

Symposium title: Cancer screening and prevention in people with intellectual disabilities

Submission type: 90 minute symposium

Theme: Equity

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Symposium summary

Subpopulations with limited health skills and more complex health needs, such as people with intellectual disabilities (ID) are potentially underserved by generic cancer prevention and screening policies. This contributes to disparities across the entire cancer spectrum, leading to poorer oncological outcomes and ultimately premature mortality.

Understanding of how to optimize cancer care to people with ID, starting with cancer prevention and screening, is scarce. People with ID are overlooked in population monitoring and routine data (i.e. not identifiable as having an ID), and thus missing in relevant statistics informing policy and practice.

Moreover, people with ID are often excluded from scientific studies due to legal (e.g. difficulties in obtaining informed consent) or methodological issues (e.g. generating unwanted heterogeneity), which limits the development of new scientific knowledge. In this symposium, we will address relevant issues related to cancer and ID, with a specific focus on screening and prevention. First we will introduce the specific relationship between ID and cancer, next, we will give an overview of cancer screening and prevention policies across Europe and their attention for disability groups, and finally we will present a proposal for a collaborative research network to build equitable, disability-inclusive cancer prevention policies.

Abstract

Title: CUPID: Cancer - Understanding Prevention in Intellectual Disabilities

Authors:

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Background – There is a poor understanding of cancer prevention among people with intellectual disabilities (ID). Among the European ID population, many cancer diagnoses are symptomatic presentations following behavioural distress or physical changes. The factors that influence unequal health status, premature death from cancer, and delays in treatment and healthcare engagement are diagnostic overshadowing, paternalism, cancer screening delays, and the COVID-19 pandemic. These factors warrant further investigation.

Methods – Using coproduction, this Pan-European project research team comprising of almost 100 members will work with people with ID and relevant stakeholders to establish a knowledge base about cancer prevention strategies. A hybrid approach will enable short-term scientific exchanges, training schools, conferences, workshops, and seminars to explore highlighted issues. In addition, peer learning will be used to exchange information using active working partnerships with academics, researchers,

non-governmental organisations, carers, people with ID, policymakers, health professionals, advocacy groups and online focus groups and questionnaires.

Impact on practice – By exchanging co-produced knowledge, the project team will develop a protocol to help interdisciplinary teams understand the factors that impede or facilitate cancer prevention efforts among people with ID across Europe.

Discussion – The team will establish a research agenda and knowledge base to improve cancer prevention for people with ID in the European Union and beyond.