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Editorial

A COST Action to address challenges facing people with intellectual disabilities accessing cancer prevention and response services across Europe – Introducing CUPID - Cancer- Understanding Prevention in Intellectual Disabilities

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Editorial

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Abstract

COST Actions are grants provided by the European Union to support the establishment of networks of expertise to explore and address a scientific or social issue that impacts across Europe. This article introduces and describes one such action that started in October 2022 - CUPID - will address issues of policy and equity of access to cancer prevention initiatives by people with intellectual disabilities compared to the general population in Europe. With 82 individual members drawn from 30 countries CUPID will establish an interdisciplinary network of stakeholders representing carers, service providers, advocacy groups, educators, healthcare professionals, researchers and people with intellectual disabilities. The CUPID COST Action will be implemented over four years and will identify what needs to be addressed by the European Union and health and social services to improve cancer prevention among people with intellectual disabilities.

Key words: Intellectual disabilities; COST Action; Cancer prevention; CUPID

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1. Introduction

At the height of the COVID-19 pandemic people with intellectual disabilities, and those who provide personal care to them, faced considerable hurdles when trying to access general health care services due to segregation and discrimination (Portal et al., 2020). This inability to gain timely access to services, combined with their particular vulnerabilities, meant, for example, that in the United Kingdom (UK) the risk of people with down syndrome dying from COVID-19 was 36 times higher than in the general population (Williamson et al., 2021). Such negative service experiences, morbidity rates and mortality rates amongst people with intellectual disabilities whilst highlighted by the pandemic were not unique to it but in fact predate it (Heslop et al., 2020)

There is evidence to suggest that people with intellectual disabilities, particularly those living with family carers or in an independent setting, are regularly ignored by mainstream health services not only in terms of access to services and treatment but also in relation health screening, health promotion and illness prevention programmes (Brown et al., 2017; Doyle et al., 2022). One significant area of health care provision in which this may be a problem is cancer prevention and treatment.

This editorial introduces and outlines a new project, funded by the European Union's COST Action initiative - Cancer- Understanding Prevention in Intellectual Disabilities (CUPID). CUPID will explore the issue of cancer prevention and treatment for people with intellectual disabilities with a view to developing a pan European and international inclusive network of expertise to identify where things need to change and what type of actions need to be undertaken to change them (see: https://www.cost.eu/actions/CA21123/).

1.1 What is COST and Why Cancer?

COST is an acronym for European Cooperation in Science and Technology and is run by the European Union. COST aims to support the establishment of interdisciplinary research and innovation networks to build expertise capacity in relation to a specific issue or problem of significance to Europe. It does this through the provision of fixed annual funding (currently €125,000 per annum) for up to four years to support the development of networks, supporting 'fact finding' short scientific missions, training schools, seminars and other relevant visits (see www.cost.eu).

Cancer is the second leading cause of death in the European Union (Berchet et al., 2023). With four million cases and 1.2 million recorded deaths in 2020, Europeans account for 25% of all global cases of cancer, even though Europe only has 10% of the global population (EU Science Hub, 2022). The challenge that cancer poses to the health of Europeans means that the EU have prioritised cancer screening and prevention as one of its core public health strategies. This strategy is to be implemented across Europe in relation to the general population through the Beating Cancer Plan (European Commission, 2020).

The extensive incidence and outcomes data available on the profile of cancer across the European Union indicates that there are wide disparities in rates and outcomes between member states and between different population groups (Berchet et al., 2023). For example, cancer affects the European elderly population disproportionately when compared to other groups, accounting for 60% of new diagnoses and 73% of cancer deaths in 2020 (EU Science Hub, 2022). Within the context of the relationship of old age to the likelihood of developing cancer, it should be noted that people with intellectual disabilities are now living into old age compared to previous times (McCarron et al., 2017). There is evidence that elderly people with an intellectual disability often go undiagnosed in relation to a whole range of conditions, including cancer (Haveman et al., 2011).

It is notable, that whilst there is extensive data relating to health disparities in the general population, less attention has been paid to such issues as these impact on people with intellectual disabilities in relation to policy formulation, public health campaigns and treatment facilitation. Thus in the area of cancer impacts, access to services and screening and whether policies take account of the needs of people with intellectual disabilities in relation to their specific cognitive challenges and co-morbidities little appears to have been done, even in those European member states where broad services for people with intellectual disabilities, such as Ireland, are quite good. For example, specifically designed health information leaflets that account of cognitive abilities in relation to comprehension and proactive focus on community outreach. Thus research indicates that services are often not effective in communicating with people with intellectual disabilities in relation to their cancer diagnosis (Satgé et al., 2016). It has been found that a significant number of cancer related deaths in the population of people with

intellectual disabilities could be prevented through more timely access to services and intervention (Heslop et al., 2019).

Some jurisdictions within Europe, for example France and the UK, have been highly active in gathering data about cancer's impacts on people with intellectual disabilities. For example, the French organisation, Oncodéfi, carries out extensive research in this field (https://oncodefi.org/en/research/). Research seems to suggest that people with intellectual disabilities may be overly represented in relation to specific cancers compared to the general population (Willis et al., 2018). Alternatively, research has found that women with intellectual disabilities experience similar rates of breast cancer to that of the general population (Satgé et al., 2020).

Whilst research has identified the many challenges that people with intellectual disabilities face there is no clear pan European picture of the nature of cancer, service access and screening, and cancer prevention approaches in relation to people with intellectual disabilities. Bearing in mind that the Europe Union's Beating Cancer Plan is for the entire population of the EU, this is a significant issue that needs to be addressed. Not least, because, under the Treaty of Amsterdam (1997) and Article 168 of the Treaty on the Functioning of the European Union (2009) there are requirements for the European Union to promote population well-being via combatting discrimination and social exclusion and address issues of discrimination in relation to people with disabilities.

To address the lack of systematic knowledge across the EU about the degree to which cancer prevention strategies are responsive to the unique cognitive and healthcare needs of people with intellectual disabilities, the CUPID Cost Action aims to improve our understanding of cancer prevention among people with intellectual disabilities through the establishment of an interdisciplinary network of stakeholders representing carers, service providers, advocacy groups, educators, healthcare professionals, researchers and people with intellectual disabilities to explore what needs to be addressed by the European Union and health and social services.

2. The objectives of the CUPID COST Action and how it will achieve them

To achieve its overall aim, CUPID brings together expertise drawn from across Europe and the wider world. Currently, it has 82 individual members representing a wide range of medical, nursing, health and social science disciplines from across 30 countries.

CUPID has five objectives to fulfil its overall aim during the lifetime of the Action. These are:

- To establish 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.
- Create a 'state of the art' national and cross-national co-produced knowledge base in relation to policies and initiatives relating to cancer prevention amongst people with intellectual disabilities referenced to their expressed needs.
- Develop a responsive research agenda that addresses identified challenges to address the unique needs of people with intellectual disabilities and that also addresses their expressed identified priorities.
- Promote new collaborative funding applications from network members including national and EU funding opportunities in cancer prevention strategies and support early career researchers in the field.

The COST Action framework requires the establishment of a Management Committee to oversee its activities. Currently, there are 30 members of this Committee drawn from 21 European countries. Membership is mostly from EU member states but the level of interest in CUPID is such that more than a third of the Management Committee consists of representation from non- EU states - Bosnia, Israel, Macedonia, Serbia, Switzerland, Turkey, and the United Kingdom.

Action activities and participants are organised, as per COST requirements, through working groups. These working groups are assigned a series of tasks referenced to a set of deliverables to be achieved across the four years of the Action. CUPID has four interdisciplinary working groups. The first is tasked with the co-production of a knowledge base about cancer prevention strategies for people with intellectual disabilities across the European Union. The second, will look to explore and analyse EU policy in the area of cancer prevention and challenges faced by people with intellectual disabilities of access to cancer screening programmes across the EU. The third working group will focus upon combining the findings generated by the other two working into a comprehensive plan for a multidisciplinary approach that includes the involvement of people with intellectual disabilities referenced to concepts of citizen science to establish a

research agenda that contributes to the development of a universal EU cancer prevention strategy and set of policy guidelines that are responsive to the unique needs of people with intellectual disabilities. The final working group focuses on building a communications and dissemination strategy for the CUPID Action and its implementation.

3. Action Programme for 2023

Formally CUPID was initiated on October 25th, 2022, with a first meeting of the Management Committee for the Action which also involved the assigned administrative and science officers from COST, based in Brussels. Their role is to provide support and guidance to the Management Committee in relation to COST rules and requirements. The first requirement of COST is for the Management Committee to draw up a budget to support the Action for the coming year (November 2022 to October 2023). Through a subcommittee of the Management Committee a budget for activities in year 1was developed and has been approved. Activities will begin from February 2023. These activities will involve a series of consultative workshops taking place in Ireland, the Netherlands and Turkey with service and advocacy groups to establish baseline issues that subsequently need to be addressed in the coming three years. In addition, CUPID will be engaged with networking activities in Poland, the Netherlands and Switzerland and meetings with EU policy makers in Brussels (facilitated by the European Association of Service providers for Persons with Disabilities). Envisioned for the end of this first year of the Action will be three open access publications outlining the challenges faced by people with intellectual disabilities accessing cancer services and the nature of current national and EU policy in meeting their needs. CUPID will also establish a website where a depth explanation of the project will be available. The website will also provide access to data as it is gathered by the Action and information on how to become involved in CUPID through national contact points or via the COST Action website, as well as news about people with intellectual disabilities and services for the prevention of cancer.

4. Conclusion

A COST Action is a valuable networking opportunity which promotes pan European collaboration and indeed, collaboration with stakeholders beyond the European Union. CUPID Cost Action will facilitate European stakeholders (both researchers, clinicians, advocacy groups, carers and service users) and stakeholders outside of Europe to address an important health and social justice issue – the full recognition and rights of people with intellectual disabilities to access and receive cancer prevention services to equalise their outcomes as part of the general population. If you are interested in CUPID or wish to join the Action, please visit https://www.cost.eu/actions/CA21123/

Conflict of Interests

Author has no conflicts of interest.

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