

Brussels, 27 May 2022

COST 037/22

## DECISION

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Subject: Memorandum of Understanding for the implementation of the COST Action “Cancer-Understanding Prevention in Intellectual Disabilities” (CUPID) CA21123

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The COST Member Countries will find attached the Memorandum of Understanding for the COST Action Cancer- Understanding Prevention in Intellectual Disabilities approved by the Committee of Senior Officials through written procedure on 27 May 2022.

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## **MEMORANDUM OF UNDERSTANDING**

For the implementation of a COST Action designated as

### **COST Action CA21123 CANCER- UNDERSTANDING PREVENTION IN INTELLECTUAL DISABILITIES (CUPID)**

The COST Members through the present Memorandum of Understanding (MoU) wish to undertake joint activities of mutual interest and declare their common intention to participate in the COST Action, referred to above and described in the Technical Annex of this MoU.

The Action will be carried out in accordance with the set of COST Implementation Rules approved by the Committee of Senior Officials (CSO), or any document amending or replacing them.

The main aim and objective of the Action is to A key challenge is the lack of systematic knowledge across the EU about the degree that cancer prevention strategies respond to the unique cognitive and healthcare needs of people with intellectual disabilities. CUPID knowledge generation will be responsive to the and healthcare needs of people with intellectual disabilities.. This will be achieved through the specific objectives detailed in the Technical Annex.

The present MoU enters into force on the date of the approval of the COST Action by the CSO.

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**OVERVIEW**

**Summary**

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** establishes 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. Other network funding streams will not support this kind of activity.

<p><b>Areas of Expertise Relevant for the Action</b></p> <ul style="list-style-type: none"> <li>• Health Sciences: Health services, health care research</li> </ul>	<p><b>Keywords</b></p> <ul style="list-style-type: none"> <li>• Cancer</li> <li>• Screening</li> <li>• Intellectual Disabilities</li> <li>• Prevention</li> <li>• Adults</li> </ul>
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**Specific Objectives**

To achieve the main objective described in this MoU, the following specific objectives shall be accomplished:

Research Coordination

- Creation of 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.
- 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.
- Development 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.
- Promote new collaborative funding applications from network members including national and EU funding opportunities in the area of cancer prevention strategies.

### Capacity Building

- The appointment of leads in the network who will be responsible for engaging with researchers and other key stakeholders within and outside the network to develop discussion, explore current thinking and progress thinking in the area both nationally and internationally
- Creation of a database of experts to assist in the planning and conduct of primary research in cancer prevention in the intellectual disabilities populations
- Involve Early Stage Researchers, young researchers and researchers from less research intensive countries in the CUPID network, thus improving their career prospects by supporting researcher mobility and expanding professional networks.
- Develop and establish both short (Continuous Professional Development) and long term (MSc and PhD) programmes in the emerging areas of interest developed by the activities of the CUPID network
- Foster collaboration between a diverse network of researchers, including co-researchers from the intellectual disabilities community, that will build capacity to develop joint research initiatives

## TECHNICAL ANNEX

### 1. S&T EXCELLENCE

#### 1.1. SOUNDNESS OF THE CHALLENGE

##### 1.1.1. DESCRIPTION OF THE STATE OF THE ART

Intellectual disability is characterised by significant limitations in both intellectual functioning and adaptive behaviour as expressed in conceptual, social and practical skills and which originates before 22 years of age (Schalock et al., 2021). The prevalence of intellectual disabilities in Europe is estimated at or below 1% with variability both across and between countries due to different reporting structures (European Intellectual Disability Research Network, 2003). The needs of the intellectual disabilities population are often marginalised and overlooked, particularly in mainstream health care (Heslop et al., 2019). Sixty-three per cent of people with learning disabilities die before reaching the age of 65, compared to 15 per cent in the general population (Heslop et al. 2021). Mortality from non-COVID-19 and other causes was elevated before and during the pandemic for people with intellectual disabilities (Das-Munshi et al., 2021). This recent UK cohort study highlighted that people with intellectual disabilities had over nine times higher COVID-19 standardised mortality ratio during the pandemic exacerbating longstanding health inequalities with the general population (Das-Munshi et al., 2021).

Cancer prevention relating to the needs of people with intellectual disabilities is one area of health services that is poorly understood. The CUPID COST Action (Cancer- Understanding Prevention in Intellectual Disabilities) will bring together expertise across Europe and beyond to address this issue. CUPID will raise the profile of cancer prevention for people with intellectual disabilities through multiplier activities that establish both a forum to exchange information and a research agenda grounded in a human rights approach to improve both our understanding of this marginalised group's needs and how services across Europe can better meet them in the area of cancer screening and prevention.

##### ***CUPID's interface with the State of the Art in Policy***

The European Union aims to promote population well-being via combatting discrimination and social exclusion. The Treaty of Amsterdam (1997) addresses issues of non-discrimination in relation to people with disabilities and interfaces with the provisions of Article 168 of The Treaty on the Functioning of the European Union foster cooperation in national policies and healthcare (European Parliament Council of the European Union and European Commission, 2017). The **CUPID** concept, reflective of the declarations of these treaties, aligns itself to the aims of the European Pillar of Social Rights to respond to the current and future challenges associated with equitable healthcare for people with intellectual disabilities across the pan- European area.

The Union of Equality: Strategy for the Rights of Persons with Disabilities 2021-2030 aims to tackle the diverse challenges faced by people with disabilities and prioritises progressing all areas of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) at both EU and member state level. UNCRPD Article 25 recognises the right of people with disabilities to the enjoyment of the highest attainment of standard of health without discrimination based on disability (UN General Assembly, 2007). The **CUPID** COST Action not only reflects these priorities but will progress and translate into action these EU policy goals in relation to people with intellectual disabilities as set out in EU Treaty obligations, policies, reports and networks, (see Table 1 on pg 4).

*The State of the Art of Knowledge relating to addressing the needs of an ageing population of people with intellectual disabilities referenced to policy that **CUPID** seeks to address*

Life expectancy of people with intellectual disability has considerably increased as a result of technological advancements, improved medical care and environmental conditions (Wilkinson and

Cerreto, 2008). Consequently, there now exists an ageing population of people with a wide range of intellectual disabilities that have multiple and complex healthcare needs but whose needs remain largely under-researched/ unmet in many EU countries. The Council of Europe Disability Strategy 2017-2023, recognises that health care systems fail to engage with and include people with disabilities (Council of Europe, 2017). The increased life expectancy of people with intellectual disabilities now poses a challenge in this regard since services in the past did not have to contemplate dealing with this group who are now subject to all the same health challenges as the mainstream aging population, including cancer, in addition to the often profound challenges of their primary disability (McCarron et al., 2017).

Research appears to indicate that EU member states face this common problem but different national policies and knowledge lead to widely differing outcomes in terms of supply and access to services in relation to people with intellectual disabilities. In part, this is the result of cultural and historical artefacts in each jurisdiction reflecting the variety of pre-existing definitions, linguistic categories and institutional arrangements of care (Rowell, 2017). It also reflects the degree of EU policy implemented at member state level in relation to people with intellectual disabilities (Rowell, 2017). For example, Brown et al. (2017) explored programmes, policies and practices in care provision for people with intellectual disabilities in four European countries. Current reforms of institutionalised care and provision of community care were found to be significantly different in terms of availability and quality between these four countries (Brown et al., 2017). This echoed substantial differences of engagement and knowledge within healthcare services about the healthcare needs of this population within each state (Brown et al., 2017).

It is clear in terms of treaty obligations and international and EU policy declarations that people with intellectual disabilities have a right to timely access to preventative healthcare. Consequently, healthcare systems must become more accessible across the EU for people with intellectual disabilities and their careers. However, as indicated there appears to be significant inequality in access to preventative healthcare for an ageing intellectual disabilities population in varying degrees across the Europe. The European Commission's State of Health in the EU cycle supports member states to share knowledge to improve European healthcare systems including issues such as equitable access to services (Ponti et al., 2017). **CUPID** will inform and progress this initiative.

*The State of the Art of knowledge in relation to the burden of cancer amongst people with intellectual disabilities and the 'cancer gap' in recent EU initiatives that **CUPID** seeks to address*

Cancer is a major public health burden in the European Union causing more than 1.3 million deaths every year (Ponti et al., 2017). People with intellectual disabilities face significant difficulties in intellectual functioning that influences their engagement with healthcare services, including cancer screening services, which results in long-term consequences on their health. People with intellectual disabilities die 20 years younger than the general population, with women with intellectual disabilities experiencing a greater inequality compared to the general population (O'Leary et al., 2018). This re-emphasises the urgent need to advance the research agenda to improve healthcare with and for people with intellectual disabilities across the pan-European area.

Substantial increases in avoidable cancer death rates resulting from diagnostic delays and the identification of later stage disease with worse outcomes due to the COVID-19 pandemic are predicted (Maringe et al., 2020; DeGroff et al., 2021). Consequently, it is vital that any preparedness and response planning in relation to cancer screening must be inclusive of and accessible to people with intellectual disabilities (Maringe et al., 2020; Armitage and Nellums, 2020).

Many cancer deaths in people with intellectual disabilities are premature and preventable through the provision of accessible healthcare systems (Heslop et al., 2019). However, among the intellectual disability population there is evidence of different tumour profiles in relation to organ distribution, age of onset, genetic and biological distribution and atypical clinical presentation observed (ONCODEFI, 2016).

Research from the UK observed that death rates from colorectal cancer in people with intellectual disabilities are significantly higher than among the general population (Glover et al., 2014). Likewise, a review by Willis et al. (2018) suggested that colorectal cancer frequency among people with intellectual disabilities is similar to that of the general population (Willis et al., 2018). A recent French national

registry study observed that breast and reproductive cancers have a similar incidence among women with intellectual disabilities and women in the general population (Sotgiu et al., 2020). Sotgiu and colleagues conclude that people with intellectual disabilities should be included in cancer prevention policies and cancer screening programmes (Sotgiu et al., 2020). It may be case that these atypical cancer profiles are not recognised by the multidisciplinary team of healthcare professionals, caregivers or the person with the intellectual disabilities resulting in the late diagnoses of many symptomatic cancer cases across Europe which warrants further investigation (ONCODEFI, 2016; Heslop et al., 2019).

The distribution of potential cancer risk factors is also different among people with intellectual disabilities from the general population. Smoking rates are increasing among those with mild to moderate intellectual disabilities (Taggart and Temple, 2014). Those with mild or borderline intellectual disability, dual diagnosis with mental health issues and forensic or severe maladaptive behaviours, are especially at risk for developing substance abuse disorders such as alcohol misuse (van Duijvenbode et al., 2015). Adults with intellectual disability have decreased cardiovascular fitness, lower rates of physical activity and higher incidence of obesity compared to persons without intellectual disability (Ranjan et al., 2018), which could lead to earlier cancer presentation of obesity related cancers (Cartwright et al., 2017). Estimates suggest that more than one third of the cancer burden could be reduced by modifying key lifestyle risk factors, in addition to adhering to the “European Code Against Cancer” recommendations, including participation in population based screening programmes (Schuz et al., 2015).

Population based screening programmes detect early forms of disease (International Agency for Research on Cancer, 2012). EU Member States have adopted significant measures to deliver systematic evidence based population-based screening programmes for breast, cervical and colorectal cancers as per the Council Recommendation of 2 December 2003 on Cancer Screening (2003/878/EC) (Ponti et al., 2017). However, differences occur across the EU in the implementation of screening programmes: established in some countries and under development in others (Ponti et al., 2017). Within the Horizon Europe Framework Programme for Research and Innovation (2021-2027), the Mission Board for Cancer aims to deliver solutions to the development and implementation of effective cancer prevention strategies and knowledge exchange on a pan- European platform (European Commission, 2020). Currently, research concerning the participation of people with intellectual disabilities in cancer screening programmes is very limited within an EU context.

A notable exception is the POMONA 2 project that developed health indicators for people with intellectual disabilities throughout 14 member states in 2005-2008 inclusive of screening participation rates in breast and cervical screening programmes (Noonan Walsh et al., 2008). Rates of cancer screening participation are useful to evaluate disparities in preventive healthcare access for people with intellectual disabilities (Xu et al., 2017). Much lower screening uptake rates are found among people with intellectual disabilities when compared to the general EU population (Noonan Walsh et al., 2008; Dowling et al., 2010).

One of the reasons for this disparity may be that the processes inherent to cancer screening pose particular challenges for adults with intellectual disabilities. The colorectal cancer screening service sends kits to individuals to produce specimens of their faeces for testing for blood. Whether people with intellectual disabilities manage to obtain and send back usable specimens is likely to depend on whether a carer is available to help (Primary Care Domain, 2016). Cervical cancer screening is difficult for women with intellectual disabilities whose capacity to understand and consent to the examination poses great difficulty for both the women and the healthcare professional (Primary Care Domain, 2016). The provision of specialist services in local areas is required to anticipate and plan for the potential concerns of females with intellectual disabilities (Primary Care Domain, 2016). The system is failing people with intellectual disabilities at all stages of the cancer screening process.

Early cancer diagnosis via screening and prompt treatment improves the chances of cancer survival. This is more likely in people who are well informed and alert to early warning signs and able to negotiate the health care system to initiate early investigation. Currently, this is a major obstacle for people with intellectual disabilities given their cognitive limitations. In addition, a limited EU wide research agenda focusing on the unique needs of people with intellectual disabilities to navigate healthcare systems, including cancer screening, leads to ultimate systems failure for people with intellectual disabilities. Two EU research networks focused on improving cancer prevention health promotion and reducing



screening inequalities among marginalised groups: EU-TOPIA (Towards improved screening for breast, cervical and colorectal cancer in All of Europe) funded by Horizon 2020 which finished in 2020 and the iPAAC Joint Action (Innovative Partnership for Action Against Cancer), co-funded by the Health Programme of the European Union. However, neither of these research agendas address how to improve cancer screening access tailored to the unique needs of people with intellectual disabilities. **CUPID** will therefore address this gap.

#### **CUPID's engagement with Citizen Science**

Internationally, there is both growth and acceptance of 'citizen science' by researchers and policy makers. 'Citizen science' is the public involvement in interdisciplinary health research to ensure those who are most affected by an issue are partners/ co-producers in the research process and thereby inform/ lead improvement in health care (NIHR INVOLVE, 2020). **CUPID** is strongly committed to the involvement of people with intellectual disabilities and their families as citizen scientists and co-producers of knowledge in accordance with the Work Programme 2018-2020 of "Science with and for Society" (SwafS) in Horizon 2020 and the Cluster 1: Health in Horizon Europe. As a core dimension of **CUPID** this commitment facilitates the active and meaningful involvement of the intellectual disabilities community and those who support them in knowledge creation and development of a research agenda reflective of the multicultural composition of Europe.

**CUPID** will actively create and support a networked relationship between academics, researchers, interest groups, caregivers and the intellectual disabilities community with a direct interest in promoting wellbeing for people with intellectual disabilities to work together to scale up a pan- European response that reflects a meaningful citizen science commitment and impact to reduce health inequalities for people with intellectual disabilities because people with intellectual disabilities and those that support them will be significant stakeholders in **CUPID's** processes and work programme.

**Table 1: EU and International Treaties, Policies, Reports and Networks**

EU Treaty- Disability focus	EU and International Disability Convention and Policy	EU Cancer Screening Reports and Cancer Mission	Research Networks	Social Rights and Patient Public Involvement
Treaty of Amsterdam	UN Convention on the Rights of Persons with Disabilities	Against Cancer- Cancer Screening in the EU	EU- TOPIA	European Pillar of Social Rights
Treaty on European Union	Union of Equality: Strategy for the Rights of Persons with Disabilities 2021-2030	Conquering Cancer: Mission Possible	iPAAC Joint Action	NIHR Involve
Treaty on the Functioning of the European Union	Council of Europe Disability Strategy 2017-2023		ONCODEFI	"Science with and for Society" (SwafS)
			POMONA 2	Horizon Europe: Cluster 1 Health

### 1.1.2. DESCRIPTION OF THE CHALLENGE (MAIN AIM)

A key challenge for **CUPID** is the lack of systematic knowledge across the EU about the degree that cancer prevention strategies are responsive to the unique cognitive and healthcare needs of people with intellectual disabilities and their human right to healthcare. To improve understanding of cancer prevention with and among people with intellectual disabilities **CUPID** will bring together interdisciplinary stakeholders representing carers, service providers, advocacy groups, educators, healthcare professionals, researchers and people with intellectual disabilities to explore these issues in terms of what needs to be addressed and how. **CUPID** will share collaborative learning with robust review that is structured to accommodate the needs of collaborators with intellectual disabilities the development of systematic knowledge. In this regard, knowledge generation will be responsive to the unique cognitive and healthcare needs of people with intellectual disabilities throughout all goals and objectives of the Action.

**CUPID** will address the cognitive limitations that preclude people with intellectual disabilities from engaging with many of the EU policy goals to improve equal access to healthcare systems, including

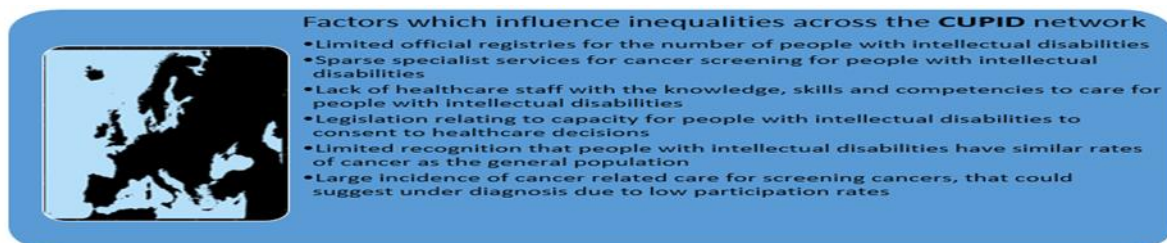


preventative healthcare. Many people with intellectual disabilities need assistance from formal or informal caregivers or advocates to assist them to navigate the healthcare system especially those with severe to profound intellectual disabilities, therefore carers will play a key role in helping people with intellectual disabilities to participate throughout the COST Action.

**CUPID** will harness the *lived experience* of people with intellectual disabilities in their capacity as champions for the intellectual disability community across Europe and beyond. This will be achieved in tandem with their advocates and caregivers to promote a more just healthcare system. **CUPID's** cross-disciplinary network working in partnership with the intellectual disabilities community includes providing training, if required, in competencies that are not present, without influences or forms of coercion in accordance with the consensus statement on how to conduct inclusive health research (Frankena et al., 2019).

Recognising the impact of the social determinants of health on the health status of people with intellectual disabilities is a key goal of **CUPID**. It is important given the variation in intellectual disability services across Europe. Some **CUPID** network members come from countries that have healthcare practitioners exclusively educated in the intellectual disabilities field, where decongregation to community living is well underway and where person-centred care is the norm. Other **CUPID** members represent countries lagging behind in these areas.

In spite of the UNCRPD and the increasing human rights agenda, inequalities in access to cancer screening programmes and their consequential outcomes on health exist across the EU for people with intellectual disabilities. To our knowledge there are limited adapted services for cancer screening in place for people with intellectual disabilities across the participating countries in the **CUPID** network leading to the existence of cancer screening inequalities. Factors which influence these inequalities across Europe and in the International Partner Country include limited official registries for the number of people with intellectual disabilities; sparse specialist services for cancer screening for people with intellectual disabilities; lack of healthcare staff with the knowledge; skills and competencies to care for people with intellectual disabilities; legislation relating legal capacity of people with intellectual disabilities to consent to healthcare decisions; limited recognition that people with intellectual disabilities have similar rates of cancer as the general population and large incidence of cancer-related care for screening cancers, that could suggest under diagnosis due to low participation rates, see Figure 1.



**Figure 1:** Factors that influence inequalities across the **CUPID** network

**CUPID** is a unique network that brings like-minded people and organisations together to develop a research agenda and a knowledge base through information exchange about a more equitable and inclusive cancer prevention strategy for people with intellectual disabilities. A key issue is that the intellectual disability population in individual countries are generally too small to address this issue nationally. Thus the crucial importance of creating a collaborative pan-European network of interdisciplinary researchers including peer researchers with intellectual disabilities cannot be underestimated. **CUPID** will exchange existing knowledge, progress the state of the art and promote collaboration to develop socially just and inclusive cancer prevention strategies for and with people with intellectual disabilities and interdisciplinary stakeholders.

The **CUPID** COST Action proposal is important and timely. Although many EU policies are inclusive of people with disabilities as a whole, the unique needs of people with intellectual disabilities need further consideration in these policies. The **CUPID** network will significantly support the EU Framework for the UNCRPD policy goals to ensure people with intellectual disabilities attain the highest possible standards of health across the EU.

## 1.2. PROGRESS BEYOND THE STATE OF THE ART

### 1.2.1. APPROACH TO THE CHALLENGE AND PROGRESS BEYOND THE STATE OF THE ART

Uniquely this action will identify, disseminate and progress a research agenda to improve cancer prevention strategies for people with intellectual disabilities across Europe. **CUPID** will do this by bringing together people with intellectual disabilities, carers, healthcare practitioners, educators, researchers, non- governmental organisations, policymakers and other stakeholders within Europe and beyond. In order to achieve this **CUPID** will leverage members' extensive networks in the field to foster and grow sustainable links with disability service providers and advocacy organisations that support people with intellectual disabilities and carers across the EU and beyond.

**CUPID** acknowledges that people with intellectual disabilities are experts on issues which impact on their lives. The **CUPID** action will use Experience-based Co-design as a methodology to access this wealth of knowledge, translating experience into actions needed to improve understanding of cancer prevention efforts with and for people with intellectual disabilities. This will progress cancer prevention knowledge for this group beyond the state of the art to provide concrete recommendations for the European Commission. **CUPID** will establish a strong knowledge base co-produced with the intellectual disabilities population for the development of an EU cancer screening strategy for people with intellectual disabilities and thereby reduce healthcare inequalities

The proposed approach is very innovative in that the recommendations to address this challenge will primarily come from people with intellectual disabilities and those who support them. Their inclusion in forming the **CUPID** network will pave the way to support a research agenda for the development of a targeted cancer prevention strategy that is responsive to the unique needs of people with intellectual disabilities and reflective of their needs.

**CUPID** will facilitate knowledge exchange and establish long-term relationships for future collaboration especially in the Inclusiveness Target countries. The immediate result will be that people with intellectual disabilities will have opportunities to participate actively in research which is something that currently does not happen at a pan- European level. They will be engaged as equal partners in health policy and service reform with respect to cancer prevention and screening. On a broader societal level, the **CUPID** Action will promote co-operation and coordination among the intellectual disabilities community and interdisciplinary stakeholders for the first time across the EU and beyond to feed into policy discussion and shape policy response.

### 1.2.2. OBJECTIVES

#### 1.2.2.1 Research Coordination Objectives

During the course of the Action, research coordination activities will be achieved through the attainment of the following specific objectives:

- **Creation of 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.** This will be achieved using the unique COST networking tools including short term scientific missions, meetings, training schools, Experience Based co-design workshops, webinar series and thematic conference over the lifetime of the action. This will be measured by the volume and diversity of participation in monthly meetings, Training Schools, co-production workshops guided by the principles of inclusivity and value of *lived experience* of the intellectual disability community and a thematic conference, and in the public domain metrics of excellence and impact, such as research publications.
- **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.** This will be achieved by specific workshops involving researchers, healthcare professionals, people with intellectual disabilities, advocacy groups, carers and other relevant stakeholders presenting the 'state of the art' which is most relevant to them. This will be measured by the production of at least two open access review publications, two accessible information publications and an accessible website aimed at cancer prevention in intellectual disabilities readership setting out the current state of play.

- **Development 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.** This will be accomplished in a series of workshops involving experts and stakeholders. This will be measured by the publication of a Consensus Statement on the research agenda in conjunction with an accessible summary for the intellectual disabilities community.
- **Promote new collaborative funding applications from network members including national and EU funding opportunities in the area of cancer prevention strategies.** This will be achieved through **CUPID** members monitoring such calls and alerting members of their existence in order to develop submissions. It will be measured by the scope and success of such applications over the lifetime of the **CUPID** network and beyond the lifetime of the COST action.

#### 1.2.2.2 Capacity-building Objectives

The core capacity-building objective is to gather a critical mass of interacting participants from all over Europe and beyond with the competencies to reach the objectives outlined above. Specific objectives will be

- **The appointment of leads in the network who will be responsible for engaging with researchers and other key stakeholders within and outside the network to develop discussion, explore current thinking and progress thinking in the area both nationally and internationally. These appointments will be made at the kick-off meeting.** The success of this objective will be measured by participant feedback and uptake.
- **Creation of a database of experts to assist in the planning and conduct of primary research in cancer prevention in the intellectual disabilities populations.** At present researchers in the field generally carry out research in their own jurisdictions. **CUPID** will build capacity by opening up the network to new researchers and, in particular, for researchers in Inclusiveness Target Countries. Success of this objective will be measured by the publication of the database on the **CUPID** accessible website in a format that is sustainable beyond the lifetime of the project.
- **Involve Early Stage Researchers and researchers from less research intensive countries in the CUPID network, thus improving their career prospects by supporting researcher mobility and expanding professional networks.** This will be achieved through the various multiplier events including Training Schools, workshops and conferences during the lifetime of the Action. Among the network there is extensive expertise in e-learning study concepts which could be used to create content for course or training schools which also have the ability to be offered in a number of languages to reflect the **CUPID** network members. This will be measured against involvement in the **CUPID** networking events and progress towards developing a joint research agenda.
- **Develop and establish both short (Continuous Professional Development) and long term (MSc and PhD) programmes in the emerging areas of interest developed by the activities of the CUPID network regarding our understanding about cancer prevention in people with intellectual disabilities that promote the aims and objectives of the CUPID network both in the lifetime of the Action and beyond.** Academic partners will be involved in developing these initiatives at their institutions. This will be measured against the number of programmes developed across the countries of the **CUPID** network.
- **Foster collaboration between a diverse network of researchers, including co-researchers from the intellectual disabilities community that will build capacity to develop joint research initiatives that tackle the research priorities that the CUPID network produces in an attempt to build awareness of targeted cancer prevention strategies across the pan-**

**European area and beyond.** This will be achieved through the various networking events during the lifetime of the **CUPID** COST Action, many of which will be sustainable beyond the lifetime of the **CUPID** COST Action. This will be measured by progress towards developing a research agenda to develop a common understanding of cancer prevention in partnership with people with intellectual disabilities.

## 2. NETWORKING EXCELLENCE

### 2.1. ADDED VALUE OF NETWORKING IN S&T EXCELLENCE

#### 2.1.1. ADDED VALUE IN RELATION TO EXISTING EFFORTS AT EUROPEAN AND/OR INTERNATIONAL LEVEL

This Action brings together researchers working in the areas of cancer prevention, intellectual disabilities and healthcare. **CUPID** will encourage a closer relationship between the academic and non-academic communities. Undoubtedly, the required level of communication will not happen without a COST Action. Furthermore, the Action will develop new methodologies to integrate knowledge into current national and European policy debates and academic discussion about cancer prevention and screening efforts for people with intellectual disabilities. This will be achieved through the research publications and Consensus Statement collaboratively developed with relevant stakeholders and proposed multiplier events. The strong collaborative connections leveraged through the expansion of the network established within the Action will certainly continue beyond its duration and will result in submission of collaborative proposals for future national and European calls.

A priority of current EU policies and research is to reduce healthcare inequalities among marginalised groups. For example, EU-TOPIA aimed to evaluate breast, cervical and colorectal cancer in European Countries and identify how to improve health outcomes, discuss similarities and differences between countries, and generate new ideas to overcome barriers and reduce inequalities in cancer burden across countries. The Innovative Partnership for Action Against Cancer (iPAAC) brings partners across Europe together with the objective to build upon the CANCON Joint Action deliverable to implement innovative approaches to cancer control by developing a roadmap for the implementation and sustainability of Cancer Control Actions. In France, the ONCODEFI research collaboration offers perspectives into the psychological, epidemiological and biological issues about cancers in people with intellectual disabilities, particularly in areas where information is lacking to progress in cancer care. The International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD) raises awareness, increase knowledge and connect policy and practice to improve the health of individuals with intellectual disability and members of this network are included in the critical mass of expertise in this group.

Although this Action cross cuts these efforts, a funded European network that focuses on bringing like-minded people together to progress a research agenda for a cancer prevention strategy for and with people with intellectual disabilities has not yet been established. **CUPID** will create a network that recognises the central importance of persons with intellectual disability being co-researchers and collaborators in this effort. **CUPID** is highly innovative and initiates an interdisciplinary and sustainable research network that will collaborate on applications for research funding and integrate solutions in the area of cancer prevention in the intellectual disabilities community. Through the implementation of a targeted cancer prevention strategy, it will be possible to make comparisons between different countries across the EU on the progress of the implementation. This will result in a robust evidence base which will inform policy across the Pan- European area to improve the prevention services and thus ensure people with intellectual disabilities achieve their right to accessible preventative healthcare.

### 2.2. ADDED VALUE OF NETWORKING IN IMPACT

### 2.2.1. SECURING THE CRITICAL MASS AND EXPERTISE

Securing the critical mass will be achieved by collaboration with COST Member States, including a large representation of network members from Inclusiveness Target Countries, and an International Partner from the United States at the offset of the Action. Specifically recognised is the crucial expertise in the area of understanding the particular needs of people with intellectual disabilities in the area of cancer prevention. Members of the proposed **CUPID** Network bring a wide range of skills and expertise to the project. Among the level of expertise available are academic researchers, medical and nursing practitioners and experts from large coalitions and federations trained specifically in the healthcare, communication and consent needs of people with intellectual disabilities across the continuum of mild, moderate, severe and profound intellectual disabilities.

Another key strength are network members who have expertise in conducting population based comparative studies into the health of people with intellectual disabilities compared to the general population, with cancer being one of the principal topics for investigation. Members of **CUPID** have expertise in working with adults with intellectual disabilities that includes supporting self-advocates, creating accessible information and cooperating with governmental and non-governmental agencies to support people with intellectual disabilities across the lifespan. Members of **CUPID** have experience in methodologies that involve the co-production of knowledge and experience in participative action research which will be essential to support the people with intellectual disabilities involved in the Action. The inclusive partnership approach values each other's skills to ensure the voice of the intellectual disabilities community is strongly heard in developing the research agenda (Frankena et al., 2019).

**CUPID** members have expertise in the development of health policy, including cancer control policies, at national and EU level. The involvement of the NGO partners is important as their objectives are clearly aligned to the objectives of **CUPID** to promote equality of access for people with disabilities to healthcare systems internationally. This provides the opportunity for extensive networking across Europe in relation to service providers for people with disabilities and people with intellectual disabilities and their families who use these services. This will help the **CUPID** network to become visible to policy makers at EU, national and regional level across Europe from the beginning of the Action. In the event that one of the partners can no longer participate, **CUPID** has a broad range of expertise available within the **CUPID** network that will facilitate the Action to progress successfully in relation to its goals and objectives.

Over the four years of the Action **CUPID's** ambition is to grow in size to encompass a significant level of added expertise to complement the expertise currently available in the network. Thus the added value of networking is that the Action will be strong in building collaboratively a community dedicated to understanding cancer prevention in people with intellectual disabilities. Crucially bringing together interdisciplinary stakeholders and expertise in a single Action will reduce the potential for work to be carried out in parallel, which ultimately impacts on the most effective and efficient utilisation of European funding.

### 2.2.2. INVOLVEMENT OF STAKEHOLDERS

**CUPID's** interdisciplinary approach, range of partners and multiplier events will raise the network's visibility to relevant stakeholders across Europe and beyond taking into account the diversity of healthcare systems and living arrangements for people with intellectual disabilities. Once identified there are a number of different avenues for relevant stakeholders to participate in the Action. Researchers and relevant stakeholders from COST countries including the Inclusiveness Partner Countries and International Partner Country will be encouraged and supported to participate in the Action. Together the network will progress cooperative research to advance the research agenda and knowledge base with underpinning principles at support inclusivity in the area of cancer prevention for people with intellectual disabilities.

**CUPID** pays particular attention to Early Stage Researchers, which ensures the development of a new generation of researchers dedicated to the field of health care inequalities, the needs of people with intellectual disabilities and health promotion and preventative strategy development. Core activities



including postgraduate study opportunities, conference presentations, Short Term Scientific Missions (STSM) and Training Schools will benefit Early Stage Researchers.

At the European level, the measures to maximise the Action's impacts will involve cooperation with academics, researchers, healthcare professionals, people with intellectual disabilities, disability service providers, carers, policymakers and other interested parties. **CUPID** is an Action designed to facilitate mutual learning among all stakeholders and recognises the contribution of people with intellectual disabilities as collaborative partners to contribute to meeting the objectives of the EU Framework for the UN Convention on the Rights of Persons with Disabilities goals. Meeting these policy goals will ensure people with intellectual disabilities attain the highest possible standards of health.

### 2.2.3. MUTUAL BENEFITS OF THE INVOLVEMENT OF SECONDARY PROPOSERS FROM NEAR NEIGHBOUR OR INTERNATIONAL PARTNER COUNTRIES OR INTERNATIONAL ORGANISATIONS

The mutual benefits of involving secondary proposers is that the Action allows for the building of trust between countries. Intellectual disabilities service delivery varies across Europe and further afield. **CUPID** will create a forum for more integration and debate between countries to advance targeted cancer prevention strategies responsive to the needs of people with intellectual disabilities. The Action will facilitate Training Schools in partner countries that is mutually beneficial to the network, and allows participants to immerse themselves in the lives of people with intellectual disabilities in different cultural contexts. In addition including researchers and stakeholders from the United States is mutually beneficial in transferring knowledge throughout the **CUPID** network. Additionally, researchers from the United States can become involved in the Training Schools that further expands the benefit of the Action for all involved. No other funding stream offers this opportunity to develop such an extensive network of researchers and stakeholders to optimise research activity in this area.

## 3. IMPACT

### 3.1. IMPACT TO SCIENCE, SOCIETY AND COMPETITIVENESS, AND POTENTIAL FOR INNOVATION/BREAKTHROUGHS

#### 3.1.1. SCIENTIFIC, TECHNOLOGICAL, AND/OR SOCIOECONOMIC IMPACTS (INCLUDING POTENTIAL INNOVATIONS AND/OR BREAKTHROUGHS)

**CUPID's** goal is to contribute to the significant improvement in cancer prevention efforts for people with intellectual disabilities across the EU and beyond. By reaching agreement on a research agenda to frame an EU cancer prevention strategy will improve cancer prevention efforts for and among the intellectual disability population. This will also increase collaborative applications for funding research on the provision of cancer prevention information and screening for people with intellectual disabilities. The Action will develop a co-produced knowledge base that will enable people with intellectual disabilities, healthcare professionals, families, service providers, health authorities and screening services to make knowledge based decisions about the provision of cancer prevention services to people with intellectual disabilities.

The scientific impacts which will accrue through the Action are to impact positively on promotion of interdisciplinary intellectual disabilities research establishing a sustainable network of researchers in different disciplines. Researchers participating in the action will benefit from mutual knowledge exchange and development of research skills, specifically in the research practices of other disciplines. In addition the promotion of the development of Early Stage Researchers and other researchers will increase their knowledge and skills through the Action's activities. The long term benefit of the action

will be an increased number of researchers from different disciplines and geographical areas, especially the Inclusiveness Target Countries, active in the field of cancer prevention targeted to people with intellectual disabilities. **CUPID** will enable a direct comparison of cancer prevention efforts for people with intellectual disabilities in participating countries.

In the short term, **CUPID** will bring together an interdisciplinary team of researchers, disability rights advocates, clinicians, people with intellectual disabilities and their carers to evaluate the factors which impede or facilitate cancer prevention activities targeting people with intellectual disabilities in the COST countries given the countries' specific demographic context and cancer screening programmes. This information will be combined in a cross country comparative literature review and an accessible version will be available on the Action website. In the Action all knowledge will be shared across all working groups and this will support the development of a framework of cancer prevention strategies, and set priorities for further research. The knowledge that is available will be shared with all of the partners collaborating in the Action via the multimedia platforms, workshops, Skype/ZOOM/ MS Teams calls, workgroup meetings and so on in order to enhance mutual learning. The expected short term impact will be a more in-depth perspective of the steps to be taken to improve cancer prevention strategies targeted to the cognitive limitations of people with intellectual disabilities in the EU, despite the range of different approaches encountered in the different countries. This new knowledge will be further disseminated by STSM's, Training Schools and conferences.

In the long term a holistic understanding of the factors which impact cancer prevention and participation in cancer screening programmes among people with intellectual disabilities will become common place among policy makers and other relevant stakeholders.

Socioeconomic benefits that will accrue through the Action are to positively impact on strategy and the practice of policymaking. Regular and targeted outreach activities expanding the Action results to policy makers and other relevant stakeholders will achieve this.

Through the networking and dissemination activities across all working groups, **CUPID** will establish long-term collaborations and lay strong foundations for policies aimed at improving cancer prevention and access to screening programmes for people with intellectual disabilities. **CUPID** will evaluate funding for the development of co-developed and co-produced cancer prevention strategy framework targeted to the unique needs of people with intellectual disabilities at EU level. In the longer term this will result in a targeted cancer prevention strategy that is supported by interdisciplinary stakeholders in participating countries who are involved in the COST Action.

The **CUPID** network activities will create awareness about cancer prevention strategies for people with intellectual disabilities and thus stimulate the development of a framework for targeted cancer prevention strategies on a regional and national level, thus benefitting all those with intellectual disabilities across Europe.

## 3.2. MEASURES TO MAXIMISE IMPACT

### 3.2.1. KNOWLEDGE CREATION, TRANSFER OF KNOWLEDGE AND CAREER DEVELOPMENT

The **CUPID** Action will have impact on four specific domains:

1. The collaboration will build networks, which will in turn lead to collaboration on new research proposals for national and EU funding opportunities. The focus on a diverse interdisciplinary stakeholder group will help the network develop a common language ideally suited to respond to specific calls and develop collaborative research calls.
2. The Action will foster more integration between countries which will allow the transfer of knowledge created in the lifetime of the Action to take place across the pan-European network and beyond. This coordination and cooperation will allow researchers and stakeholders to work together to create an impact on the lives of people with intellectual disabilities with the potential



to foster new professional understandings among multidisciplinary groups and the intellectual disabilities population to enhance access to healthcare.

3. The Action will enable Early Stage Researchers to benefit their careers through the expansion their professional network with the potential in the long run beyond traditional training programmes and into areas such as consultancy.
4. There are different groups in society who do not have the same access to healthcare compared to the general population. There is potential for the creation of knowledge transfer in targeted cancer prevention strategies for other stakeholder groups such as migrant women.

### 3.2.2. PLAN FOR DISSEMINATION AND/OR EXPLOITATION AND DIALOGUE WITH THE GENERAL PUBLIC OR POLICY

Dissemination activities will take place at all levels across the lifespan of the **CUPID** COST Action, to include but not limited to the accessible **CUPID** website, mailing lists, social media networks and the communication departments of the institutions involved in the Action. Key beneficiaries of these dissemination activities of this COST Action include people with intellectual disabilities; healthcare professionals, carers and potential new members of the **CUPID** network. In addition, other key beneficiaries include policy makers, such as advisors to the Minister for Health and strategic directors of Disability Services, while from a research perspective collaboration would be forged with agencies such as the National Cancer Control Programmes.

The dissemination and uptake of outcomes from the networking initiatives are integral to the success of this Action. The Action will make use of a multimodal and hybrid dissemination plan to mitigate against the effects of future waves of COVID-19 incorporating the following elements:

- An accessible website and social media applications such as Facebook, Twitter, Instagram, YouTube, a blog, infographics, a series of webinars and easy read documents will facilitate dissemination and communication within and beyond the **CUPID** network;
- Network meetings including integration workshops where members of different working groups meet for thematic knowledge exchange. These will also be open to relevant stakeholders;
- National and European policy makers are targets for dissemination activities via press releases on the **CUPID** website and via the information channels available from the international organisation **CUPID** network members. It is crucial to make policymakers realise the importance of research with and for people with intellectual disabilities in the area of cancer prevention and the possible applications and benefit of it;
- Up to three hybrid approach Training Schools will be organised for emerging research topics and to provide dissemination opportunities for the **CUPID** network's activities. They will mainly benefit Early Stage Researchers especially from the Inclusiveness Target Countries, but will also cover appropriate re-training as part of life-long learning;
- STSM's to provide opportunities for learning and information exchange;
- Workshops with people with intellectual disabilities and with their advocates and supporters, to develop and test ideas and encourage two way conversations from the grassroots upwards to be used to lobby government and effect policy.
- Meetings and Training Schools will be widely advertised through the website, social media platforms and mailing lists which can be subscribed to, to draw attention to the Action and attract collaborations/partners;
- Publications including annual, midterm and final reports on the progress of the Action and articles in open access peer- reviewed journals;
- Articles in national and pan- European news media on the publication of the Annual Report at other relevant times throughout the lifecycle of the Action;
- A dissemination and outreach working group will monitor impact with regular review by the Management Committee (MC) Any necessary adjustments will align the Action outputs with stakeholder needs and help ensure the relevance of the output;

- The COST Academy will be useful in training the working group with developing a successful communication strategies taking into account the variety of digital platforms available to disseminate messages;
- Open Access and Open Data will be encouraged to maximize the scientific and societal impact;
- Development by the **CUPID** network as a whole, including a Framework of Action at the end of the Action, to ensure that the work and **CUPID**'s recommendations are sustained beyond the lifetime of the Action.

## 4. IMPLEMENTATION

### 4.1. COHERENCE AND EFFECTIVENESS OF THE WORKPLAN

#### 4.1.1. DESCRIPTION OF WORKING GROUPS, TASKS AND ACTIVITIES

In order for this Action to succeed the Management Committee (MC) will coordinate the activities of the Working Groups (WG). The main task of the MC will be to supervise and coordinate the WG's activities. In this Action this task is particularly important since the basis of the whole Action centres on the coordination between people with intellectual disabilities and interdisciplinary stakeholders to tackle specific areas of interest in cancer prevention activities. The MC will have at least one named member from each of the participating countries. The MC will also implement gender policies aiming at a balanced representation of women and men in the MC itself, WG leaders, and STSM's amongst others. From the outset the current **CUPID** network has a good gender balance. It will also follow the involvement of Early Stage Researchers in the Action, using available tools to enhance their career opportunities. Finally, the MC will continually seek new partners to drive the Action forward, especially from Inclusiveness Target Countries.

Cooperation within the COST Action is organised around four closely interconnected WG's working in parallel. The rationale for establishing the WG's is twofold. First there is a need to exchange knowledge and expertise between the different groups that constitute an interdisciplinary approach to understanding integrated cancer prevention efforts for and with people with intellectual disabilities on many levels: co-production of a research agenda and knowledge base with people with intellectual disabilities and relevant stakeholder groups and at the level of policy making and resource provision. Second the timeline of the Working Groups is created to drive the Action towards the specified outcomes and enable coordination of European efforts in determining which way a multidisciplinary approach will be the most effective while meeting the rights of people with intellectual disabilities for equal access to healthcare in accordance with Section 25 of the UNCRPD.

#### **WG1: The interdisciplinary co-production team**

**Objectives:** WG1 will work 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.

**Task 1:** Creation of an international interdisciplinary team of relevant stakeholders inclusive of people with intellectual disabilities from the COST countries involved.

**Task 2:** Exchange co- produced knowledge in order to develop an understanding of factors which impede or facilitate cancer prevention efforts among people with intellectual disabilities via online platform such as online focus groups and questionnaires with the support of advocacy groups/ carers underpinned by the principles on Patient Public Involvement (INVOLVE, 2020).

**Task 3:** Suggest what kind of research and/or training would be necessary to ensure cancer prevention strategies targeted to the unique needs of people with intellectual disabilities as well as progressing the state-of-the-art in this area.

#### **WG2 – Cancer prevention policies: audit and evaluation**

**Objectives:** WG2 will focus on EU policy in the area of cancer prevention and unique challenges of access to cancer screening programmes across the partner countries.

**Task 1:** Exchange knowledge and experiences in order to identify how different national health systems function in the way they deliver cancer prevention initiatives and screening programmes in the participating COST countries.

**Task 2:** Agree, create and conduct an audit and evaluation in order to compare the different health systems in the participating COST Action, so a comparative analysis can be completed.

**Task 3:** Create and conduct an audit and evaluation to identify whether people with intellectual disabilities have equal access to care in the area of cancer prevention.

**Task 4:** Identify research and/or training which would be necessary to improve current health systems in relation to the provision of cancer prevention strategies and targeted screening programmes in order to improve equality of access to such initiatives as well as progressing the state-of-the-art in this area.

### **WG3 –Universal EU Cancer prevention strategy methodology**

**Objectives:** WG3 will focus upon 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. Development of this strategy will take into account the following key areas: 1) improving the overall health of people with intellectual disabilities taking into account the recommendations of the European Code of Cancer; and 2) responsiveness to ensure all people with intellectual disabilities should have the same right to access cancer screening programmes and that their unique needs are taken into account in the ecological approach to care provision including economic and literacy requirements

**Task 1:** Exchange knowledge and experiences based upon WG's 1 and 2 in order to design a research agenda to design guidelines for a minimum standard of equitable access to cancer prevention initiatives and screening programmes implementation beyond the Action.

**Task 2:** Generate a research agenda to develop guidelines for the different health providers of the necessary knowledge, skills and competencies needed to meet the standard-of-care requirements along with appropriate evaluation designs to investigate the outcome for each speciality.

### **WG4 – Dissemination and Outreach**

**Objectives:** WG4 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. The Action's website and social media networks serve as the main communication channels between Action members and all relevant parties (researchers, clinicians, healthcare providers, intellectual disability organisations, advocacy groups, policymakers, screening staff, people with intellectual disabilities and carers).

**Task 1:** Create an open access accessible **CUPID** Action website with all project information, including the database of experts in the field, and instructions on how to join the Action.

**Task 2:** Actively recruit COST Action members to participate in conferences, workshops, meetings and particularly Early Stage Researchers in Training Schools.

**Task 3:** Co-ordinate, facilitate and promote exchange and mobility within partners of the Action, to allow scientists/ Early Stage Researchers access to health care organisations and academic institutions within the network to learn new techniques, measurements or methodologies not available in their home country through STSM.

**Task 4:** Organise webinars on providing updates and information on key emerging areas in the **CUPID** Action to interested parties.

**Task 5:** Developing annual newsletters, including accessible versions, about project progress.

**Task 6:** Presentations and workshops of the **CUPID** Action's achievements at relevant conferences to raise the profile of the important work undertaken.

**Task 7:** Organisation of the final conference in which all the **CUPID** networks achievements are presented.

**Task 8:** The **CUPID** network will create a national and EU level roadmap to reach out to policymakers using the principles of the Research to Policy Model for Collaboration. This will help to bridge the research agenda to policy gap.

## **4.1.2. DESCRIPTION OF DELIVERABLES AND TIMEFRAME**

#### **Deliverables WG1**

- Develop a protocol on how to evaluate the inclusiveness of cancer prevention programmes including equitable access to screening based on a current literature review together with feedback from clinicians, people with intellectual disabilities, family members and other relevant stakeholders using online focus groups and questionnaires. The key foci will be 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.
- Organise a training school about cancer prevention programmes and factors impacting on equality of access for and with people with intellectual disabilities.
- Organise STSM's to facilitate training and knowledge exchange from experts across Europe.
- Liaise with the WG4 to ensure reports and working papers are published from working group meetings and information is disseminated through the Action's website; together with the other WG's, overseen by the MC, and participate in organising the Action conferences.

#### **Deliverables WG2**

- Develop a knowledge base to identify the minimum EU policy standard for cancer prevention for people with intellectual disabilities across the pan-European area.
- Organise a training school about organisational context and implementation of equitable cancer prevention strategies including access to screening programmes.
- Organise STSM's to facilitate training and knowledge exchange from experts across Europe.
- Liaise with the WG4 to ensure reports are published from workgroup meetings and information is disseminated through the Action's accessible website and social media accounts; together with the other WG's, overseen by the MC, participate in organising the Action conference.

#### **Deliverables WG3**

- To develop a research agenda to develop EU wide cancer prevention guidelines for people with intellectual disabilities.
- Organisation of a Training School about health system goals for targeted cancer prevention and screening programmes for people with intellectual disabilities
- Liaise with the WG4 to ensure reports are published from workgroup meetings and information is disseminated through the Action's website and social media accounts; together with the other WG's, overseen by the MC, participate in organising the Action conference.

#### **Deliverables WG4**

- 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 will be organised 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.

### **4.1.3. RISK ANALYSIS AND CONTINGENCY PLANS**

Risk management identifies, mitigates, and controls the known risks to meet project objectives. Risks may be foreseen or unforeseen factors that arise. Managing risk is part of all activities associated with the **CUPID** COST Action and includes interaction with stakeholders. The MC will design a Risk Management plan based on the ISO 31000: 2018 Risk Management- Guidelines.

Each working group is headed by a member of the MC and will report on the progress of their specific working group to this Committee monthly. Risks will be categorised as 'low', 'medium' or 'high' so that managing risk is efficient, effective and consistent through the lifecycle of the Action.

- Some WGs will not meet with the required regularity (due to agenda problems of WG members, for example) thus delaying the Action. WG leaders and MC will mitigate the risk by ensuring that each WG has enough expertise to deliver results and attend the meetings.
- Poor management of the working groups will be mitigated by selection of experience WG leaders. MC will provide support and where the situation does not improve the MC leader will replace the WG leader.
- Difficulty persuading stakeholders and policymakers to participate in the Action. Proposers of the Action will use their own professional networks to convince national stakeholders to participate. This will ensure the required level of expertise is sufficient within the network.
- Difficulty engaging people with intellectual disabilities due to issues such as willingness to participate, consent issues and communicative abilities. To address this key members of the **CUPID** network have specialised medical and nursing backgrounds tailored to meaningful engagement with people with intellectual disabilities to explain their involvement in the Action through their own will and preference.
- Action members lack of interest in STSM, Training Schools and conferences with only a minority contributing publications. There is even distribution of tasks among Action Members that are allocated after careful consideration of their capabilities. A mentorship programme by more experienced researchers for Early Stage Researcher's will promote their activity in the Action. Future waves of COVID-19 may disrupt the scheduled **CUPID** COST Action networking events. Contingency plans involve using technology to undertaking synchronous networking activities online or hosting hybrid events.
- Data on cancer prevention activities and screening programme data may be inconsistent or not comparable. One of the objectives of the Action is to identify multi-method methodologies to carry out high- quality comparative studies.
- It may be the case that deliverables produce few novel concepts or solutions. To counteract this it is essential that the voices of all stakeholders, most importantly people with intellectual disabilities, are listened to, in order to get new ideas and gain a deeper understanding of stakeholders' expectations.

#### 4.1.4. GANTT DIAGRAM

	Year 1				Year 2				Year 3				Year 4			
	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4
<b>General Management</b>																
Launch and meetings of the MC to establish leads of the WG																
Finalise terms of reference																
Monthly meetings (online)																
Annual report																
Midterm review																
Final report																
<b>WG 1</b>																
Start up meeting of WG																
Creation of international interdisciplinary team																
Exchange co-produced knowledge																
Training school																
STSM's																
Open access publication																
Final Report																
<b>WG2</b>																
Start up meeting of WG																
Agree, plan and scope the literature																
Extensive audit and evaluation																
Training School																
STSM's																
Open access publication																
Final report																
<b>WG3</b>																
Start up meeting of WG																
Agree, plan and scope the literature																
Exchange knowledge																
Generate a research agenda																
Training schools																
STSM's																
Final report																
<b>WG4</b>																
Start up meeting of WG																
Agree, plan and set up the accessible website																
Exchange knowledge on the website																
Recruit COST Action members																
Webinars																
Newsletters																
Final Conference																
Final report																