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Perceptions of National Cancer Prevention Policies in Europe: A Survey of Organisations Supporting People with Intellectual Disabilities

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Abstract

Background: People with intellectual disabilities, in comparison to the general population, face multiple health inequalities and poor health outcomes. Service organisations for people with intellectual disabilities are one of the key players in ensuring that people with intellectual disabilities have access to adequate healthcare. *Methods*: A cross-sectional web-based survey was implemented from 8 to 22 April 2025, focusing on organisations providing services to people with intellectual disabilities, with a peak response rate of 9%. The survey comprised 29 questions, split into three sections: general information, experience, and opinions on cancer prevention policy. *Results*: A total of 29 organisations from 14 upper-middle- and high-income European countries participated. Approximately 20% (n = 6) of organisations reported the existence of a cancer prevention policy in their country designed to address the needs of people with intellectual disabilities, with most considering them inadequate. Overall, 86.2% of organisations identified tailoring cancer prevention policy for people with intellectual disabilities to be of major importance. Respondents identified national government/ministries (n = 26, 90%), organisations for people with intellectual disabilities (n = 24, 82.8%), and research entities (n = 23, 79.3%) as the responsible stakeholders for implementing policy changes. *Conclusions*: Respondents expressed strong support for tailored policies, alongside support for a pan-European approach. From a policy perspective, findings support the critical need for policymakers to prioritise cancer prevention strategies, improve coordination, and ensure training and co-production with organisations supporting people with intellectual disabilities.

Keywords: cancer; intellectual disability; health policy; prevention; Europe

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1. Introduction

Cancer remains a major public health issue in Europe with around 2.6 million new cases and approximately 1.2 million cancer-related deaths registered every year [1–3]. It is the leading cause of death for people under 65 years old, and the second leading overall cause of death in the EU after cardiovascular diseases [4,5]. Cancer remains one of the major causes of premature death with a significant social and economic burden [1]. In 2023, the per capita health expenditure on cancer care in the EU amounted to €4169 [6], and people expect it to grow by 59% by 2050 [5].

National cancer prevention policies play an important role in reducing the overall burden of cancer by integrating evidence-based strategies such as screening programmes, public awareness campaigns, vaccination initiatives, and the promotion of healthy lifestyles. These policies aim to implement initiatives that can detect cancer at earlier, more treatable stages, reduce exposure to known risk factors, and ultimately decrease cancer morbidity and mortality. For example, regular screening programmes such as breast mammograms and colonoscopies have been shown to improve survival rates significantly by identifying cancers early [7]. Public awareness campaigns aim to educate communities about the signs and symptoms of cancer, encourage timely medical consultations, and foster healthier behaviours. Vaccination programmes, such as those targeting human papillomavirus, have proven effective in preventing infection-related cancers, particularly when administered early [8–10]. Additionally, lifestyle interventions that discourage tobacco use, unhealthy diets, and physical inactivity are essential in reducing the risk of many common cancers. Effective cancer prevention policies also recognise and address social determinants of health—such as socioeconomic status, healthcare access, and cultural factors—to ensure that prevention efforts are equitable and inclusive. According to the International Agency for Research on Cancer (IARC), implementing comprehensive national policies is a cost-effective strategy that can significantly reduce cancer-related deaths and improve population health outcomes [11].

Notwithstanding this, people with intellectual disabilities face multiple health inequalities and poor health outcomes [12,13]. Although life expectancy has improved, a significant difference remains in comparison to the general population. The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) is an international treaty adopted in 2006 that protects and promotes the human rights of people with disabilities worldwide. It establishes that people with disabilities have the same rights as people without disabilities. Two key articles address healthcare access: Article 25 (Healthcare) and Article 9 (Accessibility) require that people with disabilities have equal access to all services, including healthcare. Healthcare services must not be denied to people with disabilities or made inaccessible to them. These UNCRPD provisions establish the legal foundation for ensuring that cancer screening programmes are accessible to people with disabilities.

Cancer is now one of the leading causes of death in this population, but it does not receive the same level of recognition with regard to the known risks and differences across preventive, diagnostic, treatment, and survivorship domains [14–17]. For example, the available evidence points towards later-stage diagnosis, more restricted treatment options, and poorer overall outcomes when people with intellectual disabilities are diagnosed with cancer [18,19]. People with intellectual disabilities are known to have a 1.5 times higher cancer mortality risk than the general population [20]. They are also more likely to be diagnosed at younger ages, and their unique cancer profile highlights a different burden of disease in this population. Recent evidence also reports lower overall incidence rates for cancer more broadly, but higher rates for certain subtypes of cancer [21,22]. The evidence exists, but barriers continue to impede access, reverse early detection, and result in suboptimal care. These are avoidable contributors to increased morbidity and mortality. This constitutes a clear health inequity [23]. Internationally, from a policy perspective, it has been reported that cancer policies do not adequately account for this population [24]. According to ongoing research and European reviews, cancer policies often ignore people with intellectual disabilities [25]. This lack of inclusion, despite the poor outcomes in this population, signals that they are not being prioritised, and this is unjust. Additionally, initiatives appear to be local or parochial across European countries in trying to address the needs of people with cancer and intellectual disabilities.

The lack of standard policy inclusion, despite poorer outcomes, clearly signals the inequities that this population experiences in cancer care [17]. People with intellectual disabilities face multifaceted barriers to accessing preventive health services and cancer screening across European healthcare systems, creating substantial health inequities that manifest in dramatically reduced screening participation and poorer cancer outcomes. Communication barriers represent a fundamental obstacle, with healthcare providers consistently failing to communicate directly with patients, instead directing conversations to caregivers, while simultaneously providing information in formats that exceed health literacy levels and failing to implement accessible communication strategies required for informed consent [26,27]. Physical accessibility barriers persist despite legislative frameworks in many countries, encompassing inadequate facility design, inaccessible medical equipment, transportation challenges, and insufficient reasonable adjustments, with systematic reviews documenting widespread failures in providing accessible examination tables, appropriate signage, and adapted screening equipment [28,29]. Systemic barriers permeate healthcare organisations through fragmented care coordination, inadequate provider training—present in only 7.5% of European Union National Cancer Control Programmes—and procedural failures that exclude people with intellectual disabilities from standard care pathways [24,27,30]. Attitudinal barriers manifest through healthcare provider discrimination, with half of participants reporting unfair treatment, alongside pervasive assumptions about decision-making capacity that result in paternalistic approaches and proxy consent practices that violate supported decision-making principles [26,31].

These compound barriers culminate in devastating health consequences: population-based studies demonstrate substantially lower participation in cancer screening programmes, with people with intellectual disabilities showing 20–25 percentage point deficits across cervical, breast, and colorectal screening compared to the general population [29,32]. The resulting health disparities include 1.5 times higher cancer mortality rates, with cancers more frequently diagnosed at advanced stages and through emergency presentations rather than planned screening, contributing to the significant life expectancy gap observed in this population [20,33].

Policies provide a course of action to guide and influence decisions [34]; however, people need to easily implement and comply with policies to make them effective [34]. Yet, these may not regularly be observed for people with intellectual disabilities [35], with people with intellectual disabilities facing health inequalities and impediments to their ability to access healthcare [36]. There is a need for policy and practice statements to specifically mention people with intellectual disabilities, and describe the reasonable adjustments and accommodations to meet the needs of people with intellectual disabilities [37]. Additionally, policies can also contribute to barriers in accessing healthcare when there is limited awareness of, or inadequate enforcement of, existing laws and regulations intended to ensure equitable access to services [38]. Collectively, this underscores the need to ensure that health systems and policies are genuinely inclusive of people with intellectual disabilities [37]. Taken together, this aligns with the WHO (World Health Organization) Global Report on Health Equity for Persons with Disabilities, which emphasises that an inclusive and well-designed health policy is essential to reducing preventable inequities and improving access to preventive care. Therefore, there it is warranted to explore whether policies that relate to cancer screening and/or cancer prevention are inclusive, accessible, and implemented for people with intellectual disabilities.

Services organisations for people with intellectual disabilities are one of the key players in ensuring that people with intellectual disabilities have access to adequate healthcare. Through continuous contact with people with intellectual disabilities, they are best equipped in understanding the needs of people with intellectual disabilities, explaining the importance of healthcare prevention and availability of services, and ensuring that people with intellectual disabilities avail of these services. They also play a key role in explaining and familiarising people with intellectual disabilities with the hospital appointment process and the procedures. They provide a key link with healthcare professionals to ensure the specific needs of people with intellectual disabilities are understood and met, hence ensuring that people with intellectual disabilities can avail of those crucial prevention services. Due to this experience, they are best placed to advocate at national and European levels to ensure that the needs and challenges of people with intellectual disabilities are taken into consideration when policies, support information, and accessibility to services are being developed.

The aim of this study was to gather insights about the national cancer prevention policies from organisations providing services to people with intellectual disabilities across Europe, specifically about the extent to which national cancer prevention policies are adapted to the needs of people with intellectual disabilities, and to explore their opinions and experiences with these policies.

2. Materials and Methods

2.1. Study Design and Participants

A cross-sectional survey identified views on the national cancer prevention policies relevant to people with intellectual disabilities. This was a descriptive, exploratory study. To facilitate data collection, researchers developed a structured English survey to gather general information about the organisations, their experiences, and perspectives on national cancer prevention policies.

The survey tool was initially designed by two of the authors (V.V. and M.M.) with additional input and feedback from the remaining co-authors. The questions included in the tool were informed by a review of the relevant literature in health policy research and by the collective expertise within the COST (European Cooperation in Science and Technology) CA21123−Cancer-Understanding Prevention in Intellectual Disabilities (CUPID) Action. Although the survey was not co-designed, it was piloted prior to dissemination. The study did not seek to differentiate between organisational and professional perspectives, as it was intended as an exploratory effort to capture a broad range of existing views. Participants were asked to answer each question by selecting the option that best represented their organisation's official position or perspective. If the organisation did not have an official position on a particular question, participants were asked to provide their professional assessment as a representative with authority to respond on behalf of their organisation.

The survey comprised 29 questions that had either a binary, multiple choice, or open-ended response format (Supplementary Table S1). It started with the definition of "health policy" as the decisions, plans, and actions undertaken to achieve specified healthcare objectives within a society, as previously endorsed [39]. The survey questionnaire was split into three sections: (1) general information about the organisation; (2) experience with national cancer prevention policy; (3) opinions on cancer prevention policy. Participants were encouraged to use Google Translate to facilitate responses in their preferred or local language should they require assistance with translation. Participants were advised that the survey would take approximately 5 min to complete. However, participants could take longer to complete if they wanted to. Most took less than 10 min to complete. In order to avoid duplicate responses, a note was provided at the beginning of survey—"please fill in the questionnaire only once. If you already received it and completed it, there is no need to fill it again". European organisations advocating for and supporting this population were asked to have a representative complete this survey. Individuals in relevant organisational roles were emailed directly when contact details were known. For organisations without a known contact person, generic email addresses were used, allowing each organisation to designate an appropriate respondent.

Participants were invited to fill in the survey at any time during a two-week period, from 8 April until 22 April 2025. The survey was hosted on the Jisc Online Surveys platform. A total of 327 organisations were directly emailed in English using the author's institutional academic mail account and a gentle reminder was sent seven days later to all participants (a maximum reported response rate was 9%). Additionally, two international organisations, the European Association of Service Providers for Persons with Disabilities (EASPD), Brussels (Belgium), and the Inclusion Europe, Brussels (Belgium), advertised information about the survey on their social media and, in April, in an issue of their online newsletters. Therefore, the total number of organisations invited to take part cannot be precisely ascertained.

In order to enhance clarity, critical appraisal, and the interpretation of our findings, this cross-sectional survey study is reported according to the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guidelines for cross-sectional studies [40]. A completed STROBE checklist is provided as Supplementary Material (Supplementary Table S2).

2.2. Ethical Approval and Considerations

This survey received ethical approval from Faculty of Arts & Humanities Ethics Committee, South East Technological University, Ireland (27 March 2025). The confidentiality of all collected information was preserved and all individual responses were anonymous. Data were analysed in aggregate form to draw broader conclusions while safeguarding participants' identities. The findings derived from this analysis were used exclusively for academic research purposes, contributing to the advancement of knowledge in the relevant field. As it was anonymous, consent was deemed implicit upon participants' completion of the survey, indicating their agreement to partake in the study under these conditions.

2.3. Statistical Analyses

The data from Jisc were downloaded in an Excel CSV format for analysis. Descriptive statistics were used, and data were presented as frequencies and proportions. The Wilson Score method for calculating binomial proportion confidence interval with continuity correction was used. For the analyses, organisations were categorised into groups based on the year when they were established (<20, 20–40, >40 years ago), the number of staff currently working in organisation (<10, 10–100, >100 workers), and the approximate number of users with intellectual disability attending the organisation each month (<100, 100–1000, >1000 users). Organisations were grouped based on the World Bank's latest economic classification of the organisation's country [41] into the group of upper-middle-income countries (UMIC)—(Bosnia and Herzegovina, Serbia, Türkiye and Ukraine) and the group of high-income countries (HIC—Belgium, Bulgaria, Czech Republic, Ireland, Italy, Latvia, Lithuania, Portugal, Slovakia and Spain). Finally, based on the UN Geoscheme localisation of the organisation's country [42], we grouped them into Eastern (Bulgaria, Czech Republic, Slovakia and Ukraine), Northern (Ireland, Latvia and Lithuania), Southern (Bosnia and Herzegovina, Italy, Portugal, Serbia, Spain and Türkiye), and Western Europe (Belgium). Even though Türkiye, based on the UN Geoscheme localization, is classified as Western Asia, due to its cultural, historical, political and economic connections with Europe, we considered it as part of Southern Europe.

For comparing differences in the distribution of categorical variables, Chi-square or Fisher's exact test (where appropriate) was used. An exploratory univariate logistic regression analysis was used to examine potential predictors of the organisation's opinion that tailoring cancer prevention policy for people with intellectual disabilities was of major importance. Statistical significance was ascertained in the analyses when *p*-values were less than 0.05. Due to the sample size, all inferential analyses were considered exploratory and interpreted cautiously. The researchers performed all statistical analyses using the statistical software STATA v.17 (StataCorp LLC 2021, College Station, TX, USA).

3. Results

A total of 29 organisations from 14 European countries participated (Figure 1). Most organisations were from Serbia (n = 10, 34.5%), followed by those from Türkiye (n = 4, 13.8%) and Portugal (n = 3, 10.3%).

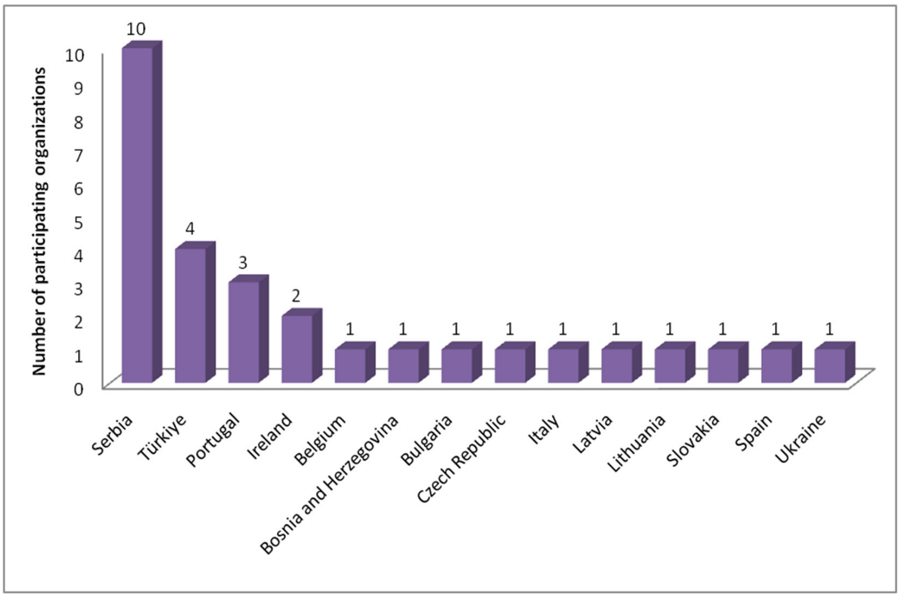

Figure 1. Number of Participating Organisations per Country.

General characteristics of the participating organisations are presented in Table 1. The majority of organisations were NGOs (n = 21, 72.4%) and with <100 users with intellectual disability attending organisation monthly (n = 16, 55.2%). Almost 90% (n = 26) were government-funded (fully/partially) and 62.1% (n = 18) interact with the national government representatives yearly, regarding any topic including health policy. There was no statistically significant difference in the general characteristics of the participating organisations based on economic classification of the organisation's country.

Table 1. General Characteristics of Participating Organisations Based on the Economic Classification of the Organisation's Country.

	Total, n (%; 95% LCI, UCI)	**UMIC, n (%; 95% LCI, UCI)**	**HIC, n (%; 95% LCI, UCI)**	***p*-Value ***
Type of organisation				
Governmental	8 (27.6; 13.5, 47.5)	4 (25.0; 8.3, 52.6)	4 (30.8; 10.36, 61.12)	0.730
Non-governmental (NGO)	21 (72.4; 52.5, 86.6)	12 (75.0; 47.4, 91.7)	9 (69.2; 38.9, 89.6)	

Table 1. *Cont.*

	Total, n (%; 95% LCI, UCI)	**UMIC, n (%; 95% LCI, UCI)**	**HIC, n (%; 95% LCI, UCI)**	***p*-Value ***
Organisation was established (years ago)				
<20	10 (34.5; 18.6, 54.3)	5 (31.3; 12.1, 58.5)	5 (38.4; 15.1, 67.7)	0.904
20–40	10 (34.5; 18.6, 54.3)	6 (37.5; 16.3, 64.1)	4 (30.8; 10.4, 61.1)	
>40	9 (31.0; 16.0, 51.0)	5 (31.3; 12.1, 58.5)	4 (30.8; 10.4, 61.1)	
Number of staff currently working in organisation				
<10	10 (34.5; 18.6, 54.3)	9 (56.3; 30.6, 79.2)	1 (7.7; 0.4, 37.9)	0.032
10–100	10 (34.5; 18.6, 54.3)	4 (25.0; 8.33, 52.6)	6 (46.2; 20.4, 73.9)	
>100	8 (27.6; 13.4, 47.5)	3 (18.7; 4.97, 46.3)	5 (38.4; 15.1, 67.7)	
Missing	1 (3.45; 0.18, 19.6)	0 (0; 0, 24.1)	1 (7.7; 0.4, 37.9)	
Approximate number of users with intellectual disability attending the organisation each month				
<100	16 (55.2; 36.0, 73.0)	10 (62.5; 35.87, 83.7)	6 (46.15; 20.4, 73.9)	0.124
100–1000	9 (31.0; 16.0, 51.0)	3 (18.75; 4.97, 46.3)	6 (46.15; 20.4, 73.9)	
>1000	3 (10.3; 2.71, 28.5)	3 (18.75; 4.97, 46.3)	0 (0; 0, 28.34)	
Missing	1 (3.5; 0.18,19.6)	0 (0; 0, 24.07)	1 (7.7; 0.4, 37.9)	
Main source of funding for the activities				
Fully government-funded	14 (48.3; 29.9, 67.1)	6 (37.5; 16.28, 64.13)	8 (61.5; 32.28, 84.87)	0.506
Partially government-funded	12 (41.4; 24.1, 60.9)	8 (50.0; 25.51, 74.49)	4 (30.8; 10.36, 61.12)	
Private funding	1 (3.5; 0.18, 19.63)	1 (6.3; 0.33, 32.29)	0 (0; 0, 28.34)	
Charitable funding	2 (6.9; 1.20, 24.21)	1 (6.3; 0.33, 32.29)	1 (7.7; 0.41, 37.91)	
Interaction of the organisation with national government representatives regarding any topic including health policy (per year)				
Never	7 (24.1; 11.02, 43.93)	6 (37.5; 16.28, 64.13)	1 (7.7; 0.40, 37.91)	0.116
A few times per year	18 (62.1; 42.36, 78.7)	9 (56.3; 30.55, 79.25)	9 (69.2; 38.88, 89.64)	
On a monthly basis	4 (13.8; 4.51, 32.57)	1 (6.3; 0.33, 32.29)	3 (23.1; 6.16, 54.02)	

n: number of respondents; *: Using Pearson's chi-squared test; where cell sizes were small, Fisher's exact chi-squared test was used. 95% LCI: lower confidence interval; 95% UCI: upper confidence interval; UMIC: upper-middle-income countries; HIC: high-income countries.

When analysts examined differences based on the approximate number of users with intellectual disabilities attending an organisation each month, they noticed that organisations with <100 users were younger (category < 20 years, 50%) with respect to those that serve ≥ 100 users (category > 40 years, 58.3%) (p = 0.031). Appropriately, those with smaller numbers of users (<100 users) had smaller numbers of staff compared to those with ≥100 users (p = 0.043) (Table 2).

Table 2. General Characteristics of the Participant Organisations Based on the Approximate Number of Users with Intellectual Disabilities Attending the Organisation Each Month.

	Approximate Number of Users with Intellectual Disabilities Attending Organisation Each Month		
	<100 Users, n (%; 95% LCI, UCI)	**≥100 Users, n (%; 95% LCI, UCI)**	***p*-Value ***
Type of organisation			
Governmental	4 (25.0; 8.3, 52.59)	4 (33.3; 11.27, 64.56)	0.629
Non-governmental (NGO)	12 (75.0; 47.4, 91.7)	8 (66.7; 35.44, 88.73)	

Table 2. *Cont.*

	Approximate Number of Users with Intellectual Disabilities Attending Organisation Each Month		
	<100 Users, n (%; 95% LCI, UCI)	**≥100 Users, n (%; 95% LCI, UCI)**	**p-Value ***
Organisation was established (years ago)			
<20	8 (50.0; 25.51, 74.49)	2 (16.7; 2.9, 49.1)	**0.031**
20–40	6 (37.5; 16.28, 64.13)	3 (25.0; 6.69, 57.16)	
>40	2 (12.5; 2.2, 39.59)	7 (58.3; 28.6, 83.5)	
Number of staff currently working in organisation			
<10	9 (56.3; 30.6, 79.3)	1 (8.3; 0.4, 40.3)	**0.043**
10–100	4 (25.0; 8.3, 52.59)	5 (41.7; 16.5, 71.4)	
>100	3 (18.7; 4.97, 46.31)	5 (41.7; 16.5, 71.4)	
Missing	0 (0; 0, 24.1)	1 (8.3; 0.4, 40.3)	
Primary source of funding for the activities			
Fully government-funded	6 (37.5; 16.28, 64.13)	7 (58.3; 28.6, 83.5])	0.132
Partially government-funded	9 (56.3; 30.55, 79.25)	3 (25.0; 6.7, 57.16)	
Private funding	1 (6.3; 0.33, 32.29)	0 (0; 0, 30.13)	
Charitable funding	0 (0; 0, 24.07)	2 (16.7; 2.9, 49.1)	
Interaction of the organisation with national government representatives regarding any topic including health policy (per year)			
Never	6 (37.5; 16.28, 64.13)	1 (8.3; 0.44, 40.25)	0.210
A few times per year	8 (50.0; 25.5, 74.5)	9 (75.0; 42.84, 93.31)	
Every month	2 (12.5; 2.2, 39.6)	2 (16.7; 2.94, 49.12)	

n: number of respondents; *: Using Pearson's chi-squared test; where cell sizes were small, Fisher's exact chi-squared test was used. Presented p-value < 0.05 is in bold. 95% LCI: lower confidence interval; 95% UCI: upper confidence interval.

Table 3 provides a comprehensive analysis of organisations' experiences with national cancer prevention policies organised by the economic classification of their respective countries. The data shows that 20.7% (n = 6) of organisations confirmed the existence of a cancer prevention policy specifically designed to address the needs of people with intellectual disabilities within their country. This includes three organisations from upper-middle-income countries (UMICs), representing 18.8% (n = 3) of that category, and three from high-income countries (HICs), accounting for 23.1% (n = 3).

Table 3. Organisations' Experience with National Cancer Prevention Policy Based on the Economic Classification of the Organisation's Country.

	Total, n (%; 95% LCI, UCI)	**UMIC, n (%; 95% LCI, UCI)**	**HIC, n (%; 95% LCI, UCI)**	**p-Value ***
Is there any cancer prevention policy specifically tailored to the needs of people with intellectual disabilities in your country?				
Yes	6 (20.7; 8.71, 40.26)	3 (18.8; 4.97, 46.31)	3 (23.1; 6.16, 54.02)	**0.047**
No	17 (58.6; 39.13, 75.9)	7 (43.8; 20.75, 69.45)	10 (76.9; 45.98, 93.84)	
I am not aware	6 (20.7; 8.71, 40.3)	6 (37.5; 16.28, 64.13)	0 (0; 0, 28.34)	
If yes, please list the types of national cancer prevention policies that exist for people with intellectual disabilities. (Select all that apply.) (n = 6)				
Screening (breast, cervical, colorectal, etc.)	6 (100; 51.68, 100)	3 (100; 31.0, 100)	3 (100; 31.0, 100)	N/A

Table 3. *Cont.*

	Total, n (%; 95% LCI, UCI)	UMIC, n (%; 95% LCI, UCI)	HIC, n (%; 95% LCI, UCI)	p-Value *
Lifestyle modifications (diet, physical activity, tobacco and alcohol cessation, sun protection, HPV (human papillomavirus) and Hepatitis B vaccination, etc.)	3 (50.0; 13.95, 86.05)	2 (66.7; 12.53, 98.23)	1 (33.3; 1.77, 87.47)	0.990
Health education	1 (16.7; 0.88, 63.5)	1 (33.3; 1.765, 87.47)	0 (0; 0, 69.0)	0.990
Genetic predisposition testing	2 (33.3; 5.99, 75.89)	2 (66.7; 12.53, 98.23)	0 (0; 0, 69.0)	0.400
If yes, do you think it currently meets the needs of people with intellectual disabilities? n = 6				
Yes	1 (16.7; 0.88, 63.52)	1 (33.3; 1.77, 87.47)	0 (0; 0, 69.0)	0.368
No	4 (66.7; 24.1, 94.0)	2 (66.7; 12.53, 98.23)	2 (66.7; 12.5, 98.2)	
I do not know	1 (16.7; 0.88, 63.52)	0 (0; 0, 69.0)	1 (33.3; 1.8, 87.5)	
If no, are you aware of any national initiative to tailor policies for people with intellectual disabilities? n = 17				
Yes	5 (29.4; 11.4, 55.9)	2 (28.6; 5.1, 69.7)	3 (30.0; 8.1, 64.6)	0.942
No	9 (52.9; 28.53, 76.14)	4 (57.1; 20.24, 88.19)	5 (50.0; 20.1, 79.9)	
I do not know	3 (17.7; 4.67, 44.2)	1 (14.3; 0.75, 57.99)	2 (20.0; 3.5, 55.8)	
What are the main barriers to implementing effective cancer prevention policies for people with intellectual disabilities? (Select all that apply.)				
Lack of awareness among policymakers	16 (55.2; 35.98, 73.05)	9 (56.3; 30.55, 79.25)	7 (53.9; 26.1, 79.6)	0.897
Insufficient funding	13 (44.8; 26.95, 64.02)	8 (50.0; 25.51, 74.49)	5 (38.5; 15.13, 67.72)	0.534
Limited expertise	14 (48.3; 29.89, 67.1)	7 (43.8; 20.75, 69.45)	7 (53.9; 26.12, 79.6)	0.588
Communication challenges	14 (48.3; 29.89, 67.1)	9 (56.3; 30.55, 79.25)	5 (38.5; 15.13, 67.7)	0.340
Inadequate healthcare training	16 (55.2; 35.98, 73.05)	7 (43.8; 20.75, 69.45)	9 (69.2; 38.88, 89.64)	0.264
Competing healthcare priorities	8 (27.6; 13.45, 47.49)	4 (25.0; 8.3, 52.6)	4 (30.8; 10.36, 61.12)	0.990
Lack of coordination between disability and healthcare services	27 (93.1; 75.79, 98.8)	16 (100; 75.9, 100)	11 (84.6; 53.66, 97.29)	0.192
Has your organisation been involved in policy-making regarding cancer prevention for people with intellectual disabilities?				
No	21 (72.4; 52.51, 86.55)	12 (75.0; 47.41, 91.67)	9 (69.2; 38.88, 89.64)	0.906
Yes, by reviewing draft documents	2 (6.9; 1.2, 24.2)	1 (6.3; 0.33, 32.3)	1 (7.7; 0.4, 37.9)	
Yes, by participating in surveys	3 (10.3; 2.71, 28.5)	2 (12.5; 2.2, 39.6)	1 (7.7; 0.4, 37.9)	
Yes, by working in policy groups	3 (10.3; 2.71, 28.5)	1 (6.3; 0.33, 32.3)	2 (15.4; 2.7, 46.3)	
Would your organisation be willing to become (more) involved in national policy development?				
Yes	21 (72.4; 52.5, 86.6)	11 (68.8; 41.5, 87.8)	10 (76.9; 45.98, 93.84)	0.515
No	1 (3.5; 0.18, 19.6)	0 (0; 0, 24.1)	1 (7.7; 0.4, 37.9)	
I do not know	7 (24.1; 11.02, 43.93)	5 (31.2; 12.1, 58.5)	2 (15.4; 2.7, 46.3)	

n: number of respondents; *: where cell sizes were small, Fisher's exact chi-squared test was used; 95% LCI: lower confidence interval; 95% UCI: upper confidence interval; N/A: not applicable.

All participating organisations indicated that these policies incorporate cancer screening measures (100%, n = 6). Furthermore, half of the organisations mentioned that policies addressed lifestyle modifications (50%, n = 3), while some mentioned genetic predisposition testing (33.3%, n = 2). Participants (93.1%, n = 27) identified the principal barrier to the effective implementation of cancer prevention policies for people with intellectual disabilities as the lack of coordination between disability services and healthcare systems. This was followed by lacked awareness among policymakers (55.2%, n = 16) and insufficient healthcare training (55.2%, n = 16), which also presented significant challenges. Approximately 27% (n = 8) of the surveyed organisations reported involvement in the policy-making process concerning cancer prevention for people with intellectual disabilities. Nevertheless, a substantial 72.4% (n = 21) expressed a desire to become more engaged in the development of national policies.

Findings were consistent when experience was analysed according to the UN Geoscheme classification of the organisation's country, revealing no statistically significant differences in experience across four European regions (refer to Supplementary Table S3). The identification of primary barriers to the implementation of effective cancer prevention policies for people with intellectual disabilities revealed notable distinctions. Specifically, significant differences were found in the areas of limited expertise (p = 0.031), competing healthcare priorities (p = 0.049), and the lack of coordination between disability services and healthcare systems (p = 0.049).

Organisations' experience with national cancer prevention policy based on the approximate number of users with intellectual disabilities attending the organisation each month is presented in Table 4. When asked about the main barriers to implementing effective cancer prevention policies for people with intellectual disabilities, all organisations with ≥100 users identified the lack of coordination between disability and healthcare services as the main barrier in respect to 87.5% (n = 14) of those with <100 users. Also, 31.3% (n = 5) of organisations with <100 users have been involved in policy-making regarding cancer prevention for people with intellectual disabilities, with 25% (n = 3) of those with ≥100 users involved in policy-making. Nevertheless, 83.3% (n = 10) and 62.5% (n = 10) of organisations with ≥100 users and <100 users, respectively, are willing to become (more) involved in the policy development.

Table 4. Organisations' Experience with National Cancer Prevention Policy Based on the Approximate Number of Users with Intellectual Disabilities Attending the Organisation Each Month.

	Approximate Number of Users with Intellectual Disabilities Attending Organisation Each Month		
	<100 Users, n (%; 95% LCI, UCI)	**≥100 Users, n (%; 95% LCI, UCI)**	***p*-Value ***
Is there any cancer prevention policy specifically tailored to the needs of people with intellectual disabilities in your country?			
Yes	5 (31.3; 12.13, 58.52)	1 (8.3; 0.44, 40.25)	0.268
No	9 (56.3; 30.55, 79.25)	7 (58.3; 28.6, 83.5)	
I am not aware	2 (12.5; 2.2, 39.6)	4 (33.3; 11.3, 64.6)	
If yes, please list the types of national cancer prevention policies that exist for people with intellectual disabilities. (Select all that apply.) (n = 6)			
Screening (breast, cervical, colorectal, etc.)	5 (100; 46.3, 100)	1 (100; 5.46, 100)	N/A
Lifestyle modifications (diet, physical activity, tobacco and alcohol cessation, sun protection, HPV and Hepatitis B vaccination, etc.)	3 (60.0; 17.04, 92.74)	0 (0; 0, 94.54)	0.999
Health education	1 (20.0; 1.05, 70.12)	0 (0; 0, 94.54)	0.999
Genetic predisposition testing	2 (40.0; 7.26, 82.96)	0 (0; 0, 94.54)	0.999

Table 4. *Cont.*

	Approximate Number of Users with Intellectual Disabilities Attending Organisation Each Month		
	<100 Users, n (%; 95% LCI, UCI)	**≥100 Users, n (%; 95% LCI, UCI)**	***p*-Value ***
If yes, do you think it currently meets the needs of people with intellectual disabilities?			
Yes	1 (20; 1.05, 70.12)	0 (0; 0, 94.54)	0.999
No	3 (60; 17.04, 92.74)	1 (100; 5.5, 100)	
I do not know	1 (20; 1.05, 70.1)	0 (0; 0, 94.54)	
If no, are you aware of any national initiative to tailor policies for people with intellectual disabilities?			
Yes	4 (44.4; 15.34, 77.35)	1 (14.3; 0.75, 57.99)	0.523
No	4 (44.4; 15.34, 77.35)	4 (57.1; 20.24, 88.19)	
I do not know	1 (11.1; 0.58, 49.33)	2 (28.6; 5.1, 69.7)	
What are the main barriers to implementing effective cancer prevention policies for people with intellectual disabilities? (Select all that apply.)			
Lack of awareness among policymakers	10 (62.5; 35.87, 83.72)	6 (50.0; 22.29, 77.71)	0.561
Insufficient funding	6 (37.50; 16.28, 64.13)	6 (50.0; 22.29, 77.71)	0.561
Limited expertise	9 (56.25; 30.55, 79.25)	5 (41.67; 16.5, 71.4)	0.579
Communication challenges	9 (56.25; 30.55, 79.25)	5 (41.67; 16.5, 71.4)	0.579
Inadequate healthcare training	7 (43.75; 20.75, 69.45)	8 (66.67; 35.44, 88.73)	0.264
Competing healthcare priorities	3 (18.75; 4.97, 46.31)	4 (33.3; 11.27, 64.56)	0.179
Lack of coordination between disability and healthcare services	14 (87.5; 60.4, 97.8)	12 (100; 69.87, 100)	0.527
Has your organisation been involved in policy-making regarding cancer prevention for people with intellectual disabilities?			
No	11 (68.75; 41.48, 87.87)	9 (75.0; 42.84, 93.31)	0.697
Yes, by reviewing draft documents	2 (12.5; 2.2, 39.6)	0 (0; 0, 30.13)	
Yes, by participating in surveys	2 (12.5; 2.2, 39.6)	1 (8.3; 0.44, 40.25)	
Yes, by working in policy groups	1 (6.25; 0.33, 32.3)	2 (16.7; 2.9, 49.1)	
Would your organisation be willing to become (more) involved in national policy development?			
Yes	10 (62.50; 35.87, 83.72)	10 (83.33; 50.9, 97.06)	0.517
No	1 (6.25; 0.33, 32.3)	0 (0; 0, 30.13)	
I do not know	5 (31.25; 12.13, 58.52)	2 (16.67; 2.94, 49.12)	

n: number of respondents; * where cell sizes were small, Fisher's exact chi-squared test was used. 95% LCI: lower confidence interval; 95% UCI: upper confidence interval; N/A: not applicable.

Organisations' opinions on cancer prevention policy were analysed (Table 5). A total of 86.2% of participating organisations identified tailoring cancer prevention policy for people with intellectual disabilities to be of major importance, with 81.3% (n = 13) from UMIC and 92.3% (n = 12) from HIC. Almost 70% believed that (n = 20) cancer prevention policy for people with intellectual disabilities should be part of a general policy, and 93.1% (n = 27) responded that a pan-European policy for cancer prevention for people with intellectual disabilities would be a helpful approach. When asked to identify who should be responsible for initiating policy changes at the national level, almost 90% (n = 26) responded national government (ministries), followed by organisations for people with intellectual disabilities (n = 24, 82.8%) and research entities—universities, research centres (n = 23, 79.3%). All organisations agreed that more training is needed to implement cancer prevention policies for people with intellectual disabilities (n = 29, 100%). According to 51.7% (n = 15) of organisations, national governments (ministries) should be primarily responsible for ensuring implementation of cancer prevention policy for people with intellectual disabilities. Also, 48.3% (n = 14) responded that future cancer prevention policies should focus on specific training programmes for healthcare providers.

Table 5. Organisations' Opinions on Cancer Prevention Policy Based on the Economic Classification of the Organisation's Country.

	Total, n (%; 95% LCI, UCI)	**UMIC, n (%; 95% LCI, UCI)**	**HIC, n (%; 95% LCI, UCI)**	***p*-Value ***
How important is it to tailor cancer prevention policy for people with intellectual disabilities?				
Not important	0 (0; 0, 14.6)	0 (0; 0, 14.56)	0 (0; 0, 28.34)	0.606
Minor importance	0 (0; 0, 14.6)	0 (0; 0, 14.56)	0 (0; 0, 28.34)	
Medium importance	4 (13.8; 4.5, 32.6)	3 (18.7; 4.97, 46.31)	1 (7.7; 0.40, 37.91)	
Major importance	25 (86.2; 67.4, 95.5)	13 (81.3; 53.69, 95.03)	12 (92.3; 62.09, 99.6)	
Should cancer prevention policy for people with intellectual disabilities be a separate document or incorporated into general policy?				
A separate document	9 (31.0; 15.98, 50.95)	6 (37.5; 16.28, 64.13)	3 (23.1; 6.16, 54.02)	0.454
Part of a general policy	20 (69.0; 49.05, 84.02)	10 (62.5; 35.87, 83.72)	10 (76.9; 45.98, 93.8)	
No adjustments needed	0 (0; 0, 14.56)	0 (0; 0, 24.07)	0 (0; 0, 28.34)	
Would a pan-European policy for cancer prevention for people with intellectual disabilities be useful?				
Yes	27 (93.1; 75.79, 98.8)	14 (87.5; 60.41, 97.8)	13 (100; 71.66, 100)	0.990
No	1 (3.5; 0.18, 19.63)	1 (6.3; 0.33, 32.29)	0 (0; 0, 28.34)	
I do not know	1 (3.5; 0.18, 19.63)	1 (6.3; 0.33, 32.29)	0 (0; 0, 28.34)	
Is more research needed in this field?				
Yes	27 (93.1; 75.79, 98.8)	15 (93.8; 67.71, 99.67)	12 (92.3; 62.1, 99.6)	0.99
No	0 (0; 0, 14.56)	0 (0; 0, 24.1)	0 (0; 0, 28.34)	
I do not know	2 (6.9; 1.2, 24.2)	1 (6.2; 0.33, 32.3)	1 (7.7; 0.40, 37.91)	
Should more funding be allocated for research on cancer prevention policies for people with intellectual disabilities?				
Yes	26 (89.7; 71.5, 97.29)	14 (87.5; 60.41, 97.8)	12 (92.3; 62.1, 99.6)	0.990
No	0 (0; 0, 14.56)	0 (0; 0, 24.07)	0 (0; 0, 28.34)	
I do not know	3 (10.3; 2.71, 28.5)	2 (12.5; 2.19, 39.59)	1 (7.7; 0.40, 37.91)	
Who should be responsible for initiating policy changes at the national level? (Select all that apply.)				
Healthcare personnel	22 (75.9; 56.07, 88.98)	13 (81.3; 53.69, 95.03)	9 (69.2; 38.88, 89.64)	0.667
Organisations for people with intellectual disabilities	24 (82.8; 63.51, 93.47)	14 (87.5; 60.41, 97.8)	10 (76.9, 45.98, 93.8)	0.632
Local government	17 (58.6; 39.13, 75.91)	8 (50.0; 25.51, 74.49)	9 (69.2; 38.88, 89.64)	0.451
National government/ministries	26 (89.7; 71.5, 97.29)	15 (93.8; 67.71, 99.67)	11 (84.6; 53.66, 97.3)	0.573
EU government	17 (58.6; 39.13, 75.91)	8 (50.0; 25.51, 74.49)	9 (69.2; 38.88, 89.64)	0.451
Research entities (universities, research centres)	23 (79.3; 59.7, 91.3)	13 (81.3; 53.69, 95.03)	10 (76.9; 45.98, 93.8)	0.990

Table 5. *Cont.*

	Total, n (%; 95% LCI, UCI)	**UMIC, n (%; 95% LCI, UCI)**	**HIC, n (%; 95% LCI, UCI)**	***p*-Value ***
Should organisations for people with intellectual disabilities be more involved in policy-making?				
Yes	28 (96.6; 80.4, 99.8)	16 (100; 75.9, 100)	12 (92.3; 62.1, 99.6)	0.448
No	0 (0; 0, 14.6)	0 (0; 0, 24.07)	0 (0; 0, 28.34)	
I do not know	1 (3.4; 0.18, 19.6)	0 (0; 0, 24.07)	1 (7.7; 0.40, 37.91)	
Is more training needed to implement cancer prevention policies for people with intellectual disabilities?				
Yes	29 (100; 85.4, 100)	16 (100; 75.9, 100)	13 (100; 71.66, 100)	N/A
No	0 (0; 0, 14.6)	0 (0; 0, 24.07)	0 (0; 0, 28.34)	
I do not know	0 (0; 0, 14.6)	0 (0; 0, 24.07)	0 (0; 0, 28.34)	
Who should be primarily responsible for ensuring implementation of cancer prevention policy for people with intellectual disabilities?				
Healthcare personnel	7 (24.1; 11.0, 43.9)	4 (25.0; 8.3, 52.6)	3 (23.1; 6.16, 54.02)	0.960
Organisations for people with intellectual disabilities	4 (13.8; 4.5, 32.6)	2 (12.5; 2.2, 39.6)	2 (15.4; 2.71, 46.34)	
Local government	2 (6.9; 1.2, 24.2)	1 (6.3; 0.33, 32.29)	1 (7.7; 0.40, 37.91)	
National government/ministries	15 (51.7; 32.9, 70.11)	9 (56.3; 30.55, 79.25)	6 (46.2; 20.4, 73.88)	
Other (please specify)	1 (3.45; 0.18, 19.63)	0 (0; 0, 24.07)	1 (7.7; 0.40, 37.91)	
Who should be primarily responsible for ensuring implementation of cancer prevention policy for people with intellectual disabilities? —Other (specify)	-	-	EU government	N/A
Future cancer prevention policies should focus on:				
Additional adaptation of screening programmes	6 (20.7; 8.7, 40.26)	3 (18.8; 4.97, 46.31)	3 (23.1; 6.16, 54.02)	0.990
Creating specialised communication materials for people with intellectual disabilities	4 (13.8; 4.5, 32.6)	2 (12.5; 2.2, 39.6)	2 (15.4; 2.71, 46.34)	
Integration of caregivers into cancer prevention	5 (17.2; 6.5, 36.5)	3 (18.8; 4.97, 46.31)	2 (15.4; 2.71, 46.34)	
Specific training programmes for healthcare providers	14 (48.3; 29.9, 67.1)	8 (50.0; 25.5, 74.5)	6 (46.1; 20.4, 73.88)	

n: number of respondents; UMIC: upper-middle-income countries, HIC: high-income countries; * where cell sizes were small, Fisher's exact chi-squared test was used. 95% LCI: lower confidence interval; 95% UCI: upper confidence interval; N/A: not applicable.

Results remained the same after stratifying answers based on the UN Geoscheme localisation of the organisation's country (Supplementary Table S4). Interestingly, 90% (n = 18) of organisations from Southern Europe found a pan-European policy for cancer prevention for people with intellectual disabilities to be useful, with 100% agreement from all other regions. For Eastern European organisations, national government (n = 29, 100%) and organisations for people with ID (n = 29, 100%) were seen as equally responsible for initiating policy changes at the national level. In contrast, Western European organisations identified healthcare personnel, organisations for people with intellectual disabilities, and local government as being primary initiators of this activity.

When analysing organisations' opinions on cancer prevention policy based on the approximate number of users with intellectual disabilities (Table 6), a statistically significant difference exists in answers about the role of the EU government for initiating policy changes at the national level, where 83.3% (n = 10) of organisations with ≥100 users identified it as responsible for this initiative regarding 43.8% (n = 7) of those with <100 users ($p = 0.036$). Around 88% of participants from organisations with fewer than 100 users and 83% of those from organisations serving 100 or more users indicated that tailoring cancer prevention policies for people with intellectual disabilities is of major importance. Similarly, 87.5% of organisations with fewer than 100 users and all organisations with 100 or more users considered a pan-European cancer prevention policy for people with intellectual disabilities to be a useful strategy.

Table 6. Organisations' Opinions on Cancer Prevention Policy Based on the Approximate Number of Users with Intellectual Disabilities Attending the Organisation Each Month.

	Approximate Number of Users with Intellectual Disabilities Attending Organisation Each Month		
	<100 Users, n (%; 95% LCI, UCI)	**≥100 Users, n (%; 95% LCI, UCI)**	***p*-Value ***
How important is it to tailor cancer prevention policy for people with intellectual disabilities?			
Not important	0 (0; 0, 24.07)	0 (0; 0, 30.13)	0.999
Minor importance	0 (0; 0, 24.07)	0 (0; 0, 30.13)	
Medium importance	2 (12.50; 2.2, 39.6)	2 (16.67; 2.94, 49.12)	
Major importance	14 (87.50; 60.41, 97.8)	10 (83.33; 50.88, 97.06)	
Should cancer prevention policy for people with intellectual disabilities be a separate document or incorporated into general policy?			
A separate document	5 (31.25; 12.13, 58.52)	4 (33.33; 11.27, 64.56)	0.999
Part of a general policy	11 (68.75; 41.48, 87.87)	8 (66.67; 35.44, 88.73)	
No adjustments needed	0 (0; 0, 24.07)	0 (0; 0, 30.13)	
Would a pan-European policy for cancer prevention for people with intellectual disabilities be useful?			
Yes	14 (87.50; 60.41, 97.8)	12 (100; 69.87, 100)	0.999
No	1 (6.25; 0.33, 32.29)	0 (0; 0, 30.13)	
I do not know	1 (6.25; 0.33, 32.29)	0 (0; 0, 30.13)	
Is more research needed in this field?			
Yes	15 (93.75; 67.71, 99.67)	11 (91.67; 59.75, 99.56)	0.999
No	0 (0; 0, 24.07)	0 (0; 0, 30.13)	
I do not know	1 (6.25; 0.33, 32.29)	1 (8.33; 0.44, 40.25)	
Should more funding be allocated for research on cancer prevention policies for people with intellectual disabilities?			
Yes	14 (87.50; 60.41, 97.8)	11 (91.67; 59.75, 99.56)	0.999
No	0 (0; 0, 24.07)	0 (0; 0, 30.13)	
I do not know	2 (12.50; 2.2, 39.6)	1 (8.33; 0.44, 40.25)	

Table 6. *Cont.*

	Approximate Number of Users with Intellectual Disabilities Attending Organisation Each Month		
	<100 Users, n (%; 95% LCI, UCI)	**≥100 Users, n (%; 95% LCI, UCI)**	**p-Value ***
Who should be responsible for initiating policy changes at the national level? (Select all that apply.)			
Healthcare personnel	13 (81.25; 53.69, 95.03)	8 (66.67; 35.44, 88.73)	0.559
Organisations for people with intellectual disabilities	14 (87.50; 60.41, 97.8)	9 (75.00; 42.84, 93.31)	0.689
Local government	9 (56.25; 30.55, 79.25)	7 (58.33; 28.6, 83.5)	0.999
National government/ministries	15 (93.75; 67.71, 99.67)	11 (91.67; 59.75, 99.56)	0.103
EU government	7 (43.75; 20.75, 69.45)	10 (83.33; 50.88, 97.06)	**0.036**
Research entities (universities, research centres)	14 (87.50; 60.41, 97.8)	9 (75.00; 42.84, 93.31)	0.175
Should organisations for people with intellectual disabilities be more involved in policy-making?			
Yes	15 (93.75; 67.7, 99.7)	12 (100; 69.87, 100)	0.999
No	0 (0; 0, 24.07)	0 (0; 0, 30.13)	
I do not know	1 (6.25; 0.33, 32.3)	0 (0; 0, 30.13)	
Is more training needed to implement cancer prevention policies for people with intellectual disabilities?			
Yes	16 (100; 75.93, 100)	12 (100; 69.87, 100)	N/A
No	0 (0; 0, 24.07)	0 (0; 0, 30.13)	
I do not know	0 (0; 0, 24.07)	0 (0; 0, 30.13)	
Who should be primarily responsible for ensuring implementation of cancer prevention policy for people with intellectual disabilities?			
Healthcare personnel	3 (18.75; 4.97, 46.31)	3 (25.00; 6.69, 57.16)	0.733
Organisations for people with intellectual disabilities	2 (12.50; 2.2, 39.6)	2 (16.67; 2.94, 49.12)	
Local government	2 (12.50; 2.2, 39.6)	0 (0; 0, 30.13)	
National government/ministries	9 (56.25; 30.55, 79.25)	6 (50.00; 22.29, 77.71)	
Other (please specify)	0 (0; 0, 24.07)	1 (8.33; 0.44, 40.25)	
Who should be primarily responsible for ensuring implementation of cancer prevention policy for people with intellectual disabilities?— Other (specify)	-	EU government	N/A
Future cancer prevention policies should focus on:			
Additional adaptation of screening programmes	2 (12.50; 2.2, 39.59)	4 (33.33; 11.27, 64.56)	0.375
Specific training programmes for healthcare providers	9 (56.25; 30.55, 79.25)	5 (41.67; 16.5, 71.4)	
Integration of caregivers into cancer prevention	4 (25.00; 8.33, 52.59)	1 (8.33; 0.44, 40.25)	
Creating specialised communication materials for people with intellectual disabilities	1 (6.25; 0.33, 32.29)	2 (16.67; 2.94, 49.12)	

n: number of respondents; * where cell sizes were small, Fisher's exact chi-squared test was used. Presented p-value < 0.05 is in bold. 95% LCI: lower confidence interval; 95% UCI: upper confidence interval; N/A: not applicable.

In the investigation of potential predictors regarding organisations' perceptions of the necessity of tailoring cancer prevention policies for people with intellectual disabilities, none exerted a significant influence (refer to Table 7).

Table 7. Predictors of the Opinion that Tailoring Cancer Prevention Policy for People with Intellectual Disabilities Is of Significant Importance.

	OR	**95% CI**	***p*-Value**
Type of organisation			
Governmental		ref.	
Non-governmental (NGO)	0.86	0.08–9.69	0.901
Economic classification of the organisation's country			
UMIC	0.36	0.03–3.96	0.405
HIC		ref.	
UN Geoscheme localisation of the organisation's country			
Eastern Europe, n (%)		ref.	
Northern Europe, n (%)		N/A	
Southern Europe, n (%)	1.89	0.14–24.79	0.628
Western Europe, n (%)		N/A	
Organisation was established (years ago)			
<20		N/A	
20–40	0.29	0.02–3.48	0.33
>40		ref.	
Number of staff currently working in organisation			
<10		ref.	
10–100	1.00	0.11–8.95	0.999
>100		N/A	
Approximate number of users with intellectual disability attending the organisation each month			
<100		ref.	
100–1000	1.14	0.09–14.68	0.918
>1000	0.29	0.02–4.80	0.384
Main source of funding for the activities			
Fully/Partially government-funded	7.67	0.37–157.36	0.186
Private funding		N/A	
Charitable funding		ref.	
Interaction of the organisation with national government representatives regarding any topic, including health policy (per year)			
Never		ref.	
A few times per year	0.83	0.07–9.69	0.884
On a monthly basis		N/A	

OR = odds ratio; 95% CI = Confidence interval; N/A: not applicable.

4. Discussion

This survey collected information from 29 European organisations that provide services to people with intellectual disabilities from 14 upper-middle- and high-income countries. The majority of participating organisations were NGOs, with <100 monthly users who were people with intellectual disabilities, and government-funded (fully/partially). Most of them interact with organisations and national government representatives on an annual basis regarding various topics, including health policy. Only 20% of surveyed organisations were aware of any national cancer prevention policy specifically tailored to the needs of people with intellectual disabilities in their country, with most of these focused on screening and lifestyle modifications. However, the majority of respondents thought that the policies did not properly meet the needs of people with intellectual disabilities. Lack of coordination between disability and healthcare services, inadequate healthcare training, and lack of awareness among policymakers were marked as the top three main barriers to implementing effective cancer prevention policies for people with intellectual disabilities. The findings were consistent, revealing no statistically significant differences in experience across the four European regions of the surveyed organisations. Opinions on cancer prevention policies of organisations from UMIC and HIC showed no statistical difference, with around 86% of all participating organisations defining tailored cancer prevention policy for people with intellectual disabilities as of major importance, and the rest as of medium importance. A substantial proportion of the surveyed organisations indicated that they perceive a pan-European policy for cancer prevention targeting people with intellectual disabilities as a beneficial approach. The majority of respondents asserted that such a policy should be incorporated into a comprehensive health strategy. The organisations participating in the survey identified three primary entities responsible for initiating policy changes at the national level: national governments or ministries, organisations advocating for individuals with intellectual disabilities, and research institutions, including universities and research centres.

The rationale for this study stems from the limited existing research on the practical perceptions of national cancer prevention policies [17,43]. This research gap is particularly evident in the views of organisations that advocate for or support people with intellectual disabilities. Persons with disabilities face significant health inequalities, including elevated rates of late-stage cancer diagnoses, diagnostic overshadowing, and increased mortality related to cancer. Inadequate access to or poorly organised cancer prevention and screening services often cause these challenges. Although there is an increasing commitment to health equity across Europe, national cancer prevention policies frequently lack specific accommodations for people with intellectual disabilities. Key frameworks at the European level, such as the European Beating Cancer Plan [44], the UN Convention on the Rights of Persons with Disabilities [45], and the EU Disability Strategy 2021–2030 [46], emphasise the right to equitable access to healthcare and preventive services for people with intellectual disabilities. However, translating these principles into actionable cancer policies remains inconsistent and insufficiently documented across member states. There is a critical deficit of systematic data concerning the extent to which national cancer prevention policies address the needs of people with intellectual disabilities throughout Europe [17]. This information gap impedes efforts to assess current practices, advocate for necessary policy reforms, and promote inclusive cancer prevention initiatives for people with intellectual disabilities [43]. Therefore, collecting insights directly from organisations engaged with people with intellectual disabilities can help to identify disparities in national policy coverage and implementation, identify essential reasonable accommodations that may be absent, and propose policy reforms consonant with the principles of equity, participation, and inclusion.

Our findings align with the recent literature highlighting the persistent underrepresentation and lack of consideration of people with intellectual disabilities in national cancer prevention policies. This aligns with a previous paper by Kowalczyk et al. and Vukovic et al. [17,24], which found that national cancer control programmes also overlooked the needs of people with intellectual disabilities. Similarly, EU CanScreen's Task 6.5 (2025) calls for targeted adjustments, such as accessible communication and disability-specific screening protocols, within national frameworks and policies [47]. Lack of coordination between disability and health services (93%), limited policymaker awareness (55%), and inadequate healthcare training (55%) mirror gaps previously identified by Vukovic et al. [17]. Notably, organisations with 100 or more users cited coordination gaps as a key barrier.

The research results highlight a strong agreement across organisations on the need to tailor cancer prevention policies for individuals with intellectual disabilities. A considerable proportion of respondents supported the establishment of a pan-European policy framework. Furthermore, the majority of participants indicated that national governments should lead policy reforms, with disability organisations and research institutions identified as key stakeholders who would closely follow this initiative. All organisations that took part agreed that more training is needed, particularly for healthcare providers, to implement inclusive cancer prevention strategies. Despite limited prior engagement in policy-making, most organisations expressed willingness to become more involved. This reflects a clear opportunity for co-production of future policies, which is an approach championed by both the COST Action CUPID (CA21123) and EU CanScreen to ensure stakeholder-driven, inclusive design. At the European level, the European Cancer Organisation (ECO) plays a key advocacy role through initiatives like the European Cancer Pulse and its Inequalities Network, facilitating evidence-informed policy engagement. To realise the ambitions of the EU's Beating Cancer Plan and ECO's rights-based framework, people with intellectual disabilities must be actively considered in prevention policy at both national and European levels. The results from the questionnaire reveal that service organisations supporting people with intellectual disabilities are willing to participate in policy design, implementation, and monitoring processes across Europe.

4.1. Organisational Consensus and Regional Variations

The survey results highlight a robust consensus among organisations regarding the critical importance of tailoring cancer prevention policies for people with intellectual disabilities. A significant proportion of respondents rated these policies as essential, with no organisation classifying them as unimportant. This unanimous perspective was consistent across various economic classifications, as a substantial number of organisations from both upper-middle-income countries (UMICs) and high-income countries (HICs) recognised the critical importance of customised policies.

Despite this shared recognition, regional and organisational differences emerged in preferences for policy structure and implementation responsibility. A majority (69%) favoured integrating intellectual disability considerations into general cancer prevention policies rather than creating separate documents. This preference appeared somewhat stronger among organisations from high-income countries compared to those from upper-middle-income contexts. Support for a pan-European policy framework was nearly unanimous, with particularly high endorsement among high-income countries and somewhat lower, though still substantial, agreement among upper-middle-income ones. Notably, organisations from Southern Europe expressed slightly less support compared to full endorsement from other regions. These findings suggest a strong appetite for harmonised European-level coordination, while also highlighting minor regional nuances.

4.2. Policy Responsibility and Stakeholder Engagement

When asked about responsibility for initiating national-level policy changes, a substantial proportion of organisations identified national governments as the primary actors. Following this, organisations focused on people with intellectual disabilities and research entities were noted, albeit to a somewhat lesser degree. However, stratified analysis revealed that organisations in Eastern Europe perceived national governments and disability organisations as equally accountable. In contrast, organisations in Western Europe highlighted a more expansive distribution of responsibility, incorporating healthcare personnel and local governments.

A statistically significant difference emerged when analysing responses by organisation size. Among those serving 100 or more individuals with intellectual disabilities, a higher percentage recognised the European Union (EU) government as responsible for instigating policy changes than those serving fewer than 100 individuals. This observation suggests that larger organisations may perceive a greater need for supranational policy leadership, potentially because of their broader operational scope and greater exposure to systemic barriers [48].

4.3. Training and Implementation Priorities

Unanimous agreement on the need for additional training to implement cancer prevention policies further reinforces the urgency of workforce development. This consensus was consistent across all economic and regional classifications. Moreover, nearly half of the organisations prioritised specific training programmes for healthcare providers as the foremost priority for future policy development, while a smaller proportion emphasised the need for to adapt screening programmes and integrate caregivers into the process.

These findings are consistent with systematic reviews highlighting persistent gaps in healthcare provider training related to intellectual disability care [49]. Specifically, residential care staff tend to have less knowledge about cancer risk factors and symptoms, which can be attributed to their lack of specialised cancer prevention training [50]. This means there may be missed opportunities for early cancer prevention [30]. European studies have shown that median instruction time on intellectual disability in health sciences curricula remains limited—often under three hours per unit—despite longstanding calls for reform [30]. The prioritisation of provider training is further supported by intervention studies demonstrating that even brief educational programmes can significantly improve provider knowledge, attitudes, and confidence [50]. However, such programmes are rarely institutionalised due to resource constraints and competing priorities.

4.4. Policy–Practice Gap and Strategic Implications

The gap between organisational recognition of policy importance (86.2%) and actual implementation remains stark. For instance, only 7.5% of health professionals across 27 EU National Cancer Control Programmes reported receiving specialised training in cancer prevention for people with intellectual disabilities [24]. This 12-fold discrepancy underscores a critical policy–practice disconnect that demands urgent attention. Moreover, evidence from population-based studies reveals that people with intellectual disabilities are significantly less likely to receive cancer screening recommendations [51,52], often due to provider knowledge gaps and negative interactions [28,29]. These disparities validate organisational calls for more inclusive and better-resourced cancer prevention strategies [53]. The strong support for pan-European coordination (93.1%) suggests that models such as the European Reference Networks—currently used for rare diseases—could be adapted to support cancer prevention for people with intellectual disabilities [7]. Additionally, the preference for policy integration (69%) indicates that disability considerations should be mainstreamed within existing National Cancer Control Programmes rather than developed as standalone initiatives.

Overall, the findings from this survey provide evidence that cancer prevention policies for people with intellectual disabilities are typically absent across organisations surveyed. Given the poor cancer outcomes experienced by this population [18,19], it is essential that people with intellectual disabilities are prioritised and included in cancer prevention policies. There is an onus on organisations to embed reasonable adjustments and adaptations within mainstream cancer prevention policies so that the needs of people are visible and accommodated. This aligns with the obligations under the UNCRPD [45] in terms of Article 25 (Healthcare) and Article 9 (Accessibility).

From an equity perspective, policies that exclude or fail to meet the needs of specific populations are discriminatory. This area requires further exploration particularly in terms of how policies can be made more to understand better and improve equity across cancer preventive programmes. In terms of implications for policy and practice, all respondents agreed that there is a need to develop training programmes that address the specific needs of people with intellectual disabilities regarding cancer prevention and care. Overall, training and education are frequently cited as a barrier towards healthcare inclusion [54] with the World Health Organisation identifying structural factors, social determinants, and health systems as barriers to access and inclusion [55]. It is from this perspective that policies and approaches must be critically evaluated and, where appropriate, re-designed to ensure they meet the needs of this population. The growing recognition of the unique risks faced by this population provides a clear avenue for addressing workforce competence and capability. Organisations and policies will play an important role in helping to bridge this gap, and their clear omission of people with an intellectual disability in cancer prevention policies signals an area where this must be addressed as a matter of urgency. In addition, Europe's Beating Cancer Plan, which has inclusion and equity at its core, provides the framework to support this cause.

4.5. Study Limitations

Several limitations should be considered. First, the survey used was developed specifically for this study without prior formal psychometric validation, limiting our confidence in the reliability and validity of the measured constructs. Second, while the survey had a relatively small number of participating organisations and a low response rate which affected generalisability, considerable efforts were made to ensure inclusivity and representation from a wide array of pan-European countries. The low response rate may have introduced wider bias insofar as organisations with greater interest may have responded, potentially influencing responses across multiple items, including the perceived importance of tailoring cancer prevention policies.

Additionally, to demonstrate statistical transparency and prevent overinterpretation of our findings, we used the Wilson Score method for calculating confidence intervals for a binomial proportion. Also, this low response rate may have biased findings toward organisations with established policies. Even though we were unable to make robust cross-country comparisons with the current sample, the survey serves as a pioneering initiative at the pan-European level, gathering insights from 12 countries classified as high-income (HIC) and upper-middle-income countries (UMIC), and representing all four regions of Europe. It serves as an exploration of the situation rather than providing definitive conclusions, given sample size limitations. Given the sample size of 29 organisations across 14 European countries, all statistical analyses, including the univariate regression models, were exploratory in nature. These analyses were conducted to identify potential associations and generate hypotheses for future research rather than to test pre-specified hypotheses. Results should therefore be interpreted cautiously and regarded as preliminary findings, requiring confirmation in larger studies. Third, the questions within the survey were provided exclusively in English, which may have limited comprehension for some respondents due to a possible language barrier. However, to mitigate this, participants were encouraged to use Google Translate as an aid for understanding the questions. Linked to comprehension, participants may have been unsure about what cancer prevention meant and, as such, may not have known (as reflected in the 'I do not know' responses) about cancer prevention policies. This may have affected the comprehensiveness of our findings and suggests potential issues with policy awareness or communication. Fourth, a follow-up email in Serbian was sent to organisations in Serbia, which, although uniform in purpose, could have introduced a selection bias and contributed to the higher representation of Serbian organisations in the survey results and the uneven distribution across European regions, limiting the representativeness of our findings. Fifth, it is also possible that some individuals may have refrained from participating due to concerns regarding unsolicited communications. However, the survey was conducted through an academic account and hosted on a reputable academic online platform, reinforcing its credibility. Moving forward, addressing these limitations will enhance the survey's inclusivity and overall effectiveness in future iterations.

5. Conclusions

This study gathered responses from 29 organisations across 14 European countries, revealing significant gaps in cancer prevention for persons with intellectual disabilities. While the majority of respondents represented NGOs, only a small percentage demonstrated awareness of pertinent national policies, and most deemed these policies inadequate. The identified barriers included insufficient coordination between health and disability services, limited training opportunities for providers, and a lack of awareness among policymakers. Despite their limited current involvement in the policy-making process, organisations expressed a strong willingness to participate actively. A broad consensus emerged regarding the necessity for tailored policies, alongside robust support for a pan-European approach. Most respondents advocated for the integration of specific measures for people with intellectual disabilities into general guidelines and emphasised the need for enhanced research and funding initiatives. All respondents concurred on the essential nature of training, with nearly half endorsing the establishment of dedicated programmes for healthcare providers. These findings challenge the urgent need for inclusive and well-coordinated cancer prevention strategies throughout Europe.

Supplementary Materials: The following supporting information can be downloaded at https://www.mdpi.com/article/10.3390/disabilities5040114/s1; Supplementary Table S1: Blank copy of the survey exported from Jisc; Supplementary Table S2: STROBE Statement—Checklist of items that should be included in reports of cross-sectional studies; Supplementary Table S3: Organisations' experience with national cancer prevention policy based on the UN Geoscheme localisation of the organisation's country; Supplementary Table S4: Organisations' opinions on cancer prevention policy based on the UN Geoscheme localisation of the organisation's country.

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Informed Consent Statement: As participation was anonymous and online, consent was deemed implicit upon participants' completion of the survey, indicating their agreement to partake in the study under these conditions.

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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Disability Language/Terminology Positionality Statement: Person-first language is used throughout this article. As the study did not include people with intellectual disability, we were not able to check their language preferences. Consequently, we adopted person-first language as it is the more commonly used terminology.

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