list-style-type: none"> • Cancer screening research evidence is has been scattered across Europe; • Urgent need for a coordinated and joint effort to build a collaborative platform linking science, industry, and management; • Raise awareness; • Bring added value of belonging to a multidisciplinary network involving numerous countries; • To spark new collaborations. • People with ID have different needs in preventative healthcare, information provision, and decision-making and may be exposed to different cancer risks as compared to the general population • Many countries have developed cancer screening and prevention policies as part of their cancer control strategies, that do not adequately address healthcare needs of people with ID, generating health disparities.
<p>WHAT are the key messages from each group:</p>	<p>Working Group 1 :</p> <ul style="list-style-type: none"> • Literature review on best practices in relation to co-producing knowledge with people with ID and their carers (professional and non- professional) • Feedback from clinicians, people with intellectual disabilities, family members and other relevant stakeholders using online focus groups and questionnaires to establish how people with intellectual disabilities and their relatives perceive cancer prevention and access to screening programmes; and how involved are people with intellectual disabilities in the decision making process to participate in such programmes • A protocol on how to evaluate the inclusiveness of cancer prevention programmes including equitable access to screening based on the literature review and feedback. <p>Working Group 2:</p> <ul style="list-style-type: none"> • Insight into the variety of policies across Europe and the extent to which the needs of people with ID are addressed. • Development of a knowledge base to identify the minimum EU policy standard for cancer prevention for people with intellectual disabilities across the pan-European area. <p>WG 2 will evaluate policies at the national level. However, rather than providing country-specific recommendations, the group will collate a</p>

	<p>broad view and identify common themes and disparities. The added value will be in similarities and differences when comparing countries. A starting point will be a commentary/position paper for a scientific journal (under review).</p> <p>Method for collecting and evaluating policies: aim to submit the protocol for collecting and screening policies in an online repository</p> <p>Evaluation results and recommendations (year 3 and 4 of the Action):</p> <p>Working Group 3:</p> <ul style="list-style-type: none"> • Development of a research agenda to develop EU wide cancer prevention guidelines for people with intellectual disabilities. <p>Working Group 4 :</p> <ul style="list-style-type: none"> • Dissemination plan for knowledge base developed during the CUPID Action to all relevant stakeholders including easy read versions for people with intellectual disabilities including annual, midterm and final reports. • Development and launch of an accessible CUPID website and social media. • Annual online newsletters describing the progress of the Action produced. • Open access webinars developed and delivered at strategic times during the Action. • A final conference to ensure all knowledge developed during the CUPID Action is disseminated to all relevant stakeholders, policymakers and other interested stakeholders. • Additionally future prospects of the knowledge developed during the CUPID action will be discussed.
<p>WHO is the target audience?</p>	<ul style="list-style-type: none"> • Scientific community, Scientists, Academia; • Businesses, industry, SMEs; • NGOs, Citizen organisations, patient groups; • Authorities, Policymakers and specify at what level: local; regional; national; European or international; • Clinicians; primary care providers, oncologists, ID care providers • Public health professionals.
<p>WHERE and how to communicate & disseminate?</p>	<p>A range of methods will be used</p> <p>CUPID Website;</p> <p>Social media;</p> <p>Training schools:</p> <p>Scientific publication of findings;</p>

	<p>Easy-read materials for publication on website, social media;</p> <p>Presentation/symposia/roundtables at relevant conferences;</p> <p>Final Conference</p>
<p>WHEN it is appropriate to start communicating & disseminating?</p>	<p>Communication will occur from the start to the end beginning with the website and establishing a social media presence.</p> <p>Dissemination will begin in year 1 and continue until project completion through conferences and scientific papers as outlined the in Working Groups communication plan.</p> <p>Valorisation activities will take place from years 2 to four, culminating in the final Cupid Conference.</p> <p>-</p>