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Advancing a Universal European Cancer Prevention Methodology for People With Intellectual Disability: Findings From CUPID Workshops in Ireland and Türkiye

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ABSTRACT

Background: People with intellectual disability have higher rates of cancer mortality than the general population. Cancer prevention programmes and screenings are recommended in adults, including those with intellectual disability. The opinions of relevant parties are important to ensure that people with intellectual disability can achieve equity in cancer outcomes. The aim of this paper is to report the findings of two workshops held in Ireland and Türkiye in 2023, which identified key issues affecting prevention, diagnosis and management of cancer in people with intellectual disability.

Methods: Researchers, practitioners, policymakers and other stakeholders with a role in cancer prevention programmes or cancer care ($n = 44$) participated in 'World Café' workshop meetings in Dublin and Ankara. The findings were synthesised under the Dahlgren and Whitehead (1991) Social Determinants of Health framework.

Results: Both workshops identified that people with intellectual disability face challenges including: limited available cancer data in this population, health issues overshadowing cancer diagnosis, and social barriers such as low health literacy. Involving families, professionals and promoting self-advocacy, while tailoring health services with inclusive decision making were prominent themes in both workshops as solutions. Research and person-centered healthcare were identified as critical for developing effective cancer prevention programmes.

Conclusion: For people with intellectual disability to benefit from effective cancer prevention programmes, reasonable adjustments must be made by policymakers, health institutions, primary healthcare professionals and non-government organisations, and research evidence must underpin decisions.

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Summary

- There is a poor understanding of cancer prevention among people with intellectual disability.
- A European Union grant called CUPID has given money to help improve this situation by developing solutions to make this better across Europe and beyond.
- We used some of this money to hold two workshops in Ireland and Türkiye to identify how this situation can be improved for people with intellectual disability.
- In the workshops, we were told that people with intellectual disability should be at the heart of decision-making and that reasonable adjustments and research should support any approach to help make things better.

1 | Background

Intellectual disability, affecting 1% of the global population, includes delays and limitations in functioning that manifest during development (McKenzie et al. 2016). People with intellectual disability tend to have poorer health than the general population and die younger (McMahon and Hatton 2021; Heslop et al. 2013). Increasingly, the incidence of cancer, and poorer cancer outcomes for people with intellectual disability are becoming a concern. Two recent Canadian studies (Mahar et al. 2023; Hansford et al. 2024) found that adults with intellectual disability are more likely to be diagnosed with metastatic cancer than the general population and, among people diagnosed with cancer, cancer is more likely to be given as the cause of death. These findings have been replicated recently in England (Heslop et al. 2022) and Scotland (Ward et al. 2024). Consistent across these studies is the late-stage diagnosis experienced by this population (McMahon, McCallion, and McCarron 2023). However, the specific factors affecting cancer outcomes in people with intellectual disability are not known and require further research.

People with intellectual disability have greater exposure to social determinants of health than the general population (Emerson and Hatton 2014; Chapman et al. 2024). Individual factors, health and lifestyle behaviours, and structural and institutional factors (including the organisation and delivery of healthcare and social care) put people with intellectual disability at greater risk of cancer and poor outcomes (McMahon, McCallion, and McCarron 2023). The needs of people with intellectual disability are often overlooked in healthcare delivery (Doherty et al. 2020; Hemm, Dagnan, and Meyer 2015) and, in terms of access to primary healthcare, several barriers and facilitators have been identified including education; knowledge and awareness; communication; fear and shame; participation in decisions, and lack of time (Doherty et al. 2020). Arguably, these indicate a need for greater care, dignity, respect, collaborative relationships, and reasonable adjustments.

Challenges to cancer prevention and screening in people with intellectual disability are evident across Europe and beyond, and this topic is the focus of a recent European Union Cost Action CUPID ‘Cancer—Understanding

Prevention in Intellectual Disability’ (COST ACTION 2023; Vukovic et al. 2023). The primary objective of the CUPID COST Action is to address issues of policy and equity of access to cancer prevention initiatives by people with intellectual disability compared to the general population in Europe. However, individual European countries have varying and sometimes unique challenges in this area. Furthermore, differing healthcare systems, socio-economic, societal and cultural contexts are likely to require different strategies to produce meaningful change in behaviours and outcomes.

2 | The Cancer Landscape in Ireland

With an annual population new cases incidence rate of 0.22, cancer is now the leading cause of death in Ireland (National Cancer Registry of Ireland, NCRI 2023). Like other EU countries, cancer of the (female) breast, lung, bowel, prostate, and skin account for most diagnosed cancers (NCRI 2022). Cancer deaths are increasing due to increasing longevity (OECD 2023) but, for the most common cancers, mortality rates have been decreasing (OECD 2023) signalling an increased focus on detection and treatment. Recent data identified that Ireland compared marginally better than the European average for 5-year net survival for most common cancers, but timely patient access, especially before diagnosis, remains a problem in Ireland (OECD 2023).

Ireland has three national cancer screening programmes (breast, cervical and colorectal) offering free screening to eligible populations. The breast cancer programme screens women aged 50–69 years every 2 years. The cervical programme screens people with a cervix aged 25–65 years (every 3 or 5 years), and the bowel programme screens people aged 59–69 years every 2 years. Population uptake rates are 74.8% (breast), 73.0% (cervical) and 46.6% (bowel) (National Screening Service 2023a, 2023b). In 2017, Ireland adopted its third National Cancer Strategy with a particular focus on care delivery. The National Cancer Control Programme (NCCP) is responsible for implementing cancer policy in Ireland to ensure all care elements are delivered optimally. The current strategy has particularly emphasised raising ‘cancer awareness and prevention initiatives and prioritising disadvantaged populations and hard-to-reach groups’ (p.44) and focusing ‘on deprived areas, (and) minority populations where cancer outcomes are currently poorest.’ (p.56) (Department of Health 2017). The cornerstone is early diagnosis, which could produce meaningful changes in mortality and survival. Despite this being the policy objective, in Ireland there is no current mandate to focus on people with intellectual disability, whose cancer outcomes are among the worst in the population (Heslop et al. 2022; Mahar et al. 2023; Ward et al. 2024).

3 | The Cancer Landscape in Türkiye

According to 2018 data, the annual new cases incidence of cancer in Türkiye was 225.2 per hundred thousand. Breast cancer is the most common type of cancer in women. The frequency of colorectal cancer is 24.8 per hundred thousand in

men and 14.7 per hundred thousand in women. The incidence of cervical cancer is 4.2 per hundred thousand.

There is a 'National Cancer Control Programme' in Türkiye. Within the scope of this programme many activities such as 'Turkey Nutrition Guide', 'Türkiye Excessive Salt Consumption Reduction Program' and 'Turkey Diabetes Program' are carried out. In addition, this program includes national cancer screening strategies and programmes (Republic of Turkey Ministry of Health General Directorate of Public Health 2021). Türkiye has three cancer screening programmes for breast (women aged 40–69), cervical (women aged 30–65) and colorectal (women and men aged 50–70) cancers (Republic of Turkey Ministry of Health General Directorate of Public Health 2021). These cancer screenings are offered free of charge to the public, but breast (34.9%) and cervical screening (38.8%) rates in Türkiye (Başara et al. 2023) are lower than the European average (European Commission 2024). Unlike in many European countries, the human papillomavirus (HPV) vaccine is not given routinely (Ministry of Health 2023).

Although there are current national action plans for cancer control and monitoring in the population, there is no specific programme for protecting people with intellectual disability from cancer risks despite the 'Disability Rights National Action Plan 2023–2025' objective to attain high levels of health and well-being in this population (Republic of Türkiye Ministry of Family and Social Services 2023).

Ireland and Türkiye have representation in the CUPID COST Action. Ireland is a Western European country with a well-established healthcare infrastructure, while Türkiye is a South-east European/Asian country that provides a different cultural and healthcare context that represents challenges for marginalised groups such as those with intellectual disabilities. The rationale for including both countries was to generate a broad overview of the barriers and facilitators to enhance the applicability and generalisability of findings leading to more inclusive and adaptive preventative strategies. Consequently, the aim of this paper is to report on the findings of two workshops held in Dublin and Ankara in 2023 which discussed and synthesised key issues affecting prevention, early detection, diagnosis and management of cancer among people with intellectual disability, to inform recommendations for policy, practice, and research.

To achieve this aim, three substantive objectives were set:

1. Bring together researchers, practitioners, policymakers and key stakeholders involved in cancer prevention programmes, as well as professionals who work in cancer prevention, diagnosis and management.
2. Use the Social Determinants of Health framework (Dahlgren and Whitehead 1991) to explore influences on cancer prevention, diagnosis and management for people with an intellectual disability.
3. Inform and make recommendations for policy, practice and research that focus on cancer prevention, diagnosis and management for people with an intellectual disability, and which account for the inequalities and influences identified in objective 2.

4 | Methods

4.1 | Workshop Theoretical Underpinning

The workshops were framed around the Social Determinants of Health Framework (Dahlgren and Whitehead 1991). Social determinants are the non-medical factors that influence a wide range of health outcomes (World Health Organization 2023), such as where people are born, live, learn, work, play and worship, and which are shaped by political, social, and economic forces. According to Dahlgren and Whitehead (1991), social determinants are multi-layered in their influences on health, including personal characteristics (such as age, sex and ethnicity); individual behaviours (in relation to cancer these could include tobacco use, physical inactivity and poor diet); social and community factors (including family support, relationships and wider social inclusion); and general socio-economic, cultural and environmental conditions (such as living and working conditions, housing, and access to healthcare). The Social Determinants of Health Framework was used for the workshops as it provides a structure for factors that can determine health outcomes, whilst also referencing the effects of social and economic inequalities (Dahlgren and Whitehead 1991).

4.2 | Participants

A wide range of representation across both countries was sought and invitations were sent to governmental, local, voluntary and non-governmental organisations in both Ireland and Türkiye. The participants who attended the workshop represented a diverse range of expertise ensuring that discussions relating to cancer screening and prevention were informed by attendees with direct specialised experience and knowledge in the areas of intellectual disability but also more broadly in the sphere of and healthcare policy and implementation.

4.3 | Türkiye

The workshop was held in May 2023 over 3 days in Ankara. There were 26 participants with expertise and direct knowledge in the area of cancer prevention more broadly, and also specific to people with intellectual disability: 18 academics and researchers from Türkiye and eight people who participated as stakeholders: two managers from the cancer screening policy unit within the Ministry of Health, one manager from the policy unit for disabled people in the Ministry of Family and Social Services, four managers from a rehabilitation centre (where 760 people with intellectual disability live), and one relative of a person with intellectual disability.

4.4 | Ireland

The workshop took place in April 2023 in Dublin. There were 18 participants, and similarly included participants with expertise and direct knowledge in the area of cancer prevention more broadly, and also specific to people with intellectual

disability. Representatives from across Ireland from cancer organisations, healthcare professionals, healthcare organisations, advocacy groups and academic institutions conducting research in health inequalities and people with intellectual disability participated.

4.5 | Synthesis of Workshop Findings

A blended World Café approach was used in Ireland and Türkiye, incorporating underpinning principles derived from the ‘workshop discussion’ approach (Ørngreen and Levinsen 2017). The workshops, characterised as an applied scientific teaching technique, were planned to allow collaborative exploration, critical thinking, and shared learning by bringing together key stakeholders to explore influences on cancer prevention, diagnosis, and management for people with an intellectual disability. The discussions were facilitated by M.Mc.M., M.O’C. and C.M. in Ireland and by E.A., S.G. and A.I. in Türkiye and were conceptually framed around the questions below (see Table 1) in relation to the Social Determinants of Health Framework (Dahlgren and Whitehead 1991). Both workshops had three facilitators who ensured that conversations stayed on topic and took notes as discussions were ongoing. After each workshop, the workshop facilitators transcribed their notes from participants’ conversations, met with the other facilitators to discuss outcomes and subsequently identified the main themes and key issues. When this activity was completed following both workshops, each completed individual analysis akin to content analysis, using the Social Determinants of health as a framework. Both sets of analysis following the workshops were then combined and synthesised to generate one set of data. The results, presented below, are a synthesis of views (under main themes) expressed by workshop participants only and not those of this manuscript’s authors synthesised as common to both Ireland and Türkiye, and specific to each country where appropriate.

TABLE 1 | The conceptual framework followed in workshops in Ireland and Türkiye.

Personal characteristics and individual lifestyle factors	What is the problem? Why is it happening? What can be done about it? How will we know we are doing the right thing? What needs to happen next?
<ul style="list-style-type: none"> Personal characteristics: Age, sex, ethnic group, hereditary factors, level of intellectual disability Individual lifestyle factors: Tobacco use, physical inactivity, overweight and obesity, poor diet, alcohol use 	
Social and community networks and living and working conditions	
<ul style="list-style-type: none"> Social and community factors Social and community influences (family support, family support systems) Social circle of the family: its relationship with the society, its adaptation/ isolation (family, wider social circles, social isolation) 	
General, socioeconomic, cultural and environmental conditions	
<ul style="list-style-type: none"> Socioeconomic status: living and working conditions, employment, education, housing, welfare services, social support from community, health insurance Screening equity, macro level influences, national health infrastructure, healthcare services Passive smoking Sun exposure, radiation exposure 	

5 | Results

5.1 | Main Findings From the Two Workshops

The findings obtained from the two workshops were combined and categorised in line with the Social Determinants of Health Framework, including facilitators and barriers to cancer prevention (Table 2). In addition, the similarities and differences of discussions across the two workshops are demarcated in Appendix S1.

1. Personal Characteristics and Individual Lifestyle Factors

Barriers and facilitators related to personal characteristics and lifestyle factors common to both Ireland and Türkiye were:

- Lack of data on personal characteristics and individual lifestyle factors:* Workshop participants expressed that research on these aspects in people with intellectual disability is insufficient in both countries. Research is needed to collect data on lifestyle risk factors and cancer development among people with intellectual disability.
- Obesity and gastrointestinal problems as frequent health problems:* In both countries people with intellectual disability presented with high levels of gastrointestinal problems such as heartburn or gastro-esophageal reflux disease (GERD), often related to poor diet. This issue was raised and discussed given that gastrointestinal conditions can increase the risk of some cancers. Obesity and physical inactivity are common problems. People with intellectual disability are more likely to be obese compared to the general population, with many having sedentary lives and unhealthy diets. Furthermore, individuals with intellectual disability who live in institutions or supported care facilities may have little control or choice over diet. The situation for those living in the family home varies and is often unknown.

TABLE 2 | Facilitators and Barriers to Cancer Prevention in People with Intellectual Disability—Insights from Workshops in Ireland and Türkiye.

	Facilitators	Barriers
Personal Characteristics and Individual Lifestyle Factors	<ul style="list-style-type: none"> • None discussed 	<ul style="list-style-type: none"> • Lack of data on personal characteristics and individual lifestyle factors • Obesity and gastrointestinal problems as frequent health problems • Multiple co-morbidities
Social and Community Networks and Living and Working Conditions	<ul style="list-style-type: none"> • Family members as facilitators to access cancer prevention services • The importance of relationships with primary healthcare professionals • Supporting and teaching people with intellectual disability to advocate for themselves • Education and awareness among health and social care professionals 	<ul style="list-style-type: none"> • Lack of data on housing and working conditions • Elderly parents may have difficulty supporting • Perceptions of cancer screenings as unnecessary and difficult • Deficits in education and awareness of cancer prevention/cancer risk factors • Lack of appropriate educational materials for people with intellectual disability • Low health literacy and digital literacy levels of people with intellectual disability and their relatives • Families not accepting or hiding their child's diagnosis
General, Socioeconomic, Cultural And Environmental Conditions	<ul style="list-style-type: none"> • Annual health assessment for people with intellectual disability • Bespoke health services for people with intellectual disability and improving accessibility to services • People with intellectual disability need to be active participants in decision making: 	<ul style="list-style-type: none"> • Lack of research • Absence of national database for resources • Lack of policies and resources • Deficit in national guidelines • Lack of coordination across services • Stigmatising views • The perception that cancer does not occur in people with intellectual disability • Inequalities in the current health system • Difficulties in accessing healthcare • Complex and varying healthcare needs • Limitations in primary care • The over complexity in services and complicated systems • Financial concerns and low socioeconomic position • Limited activities of NGOs

- c. *Multiple co-morbidities*: People with intellectual disability typically present with multiple co-morbidities. This was identified as a risk of cancer under-diagnosis due to diagnostic overshadowing.
- 2. Social and Community Networks and Living and Working Conditions

Barriers and facilitators related to social and community networks and living and working conditions common to both Ireland and Türkiye were:

- a. *Family members as facilitators to access cancer prevention services*: People with intellectual disability who are living with family (and not attending generic intellectual disability services) may only go to their doctor or attend cancer screening if supported by family members.
- b. *Elderly parents may have difficulty supporting*: Many people with intellectual disability are supported by elderly parents who themselves require support and may be limited in the assistance they can give to the family member with intellectual disability in terms of healthcare appointments. Furthermore, when elderly parents die, individuals may have no-one to advocate for their healthcare needs.
- c. *The importance of relationships with primary healthcare professionals*: It is crucial that people with intellectual disability have established relationships with the GP, with the benefits of increased trust and continuity of care.
- d. *Supporting and teaching people with intellectual disability to advocate for themselves*: Supporting people with intellectual disability to self-advocate may empower them to make their own health decisions. For example, in Türkiye individuals with intellectual disability have some priority rights in healthcare (such as co-payment exemptions, priority in inspections of doctor/nurse), so it is essential to increase awareness of rights in people with intellectual disability and their families.
- e. *Education and awareness among health and social care professionals*: Increased training and education for generic health professionals (e.g., GPs) is needed, particularly in relation to the different health needs of this population. Professionals need to be confident in determining that people with intellectual disability have understood provided information. Specific training around communication with people with intellectual disability is also required and may be an important addition to general healthcare professional training.
- f. *Perceptions of cancer screenings as unnecessary and difficult*: Both workshops discussed that family members can find the thought of their relative undergoing cancer screening (especially cervical screening) difficult and they may argue against the requirement to screen, particularly if they are not sexually active.
- g. *Lack of education and awareness of cancer prevention and cancer risk factors*: This was a frequently noted problem in both workshops. Gaps in knowledge about lifestyle risk factors for cancer among people with intellectual disability

are reported to be critically important. This population group may be unaware of cancer symptoms; similarly, many carers/family members are unfamiliar with how to check a person with intellectual disability for unusual 'lumps and bumps'. A holistic, ongoing approach to cancer prevention education was reported as important. For example, conversations about longer-term diet and physical activity may be more important to cancer prevention than a conversation about screening. In Ireland participants suggested using social clubs for people with intellectual disability, Special Olympics Ireland, or the Gaelic Athletics Association (national association for Gaelic games) for educating people with intellectual disability about cancer and cancer prevention (e.g., monthly talks on different aspects of cancer prevention could be delivered).

- h. *Lack of appropriate educational materials for people with intellectual disability*: Existing health promotion materials around healthy living, diet, exercise, and cancer prevention are designed for the general public, and there is a strong need for accessible, understandable cancer prevention resources (appropriate educational materials) for people with intellectual disability. These should be co-designed with stakeholders and people with intellectual disability, using Easy Read and accessibility principles.
- 3. General, Socioeconomic, Cultural and Environmental Conditions

Barriers and facilitators related to general, socioeconomic, cultural and environmental social conditions common to both Ireland and Türkiye were:

- a. *Annual health assessment for people with intellectual disability*: In Ireland it was stated that there is a need for access to an annual health assessment for this population, for example, the Head-to-Toe assessment. A component of this assessment examines the body, checking for lumps and bumps. However, not every care center offers this assessment and there is a lack of awareness among practitioners. While participants felt initiatives such as the Head-to-Toe assessment should be delivered across Ireland, they also highlighted that a 'one size fits all' approach will not work in addressing the individual cancer needs of people with intellectual disability. In Türkiye it was thought that the family physician and family health nurse should play a mentoring role in the booking and follow-up of cancer screening appointments for people with intellectual disability.
- b. *Bespoke health services and improving accessibility to services*: Bespoke health services that consider time, language, and individual needs of those intellectual disability would help reduce barriers to access. Examples of reasonable accommodations (e.g., dimming the lights for someone with sensory issues or autism) for appointments were highlighted across workshops. It is important that healthcare staff are prepared for the visit of a person with an intellectual disability, as is preparing the individual for the appointment so they know what to expect. Physical barriers were discussed in terms of environmental issues where people with intellectual disability may not be

- familiar with equipment which may cause distress. Additionally, staff may lack awareness of ways to reduce anxiety and so training staff in screening centers may be beneficial. In Ireland, having access to self-tests, for example, HPV self-sampling for cervical cancer screening, could overcome barriers to attendance. For example, being able to do a screening test in the individual's own home or local day centre, could reduce procedure fear. Existing screening methods (mammography, HPV DNA test, pap smear, colonoscopy) can be challenging and there is a need for non-invasive methods of cancer screening. Importantly, the HPV vaccine, which helps protect those vaccinated against HPV-related cancers such as cervical, anal and penile cancers, is not included in the routine vaccination schedule in Türkiye. Risky sexual behaviours, such as having multiple partners, are not unusual in people with intellectual disability, and so the HPV vaccine should be available to intellectual disabled individuals.
- c. *Lack of research*: There is a lack of research data on cancer incidence, staging and outcomes in people with intellectual disability, and there is limited research into the factors affecting the access of individuals with intellectual disability to screening (and healthcare more generally). Qualitative and quantitative studies are needed to increase our understanding of the participation decisions of people with intellectual disability in cancer screening, and their knowledge and behaviours in relation to cancer prevention. Research in both areas could inform the development of interventions, whether informational or practical. In Türkiye research involving people with intellectual disability is limited with workshop participants reporting that in many health research studies, having an intellectual disability is typically an exclusion criterion. Open data biobanks may be useful, enabling the use of different forms of data (biomaterial, blood, saliva, subjective data, etc.) from people with intellectual disability to be used in other studies, in line with ethical principles.
 - d. *Absence of national database for resources*: It was raised by workshop participants that there is a need for national databases of resources to support healthcare professionals and researchers on cancer prevention in people with intellectual disability.
 - e. *Lack of policies and resources*: Workshop participants expressed that there is insufficient evidence to support the development of specific policies around cancer prevention and screening in people with intellectual disability, potentially due to a lack of lobbying for this group. The allocation of dedicated funding would assist with producing much needed research to inform policy development. In Ireland the emphasis of current national health policies is on inclusiveness and diversity, but only with a focus on some excluded or stigmatised groups, such as the LGBTQ+ community, but not people with intellectual disability.
 - f. *Deficit in national guidelines*: There are no national guidelines for cancer prevention for this specific population. These guidelines should be practical and actionable.
 - g. *Lack of coordination across services*: In both workshops it was reported that there is no national approach to cancer prevention specifically for people with intellectual disability. There is some excellent practice in individual care centres but practice is not nationally standardised. A national collaborative approach across services offered to people with intellectual disability is urgently required, and this needs to be properly resourced and based on evidence. For this to happen, needs assessments should be conducted and a consultative process with all stakeholders should be undertaken to create a supportive environment for patients accessing services. In Ireland, staff working with people who have intellectual disability are often very isolated and there can be no communication or linking across services. In Sláintecare, Ireland's proposed roadmap for a world class universal healthcare system, there should be recognition of the needs of those with intellectual disability, and priority actions to address needs in relation to cancer prevention and treatment.
 - h. *Stigmatising views*: In both countries there are widely held assumptions that the health needs of this population are met in institutional services rather than primary care, thereby limiting access to services. In Türkiye a programme is needed within the media and school curricula to increase awareness of individuals with intellectual disability, to reduce levels of social exclusion and increase integration.
 - i. *The perception that cancer does not occur in people with intellectual disability*: Across workshops there was a reported tendency to believe that people with intellectual disability do not get cancer. When probed in the Irish workshop, this was explained in terms of people with intellectual disability dying younger from respiratory diseases as opposed to cancer. This inaccurate perception may influence the lesser uptake of screening.
 - j. *Inequalities in the current health system*: there is a risk of people with mild or undiagnosed intellectual disability 'falling through the cracks' in terms of their healthcare. It was discussed that a minority of people with intellectual disability are accessing healthcare. People with mild or undiagnosed intellectual disability are often living at home and not recognised by services. In Türkiye it was suggested that positive discrimination for cancer screening in people with intellectual disability should be undertaken.
 - k. *Difficulties in accessing healthcare*: This was noted as a particular issue for people with intellectual disability living rurally in both countries. In Türkiye, people with intellectual disability and their families face difficulties in accessing health institutions in rural and urban areas. Using a case management model, tele-consultation (or tele-health) and artificial intelligence applications for the protection of individuals with intellectual disability from cancer, were recommended. Access of people with intellectual disability who live at their homes to health and social services can be more difficult than in those who receive institutional care. Access to cancer screening centres should be facilitated for people with severe disability living at home to participate in cancer screenings.

in Türkiye. Home health services should be accessible and strengthened for intellectual disabled individuals living at home.

- l. *Complex and varying healthcare needs:* This population has complex and varying needs in terms of healthcare. There are sub-groups of people with intellectual disability who are particularly vulnerable, for example those with challenging behaviours, severe, profound, and/or multiple intellectual disability.
- m. *Financial concerns and low socio-economic position:* Families with intellectually disabled children are often unable to work full-time and high-income jobs to provide care. This situation lowers their socioeconomic position. Financial concerns about life override motivations for cancer prevention and participation in screenings in this group.

5.2 | Barriers and Facilitators Specific to Türkiye

- a. *Lack of data on housing and working conditions:* In Türkiye, workshop participants thought that there was insufficient knowledge of the housing and working conditions of people with intellectual disability. In some areas individuals with intellectual disability who stay at home for a long time may be at increased risk of passive exposure to cigarette smoke.
- b. *Low levels of health literacy and digital literacy in people with intellectual disability and their relatives:* In Türkiye, low levels of health literacy and digital literacy regarding access to healthcare services in people with intellectual disability and their relatives was problematic and should be targeted.
- c. *Families not accepting or hiding their child's diagnosis:* In Türkiye it is not uncommon for families to reject or hide that their child had an intellectual disability, providing a barrier to the provision of reasonable adjustments to healthcare, including cancer-related care. Acceptance and determination therapies should be provided to families of people with intellectual disability to help them accept the disability.
- d. *Limited activities of NGOs:* In Türkiye the activities of non-governmental organisations related to intellectual disability and cancer prevention and screening, are limited. Non-governmental organisations should organise activities related to cancer prevention and cancer screening for people with intellectual disability. Action plans should be established for increasing the participation of intellectual disabled individuals in cancer screening. NGOs could cooperate with health institutions, plan projects to prevent cancer in individuals with intellectual disability, and increase the awareness of people with intellectual disability and their families about cancer.

5.3 | Barriers and Facilitators Specific to Ireland

- a. *People with intellectual disability need to be active participants in decision making:* In the Irish workshop it was

reported that there is a need for people with intellectual disability to be active and included in all care decisions. They should be supported to self-advocate and use their citizenship rights to choose and access healthcare. In Ireland the named next of kin was sometimes identified as a problem, when they incorrectly believed they had the authority to endorse or refuse treatment. However, the enactment of the Assisted Decision Making (Capacity) Act 2015 in 2023, should help support people with intellectual disability make informed healthcare decisions, within a statutory framework which will provide protection to people who lack capacity to make informed decisions. This change may positively influence access to cancer service and relevant health outcomes. In Türkiye it was reported that families should be encouraged to participate in the activities of non-governmental organisations to help improve services available to this population.

- b. *The over-complexity in services and complicated systems:* In Ireland it was thought that people with intellectual disability were becoming isolated from services through dismantling larger residential services. For example, healthcare needs were once met in larger residential settings by a multidisciplinary team with medical input and now they must compete on a social capital level with the general population. This is a particular problem in community disability settings where there can be a lack of nursing and medical input meaning there health needs are not been met.
- c. *Limitations in primary care:* People with intellectual disability may require longer primary care consultations. However, in Ireland primary healthcare practices (e.g., GP practices) are often under severe pressure, with several competing issues to deal with. Therefore, this population is competing with other patients who also need to be seen by their GP or practice nurse. With an additional time and cost associated with providing longer consultations, this was identified as a problematic issue.

6 | Discussion

6.1 | Brief Summary of Findings

Workshop discussions were held with stakeholders in two European countries on cancer prevention and screening in people with intellectual disabilities, informed by the Social Determinants of Health Framework (Dahlgren and Whitehead 1991). Factors were identified on all three levels of the framework (personal characteristics and individual lifestyle factors; social and community networks and living and working conditions; and general, socioeconomic, cultural and environmental conditions) that raise considerable issues regarding cancer prevention and screening in people with intellectual disability. Overall, these barriers and facilitators broadly related to: limited epidemiological data on cancer and people with intellectual disability; complex health needs and diagnostic overshadowing; societal barriers and health literacy; the role of family and caregivers; professional relationships and training needs; inclusivity, assisted decision making and self-advocacy; reasonable adjustments with a focus on accessibility; research; person centered (health)care and policy initiatives.

In terms of the barriers to cancer prevention in people with intellectual disabilities identified in the workshops, these are somewhat consistent with what has been reported in the published literature. For example, the dearth of epidemiological data on cancer and people with intellectual disability has been alluded to elsewhere (Cuypers et al. 2020; Sullivan et al. 2004; Ward et al. 2024). The identification of cancer symptoms being overshadowed by the manifestation of intellectual disabilities traits is increasingly recognised as a challenge in the diagnosis and treatment of cancer in people with intellectual disability (Satgé et al. 2016; McMahon, McCallion, and McCarron 2023).

In addition, multiple publications refer to societal and intra-personal barriers. Geukes et al. (2018) highlighted that people with low levels of health literacy are more likely to fall ill, are more likely to use in-patient hospital settings, because of poor disease management or poor health maintenance skills, often leading to a reduced life expectancy. The findings from the workshops reported a lack of accessible and appropriate information for people with intellectual disability, which could mean they are not able to utilise the health information around healthy living, diet, exercise, and cancer prevention strategies such as screening. This may require the support of family and caregivers to share and help them understand health information (Geukes et al. 2018) and to physically support people to attend appointments such as screening (Chan et al. 2022).

It was documented across both workshops that cancer prevention and screening in people with intellectual disability may be influenced by the relationship with healthcare professionals (such as GPs) and a lack of training in these populations on the needs of people with intellectual disability. A 2017 survey of 272 GPs found that 64% had less than 1 days training on how to meet the needs of people with intellectual disability and autism, and 44% wanted additional training on cancer screening for people with intellectual disability (Dimensions UK 2018).

From a systems perspective, ensuring services employ reasonable adjustments with a focus on accessibility and ensure that (health)care is person centered is a recurring theme within intellectual disability literature. Person-centered care is a model where healthcare providers are encouraged to deliver personalised care that provides people with high-quality care they need and to improve the efficiency and effectiveness of health care systems (Santana et al. 2017). Person-centeredness can be achieved by employing reasonable adjustments within the cancer screening services but there is a need to explore why people do not access screening services (Sykes et al. 2022). Yet, 60% of people in a 2017 survey said their GP made reasonable adjustments for them (Dimensions UK 2018). Some examples of adjustments could be offering pre-appointment meetings to become familiar with environments (Tuffrey-Wijne et al. 2015), but this requires the person to be identified as having an intellectual disability, and the healthcare professionals knowing how to implement adjustments. This can be supported given the success of identifying people with intellectual disabilities and flagging them to a screening liaison nurse who employed by a healthcare provider, who can help support the person to complete screening, and offer reasonable adjustments as well as awareness raising to families and support staff (Marriott et al. 2015). Although some country-specific factors were

identified, many factors were common to Ireland and Türkiye. The workshop discussions identified a range of ways in which people with intellectual disability can be disadvantaged in relation to the prevention and identification of cancer, with an identified lack of generic and country-specific research evidence into the causes of problems and ways to ameliorate them. The findings from the workshops reinforce the health inequalities that people with intellectual disability experience more broadly (Chapman et al. 2024; McMahon and Hatton 2021) and in terms of cancer diagnosis (Mahar et al. 2024; Heslop et al. 2022) and cancer survival (Cuypers et al. 2020).

At this stage, the emerging evidence relating to cancer and intellectual disability is stark and there is an urgent need to develop effective strategies aimed at reducing this inequity (McMahon, McCallion, and McCarron 2023).

6.2 | Strengths and Weaknesses of the Work

The workshops included 44 stakeholders from a range of backgrounds, with detailed discussions at both sites being informed by the same framework. Discussions were held at length in small groups with ideas being developed and refined following feedback to whole groups on each site. Consolidation of the findings across the two jurisdictions, allowed an indication of the extent to which findings were generic or country-specific. Although there were significant numbers of participants, the discussion was limited to two European countries. The countries were chosen because of the substantial differences between them in terms of culture, economic activity, and healthcare funding and delivery. However, they were similar in their population-wide cancer screening programmes, although HPV vaccination is part of the free national school-based immunisation programme in Ireland and not in Türkiye. Participants self-selected and this may have introduced bias. Finally, people with intellectual disability did not participate in this workshop and therefore lived experiences are absent. Notwithstanding this, another CUPID Working Group is developing the 'Patient and Public Involvement' component of the ACTION and these perspectives will be integrated as the COST ACTION develops and these findings will be revisited, further refined and further validated as this work progresses.

6.3 | Contributions of the Work

There has been relatively little previously published work into cancer prevention in people with intellectual disability and so this research represents a meaningful addition. Several studies have previously been published into the participation of people with intellectual disability in various national cancer screening programmes, but these have tended to be somewhat placeless, often lacking an indication of the extent to which their findings apply to just one country or more widely (Kellen et al. 2020, Reidy, Denieffe, and Foran 2014). Another contribution of this work is that some of the findings are specifically related to individual countries, allowing an insight into similarities and differences. This is the first time that the much-cited causal framework, Social Determinants of Health, has been applied to

understanding the key issues around cancer prevention in among people with intellectual disability, and its use allowed insights to be made into causes and the potential for interventions, directed to a range of actors and settings.

7 | Implications

7.1 | Policy and Practice Implications

Article 25 of the UNCRPD needs to be realised for people with an intellectual disability to receive equitable access to health-care with a specific focus on cancer prevention programmes. Cancer and health promotive policy should incorporate the bespoke needs of this population regarding lifestyle factors and the high risk of certain cancers (e.g. gastrointestinal cancer). Additionally, Article 9 of the UNCRPD clearly enshrines accessibility and this needs to be incorporated across all health care facilities and adopted in screening, preventative and treatment mechanisms to ensure that people with intellectual disability are fully included. This relates not only to physical accessibility but also to reasonable adjustments to ensure that information is understandable by this population. Mandatory training programmes aimed at improving health professionals' understanding of intellectual disability in terms of communication, diagnostic overshadowing and reasonable adjustments should be the cornerstone of policy in this area. Inherent in all aspects of policy, should be that the person with an intellectual disability is recognised as an autonomous and independent decision maker in which their 'will and preference' is promoted and respected. Finally, policy should reflect the role of family and caregivers and ensure they are aware of the importance of cancer prevention and detection.

7.2 | Research Implications

The workshop discussions revealed a lack of research into several aspects of the findings. In some cases, the reported views of participants were underpinned by external empirical research and there were clear causal explanations for findings. However, in other areas research was lacking both for causal explanations and possible interventions, and which is clearly needed. There is a clear need to undertake epidemiological research focusing on prevalence, incidence, risk factors and outcomes of cancer. This research will help services plan and allocate resources appropriate to the degree of need. Exploring what health literacy and communication strategies work for this population is also critically important; however, there is a need to develop and evaluate interventions to determine their benefit. Essentially, there needs to be an evidence base underpinning any targeted interventions focusing on international translation. Moreover, research in training effectiveness and identifying the barriers and facilitators to access cancer prevention services is also required. Furthermore, surveillance, detection, screening and treatment approaches need to be considered along with the bespoke and varied needs of this population; again, there should be an evidence base underpinning such approaches. Finally, there needs to be an evaluation of the effectiveness of existing and future policies for this population. Such approaches will help improve

cancer prevention and detection in the intellectual disability population. Many of the research priorities identified from the workshops are echoed in a recently published editorial on improving cancer care for people with intellectual disabilities (Cuypers et al. 2024).

8 | Conclusions

The findings from these workshops provide important insights from two European countries into the challenges that people with an intellectual disability experience in terms of prevention, early diagnosis, and the management of cancer. The participants in both workshops engaged in a structured discussion around the Social Determinants of Health Framework and the findings highlight the urgent need for policy, practice, and research to be inclusive, accessible and evaluated while being aligned to the needs of this population. The CUPID COST ACTION will continue to address cancer prevention by developing a knowledge and research agenda to improve cancer in this population in the European Union and beyond.

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Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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Supporting Information

Additional supporting information can be found online in the Supporting Information section.