CUPID

Cancer – Understanding Prevention in Intellectual Disability

FINAL CONFERENCE

Cancer – Understanding Prevention in Intellectual Disability: Partnering to Support Co-produced Change

CONFERENCE PROCEEDINGS

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EUROPEAN COOPERATION IN SCIENCE & TECHNOLOGY

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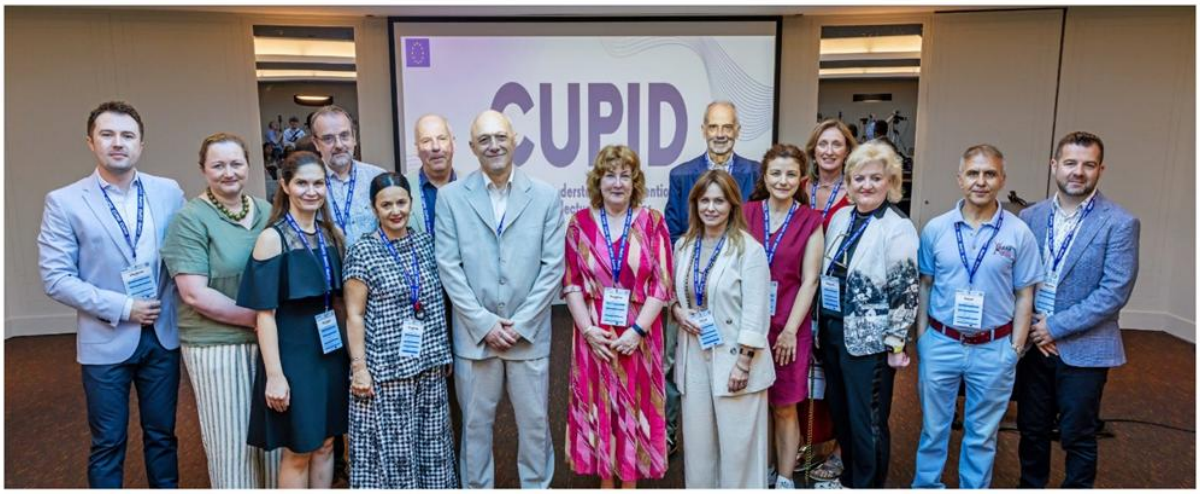
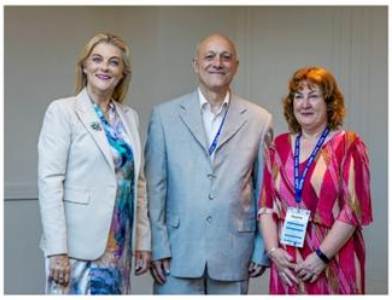

CUPID



Foreword

It is our great pleasure to present the Proceedings of the Final Conference, Cancer – Understanding Prevention in Intellectual Disability: Partnering to Support Co-Produced Change, held in Brussels, Belgium, on 23–24 June 2026. These proceedings represent the culmination of four years of collaborative work undertaken within COST Action CA21123 – CUPID (Cancer – Understanding Prevention in Intellectual Disability), bringing together researchers, clinicians, healthcare professionals, educators, policymakers, advocacy organisations, and experts by experience from across Europe and beyond.

People with intellectual disabilities continue to experience significant health inequalities, including reduced participation in cancer prevention Programmes, delayed diagnosis, limited access to screening, barriers to communication, and poorer health outcomes. Despite growing recognition of these disparities, substantial challenges remain in translating scientific knowledge into equitable healthcare policies and clinical practice. Addressing these challenges requires multidisciplinary collaboration, international partnerships, and meaningful engagement with people with intellectual disabilities, their families, carers, and the organisations that represent them.

The CUPID COST Action was established to respond to these needs by creating a European interdisciplinary network dedicated to improving cancer prevention, early detection, health promotion, education, and policy for people with intellectual disabilities. Throughout the Action, participants from numerous countries worked collaboratively across multiple Working Groups to generate new knowledge, develop practical recommendations, strengthen research capacity, promote stakeholder engagement, and facilitate the exchange of expertise across disciplines and sectors. Central to the philosophy of CUPID has been the principle of co-production, recognising that sustainable improvements in healthcare can only be achieved when people with intellectual disabilities and their supporters actively participate in the design, implementation, and evaluation of research, education, and policy initiatives.

The Final Conference provided an opportunity not only to present the scientific achievements of the Action but also to reflect on the progress made, identify remaining challenges, and establish priorities for future collaboration. The Programme brought together internationally recognised experts who presented the latest evidence on cancer prevention, screening, health literacy, communication, healthcare accessibility, inclusive research methodologies, public health, rehabilitation, and policy development. Equally important were the contributions of self-advocates, family members, clinicians, and practitioners whose experiences reinforced the importance of person-centred and inclusive approaches to healthcare.

The papers included in this volume reflect the diversity and richness of the conference Programme. They encompass original research, systematic and narrative reviews, implementation studies, educational initiatives, policy perspectives, and examples of good practice from different healthcare systems. Collectively, these contributions illustrate both the scientific advances achieved during the COST Action and the continuing need for interdisciplinary research and international cooperation to reduce health inequalities experienced by people with intellectual disabilities.

As editors, we hope that these proceedings will serve as a valuable resource for researchers, healthcare professionals, educators, students, policymakers, and advocacy organisations working to improve cancer prevention and healthcare for people with intellectual disabilities. Beyond documenting the outcomes of the Final Conference, this volume aims to stimulate further research,

inspire innovative collaborations, support evidence-informed policy development, and encourage the implementation of inclusive healthcare practices across Europe and internationally.

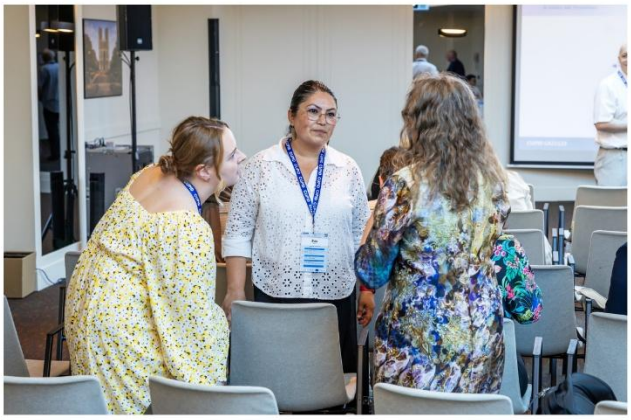
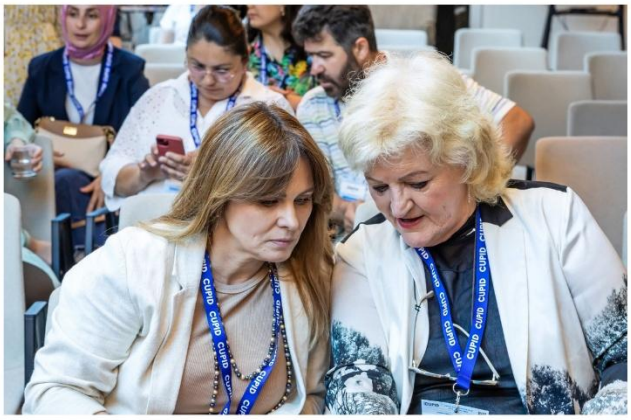
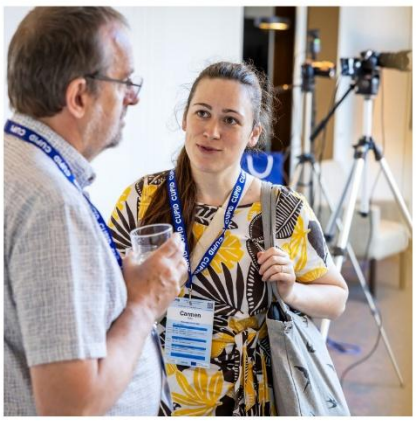
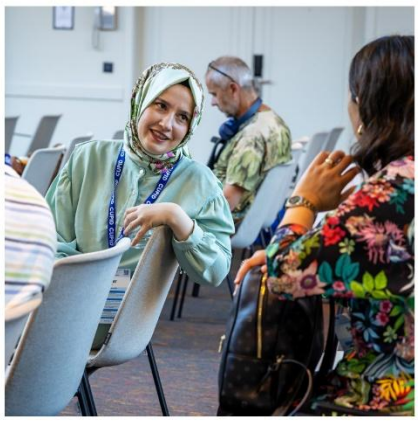
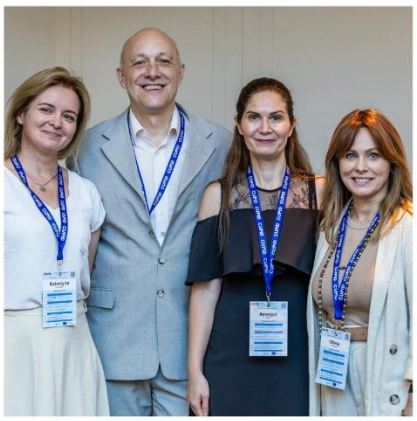
The completion of the CUPID COST Action marks not the end of a collaboration but the beginning of new opportunities for research, knowledge exchange, and societal impact. The partnerships established through this network provide a strong foundation for future initiatives that will continue to advance equitable healthcare and improve the quality of life for people with intellectual disabilities.

We extend our sincere appreciation to all authors, reviewers, conference participants, members of the Scientific and Organising Committees, the COST Association, and everyone whose dedication and expertise contributed to the success of both the conference and these proceedings. Their collective efforts demonstrate the value of international cooperation in addressing complex public health challenges and reaffirm our shared commitment to ensuring that no one is left behind in cancer prevention and healthcare.

We trust that the knowledge presented in these proceedings will contribute to advancing research, informing clinical practice, influencing policy, and strengthening collaboration in the years to come.

Editors

Dr. Suzanne Denieffe **Prof. Dr. Vladimir Trajkovski**

Acknowledgements

The Editors would like to express their sincere gratitude to everyone whose dedication, expertise, and collaboration contributed to the successful organisation of the Final Conference, *Cancer – Understanding Prevention in Intellectual Disability: Partnering to Support Co-Produced Change*, held in Brussels, Belgium, on 23–24 June 2026, and to the preparation of these conference proceedings.

First and foremost, we gratefully acknowledge the invaluable support of the COST Association and the COST Office for funding and facilitating COST Action CA21123 – CUPID (Cancer – Understanding Prevention in Intellectual Disability). Their commitment to fostering international scientific collaboration has made this multidisciplinary initiative possible and has significantly advanced research, education, and policy development in the field of cancer prevention and health equity for people with intellectual disabilities.

We extend our deepest appreciation to the members of the CUPID Core Group, Management Committee, and all Working Groups for their leadership, commitment, and collaborative spirit throughout the duration of the Action. Their scientific vision and sustained efforts have been instrumental in achieving the objectives of the project.

Our sincere thanks are also due to the Organising Committee, whose careful planning, professionalism, and tireless work ensured the smooth execution of the conference. We are equally grateful to the Scientific Committee for maintaining the high academic standards of the conference through the rigorous evaluation of submitted abstracts and their valuable guidance in developing the scientific Programme.

We warmly thank all keynote speakers, invited experts, session chairs, oral presenters, poster presenters, and workshop facilitators for sharing their knowledge, experience, and innovative research. Their outstanding contributions enriched the scientific Programme and promoted meaningful interdisciplinary dialogue and international collaboration.

We also wish to acknowledge all conference participants, including researchers, clinicians, educators, policymakers, self-advocates, family members, students, and representatives of stakeholder organisations. Their active engagement, insightful discussions, and commitment to co-production exemplify the collaborative principles upon which the CUPID Action has been built.
Special appreciation is extended to all authors who contributed their work to these proceedings. Their research and scholarly contributions represent an important legacy of the CUPID Action and provide valuable evidence to support future research, clinical practice, education, and policy aimed at improving cancer prevention and healthcare for people with intellectual disabilities.

Finally, we express our heartfelt thanks to everyone whose efforts—both visible and behind the scenes—made this conference and these proceedings possible. We hope that the knowledge shared through this volume will continue to inspire collaboration, stimulate new research, and contribute to reducing health inequalities experienced by people with intellectual disabilities across Europe and beyond.

Editors
Suzanne Denieffe Vladimir Trajkovski

Conference Outline

The Final CUPID Conference, entitled Cancer – Understanding Prevention in Intellectual Disability: Partnering to Support Co-produced Change, focused on addressing inequalities in cancer prevention, screening, and early detection for people with intellectual disabilities. The conference provided an international platform for sharing research findings, evidence-based practices, innovative approaches, accessible resources, and lived experiences that sought to improve equitable access to cancer information, preventive services, screening Programmes, and healthcare support.

Particular emphasis was placed on co-production and the meaningful involvement of people with intellectual disabilities in research, education, service development, and policy. Conference presentations addressed key themes including accessible health communication, inclusive cancer screening, healthcare professional education, reasonable adjustments within services, self-advocacy, family and caregiver experiences, cancer prevention policies, and strategies for translating research findings into sustainable practice.

The conference brought together researchers, healthcare professionals, educators, people with intellectual disabilities and other experts by lived experience, families, advocacy and support organisations, policymakers, and wider stakeholders from across Europe and beyond. It provided an opportunity to present the principal outcomes of the CUPID Action, share good practices, strengthen interdisciplinary and international collaboration, and discuss future research, practice, education, and policy priorities.

The main aim of COST Action CA21123, Cancer – Understanding Prevention in Intellectual Disability (CUPID), was to reduce inequalities in cancer prevention and early detection experienced by people with intellectual disabilities. Through collaboration across four interconnected Working Groups, the Action supported research, scientific exchanges, training activities, conferences, publications, and the development of accessible resources. Co-production remained a central principle of the Action, ensuring that people with intellectual disabilities contributed actively to the development of its research priorities, activities, and outputs.

As the CUPID Action concluded, the Final Conference celebrated the achievements of the network and considered how its knowledge, partnerships, resources, and advocacy work could continue to influence cancer prevention research, healthcare practice, professional education, and policy. The conference ultimately supported the development of more accessible, inclusive, and equitable cancer prevention and care systems in which people with intellectual disabilities were not left behind.

Tuesday 23 June 2026

08h30–09h30 | Registration

09h30–11h00 Session 1	**Prof. Dr Vladimir Trajkovski**

09h30–09h35 | Opening Address – Cynthia Ní Mhurchú

09h35–10h25 | Keynote Speakers – Dr Suzanne Denieffe; Dr Katarzyna Świeczkowska

10h25–10h45 | Questions and Answers

Refreshment Break

11h15–13h15 Session 2	**Dr Sinead Foran & Mr Florian Scheibein**

11h15–11h45 | Working Group 1 Presentation

11h45–12h15 | Working Group 2 Presentation

12h15–13h15 | Taster Sessions from the CUPID Training Schools

14h15–16h20 Session 3	**Dr Soner Dogan & Dr Dragana Milutinović**

14h15–15h15 | Five-minute Presentations

15h30–16h00 | Working Group 3 Presentation

16h00–16h20 | Working Group 4 Presentation

16h20 | Closing Remarks

Wednesday 24 June 2026

08h30–09h30 | Registration

09h30–11h00 Session 1	**Dr Bilge Güvenç Tuna & Dr Marteen Cuypers**

09h30–10h00 | Keynote Address – Sarah Collen

10h00–10h30 | Lived Experience Presentations

10h30–11h00 | Keynote Speaker – Dr Fabrizio Fea

11h30–13h10 Session 2	**Dr Martin McMahon & Dr Oliwia Kowalczyk**

11h30–12h05 | Testimonials from CUPID members

12h05–13h10 | Ten-minute Presentations

14h15–16h05 Session 3	**Moderator: Dr Suzanne Denieffe**

14h15–15h45 | Panel Discussion

15h45–15h55 | Evaluation

16h05 | Closing Remarks

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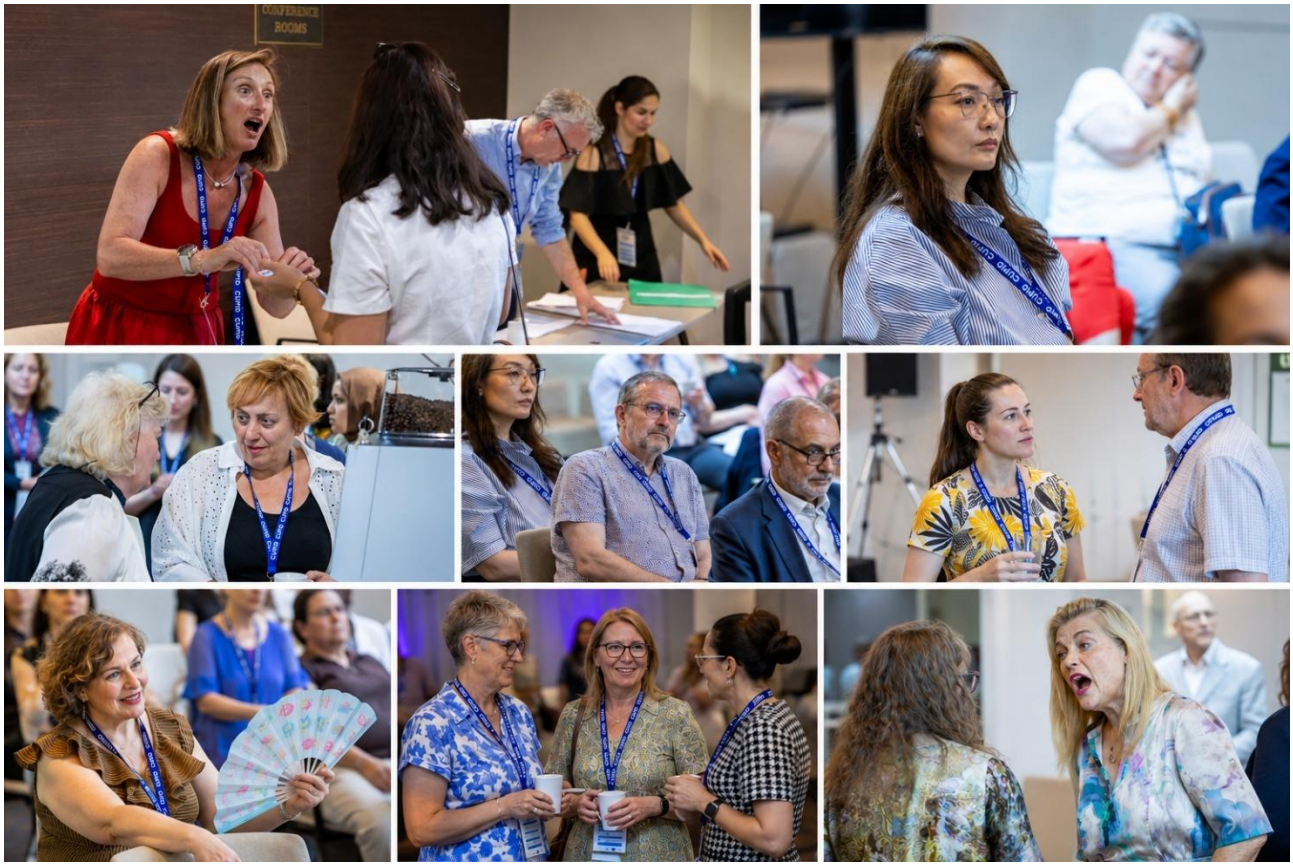
CONFERENCE
ROOMS

Keynote Speakers

Dr. Suzanne Denieffe - From Vision to Legacy: The Journey of COST Action CUPID

South East Technological University, Ireland

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Summary

COST Action CUPID (Cancer Understanding Prevention in Intellectual Disability; CA21123) was established to address persistent inequalities in cancer prevention and early detection experienced by people with intellectual disabilities across Europe. Despite considerable advances in cancer prevention, screening and treatment, evidence has consistently demonstrated that people with intellectual disabilities experience lower participation in cancer screening Programmes, later diagnosis, poorer access to accessible health information and less equitable healthcare throughout the cancer pathway. CUPID was developed in response to these disparities, bringing together an interdisciplinary network of researchers, healthcare professionals, educators, policymakers, self-advocates and family members to promote collaboration, knowledge exchange and co-production in addressing these inequalities.

The origins of the Action lay in doctoral research exploring cancer prevention among people with intellectual disabilities. This work demonstrated that barriers to participation were rarely related to individual willingness but were instead embedded within healthcare systems. Inaccessible information, inconsistent implementation of reasonable adjustments, communication barriers and fragmented healthcare pathways contributed to unequal access to cancer prevention and early detection services. These findings highlighted the need for coordinated international research and collaboration, providing the foundation for the establishment of COST Action CUPID in 2022.

Over its four-year duration, CUPID developed into a vibrant European network, growing from fewer than 50 members in its first year to more than 300 participants representing a wide range of professional disciplines and stakeholder groups. The Action successfully fostered collaboration between researchers, clinicians, educators, students, policymakers, advocacy organisations and experts by experience. This multidisciplinary approach facilitated the sharing of expertise, strengthened international partnerships and promoted innovation in research, education and practice.

The Action delivered an extensive programme of collaborative activities designed to build capacity and advance knowledge in the field. Four thematic Working Groups coordinated research and knowledge exchange across key areas of cancer prevention and care. Training Schools and Short-Term Scientific Missions supported researcher development, particularly for early career researchers, while webinars, workshops and conference presentations facilitated dissemination and networking. Collaborative publications, accessible educational resources and international partnerships further strengthened the evidence base and enhanced awareness of cancer inequalities experienced by people with intellectual disabilities.

A defining characteristic of CUPID was its commitment to co-production. People with intellectual disabilities were actively involved throughout the Action as equal partners in research, education and dissemination activities. Their lived experience informed the identification of research priorities, the development of accessible resources and the interpretation of findings. This collaborative approach ensured that outputs remained relevant, meaningful and accessible while reinforcing the principle that research should be undertaken with, rather than for, people with intellectual disabilities. The

Action demonstrated that genuine co-production not only promotes inclusion but also strengthens the quality, relevance and impact of research.

The work undertaken through CUPID reinforced existing evidence regarding inequalities across the cancer pathway. Lower participation in breast, cervical and colorectal cancer screening Programmes, delayed diagnosis, diagnostic overshadowing and inequitable access to treatment and follow-up care remained significant challenges across many healthcare systems. These findings emphasised that the disparities experienced by people with intellectual disabilities reflect systemic barriers rather than individual factors and therefore require coordinated, system-wide responses involving healthcare providers, educators, researchers and policymakers.

Beyond its scientific outputs, CUPID established a sustainable European community of practice committed to advancing equitable cancer prevention and care. The network fostered enduring collaborations, supported the development of new researchers and strengthened partnerships between academic institutions, healthcare organisations and advocacy groups. It also contributed to increasing recognition of the importance of including people with intellectual disabilities within cancer policy, research and service development, helping to shift the discourse from exclusion towards equity and inclusion.

The Action was also shaped by the leadership and contributions of individuals whose commitment significantly influenced its development. Professor, who led the original COST Action application, provided the vision for establishing an international collaborative network dedicated to addressing cancer inequalities. His emphasis on interdisciplinary collaboration, innovation and person-centred research continued to influence the Action following his death in 2026. Equally important were the contributions of experts by experience, including Eleanor Kelly, whose advocacy ensured that lived experience remained central to the work and reinforced the value of meaningful participation in research and healthcare improvement.

Although COST Action CUPID formally concludes in October 2026, its legacy will extend well beyond its funded duration. The Action established sustainable international partnerships, strengthened research capacity, generated new knowledge and demonstrated the value of co-production in addressing health inequalities. Most importantly, it highlighted the continuing need for research, policy development, professional education and accessible healthcare systems that ensure people with intellectual disabilities are fully included in cancer prevention, screening and care. The work of CUPID provides a strong foundation for future collaborative initiatives aimed at reducing health inequalities and ensuring that equitable cancer care becomes a reality for all citizens.

Dr Katarzyna Świeczkowska - From Healthcare to Healthy Living

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Summary

The understanding of disability has undergone a profound transformation over recent decades. Traditional biomedical models viewed disability primarily as a consequence of disease, impairment, or deficits located within the individual. Contemporary international frameworks, however, recognise disability as the result of the interaction between a person's health condition and the physical, social, attitudinal, and policy environments in which they live. This shift has significant implications for healthcare, rehabilitation, education, and social policy.

The International Classification of Functioning, Disability and Health (ICF), developed by the World Health Organisation (WHO), provides a comprehensive framework for understanding health and disability through a biopsychosocial lens. Rather than focusing solely on diagnosis or impairment, the ICF examines how body functions and structures, activities, participation, environmental factors, and personal factors interact to influence an individual's everyday functioning and quality of life.

According to the WHO, health is "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity." Similarly, the United Nations Convention on the Rights of Persons with Disabilities (CRPD) defines disability as arising from the interaction between persons with impairments and barriers that hinder their full and effective participation in society on an equal basis with others. These definitions move beyond a purely medical understanding of disability and place participation, inclusion, and human rights at the centre of healthcare and support systems.

The ICF demonstrates that identical medical diagnoses may result in very different levels of functioning depending on environmental and personal circumstances. For example, a person who cannot speak because of neurological impairment may experience severe participation restrictions if communication support is unavailable. However, access to augmentative and alternative communication (AAC), supportive environments, and informed professionals can substantially reduce these barriers and enable active participation in education, employment, healthcare, and community life. Likewise, mobility impairments become disabling not only because of physical limitations but also because of inaccessible environments, inadequate transportation, and social exclusion.

Environmental factors therefore play a critical role in determining health outcomes. Poverty, conflict, pollution, inaccessible healthcare, lack of education, discrimination, and limited access to assistive technology may all create or exacerbate disability. Conversely, supportive families, inclusive schools, accessible healthcare systems, community organisations, and effective rehabilitation services facilitate participation and independence.

This perspective requires healthcare systems to move beyond diagnosis-driven models towards functional assessment. While medical diagnosis remains essential for identifying health conditions and planning treatment, it provides limited information about how individuals function in daily life, what support they require, or which environmental barriers they encounter. Functional assessment enables professionals to understand the person's abilities, goals, participation, and support needs, allowing interventions to be tailored to individual circumstances.

Equally important is the transition from a paternalistic model of healthcare to person-centred care. People with disabilities should not be passive recipients of medical interventions but active partners

in decision-making regarding their health, rehabilitation, and everyday lives. Empowerment, shared decision-making, and respect for individual preferences are fundamental principles of contemporary disability policy and practice.

Person-centred healthcare extends beyond clinical settings. It requires collaboration among healthcare providers, educators, rehabilitation professionals, social workers, families, community organisations, and peer networks. Effective support depends upon coordinated, multidisciplinary approaches that recognise the individual as a whole person rather than focusing solely on medical needs.

Communication accessibility represents another essential component of inclusive healthcare and rehabilitation. Many individuals experience barriers because information is presented in inaccessible formats or communication methods are not adapted to their needs. The use of Easy-to-Read and Understand (ETR) materials, augmentative and alternative communication (AAC), sign language interpretation, plain language, accessible digital information, and assistive technologies enables people with disabilities to make informed decisions and actively participate in healthcare processes.

Participation itself is a determinant of health. Opportunities to engage in education, employment, recreation, friendships, family life, sports, and community activities contribute significantly to physical and mental well-being. Therefore, rehabilitation should aim not only to improve body functions but also to enhance participation and quality of life.

Moving from healthcare to healthy living is another important element in changing the way we think about supporting people with disabilities This approach recognises that health is sustained not only through medical interventions but also through opportunities for meaningful participation, physical activity, social inclusion, and personal development. Physiotherapy and rehabilitation remain important components of support; however, they should be integrated with broader health promotion strategies that encourage active lifestyles and community participation.

Physical activity illustrates this shift particularly well. Exercise contributes to improved fitness and physical functioning, but its benefits extend far beyond physiological outcomes. Participation in sport and recreational activities promotes friendships, self-confidence, independence, enjoyment, mental well-being, and social inclusion. These dimensions are captured in the F-words for Child Development:

- Fitness
- Functioning
- Friends
- Family
- Fun
- Future

Together, these interconnected domains reflect a holistic understanding of health that aligns with the ICF and person-centred practice. They demonstrate that successful rehabilitation should ultimately support people in living meaningful, self-directed lives within their communities.

Families, friends, peer groups, professionals, and community organisations all play indispensable roles in promoting healthy living. Supportive relationships encourage participation, facilitate access to services, strengthen resilience, and improve long-term outcomes. Rather than viewing healthcare

as a series of isolated clinical interventions, the biopsychosocial model emphasises ongoing collaboration between individuals, families, professionals, and society.

Ultimately, adopting the ICF framework requires systemic change. Healthcare, rehabilitation, education, and social services should become increasingly integrated, coordinated, and responsive to individual goals. Policies should prioritise accessibility, inclusion, functional assessment, person-centred planning, and empowerment. Such an approach not only improves health outcomes but also supports the realisation of the human rights of persons with disabilities.

The transition from healthcare to healthy living represents more than a conceptual shift. It is a practical roadmap for creating inclusive systems that enable people with disabilities to participate fully in society, achieve their aspirations, and enjoy the highest attainable standard of health throughout their lives.

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Dr Fabrizio Fea - How Research Can Improve Cancer Prevention for People with Intellectual Disabilities

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Summary

People with intellectual disabilities (PWID) experience significant inequalities in accessing healthcare, including cancer prevention, screening Programmes and early diagnosis. These disparities contribute to poorer health outcomes and are influenced by multiple factors, including communication difficulties, limited access to health information, socio-economic disadvantage, logistical barriers and psychological concerns associated with healthcare. This presentation examined how research can contribute to reducing these inequalities by providing evidence to support more accessible and inclusive cancer prevention strategies.

The presentation highlighted that healthcare professionals frequently identify challenges in everyday clinical practice but require robust evidence to understand their underlying causes and to develop effective interventions. Research was presented as an essential bridge between clinical observation and service improvement, enabling healthcare providers and policymakers to make informed decisions based on evidence rather than assumptions.

The importance of cancer prevention was emphasised throughout the presentation. Early detection through organised screening Programmes and the promotion of healthy lifestyles have consistently been shown to reduce cancer mortality and improve health outcomes. However, these benefits can only be achieved when prevention services are accessible to all members of society. For people with intellectual disabilities, inequalities in access continue to limit participation in screening Programmes and other preventive healthcare initiatives.

The presentation also considered the persistent gap between research and clinical practice. It was noted that people with intellectual disabilities remain under-represented in health research and that many existing cancer prevention Programmes are designed for the general population without considering the specific needs of this group. Consequently, evidence derived from the wider population cannot always be directly applied to people with intellectual disabilities. Greater inclusion of this population in research was therefore identified as essential for developing evidence-based interventions that are both effective and equitable.

The value of small-scale research was illustrated through the CUPID Project pilot study conducted at Associazione Scuola Viva in Rome. The study demonstrated how relatively small investigations can identify local challenges, evaluate potential solutions and generate important questions for future research. Such studies provide practical evidence that can inform improvements in clinical practice and healthcare delivery.

As part of the pilot study, a questionnaire was distributed to families to explore awareness of cancer prevention and organised screening Programmes. Fifty completed questionnaires were returned from eighty distributed. The findings indicated that awareness of cancer prevention was generally high among participating families. Forty respondents reported awareness of cancer prevention activities, while thirty-nine indicated that they were familiar with national or regional cervical, breast and bowel cancer screening Programmes. Thirty-five respondents recognised the importance of healthy lifestyle measures, including maintaining a healthy weight, healthy eating and avoiding

smoking. In addition, thirty-one respondents reported previous experience of cancer within their family.

Although levels of awareness were encouraging, the findings also demonstrated that knowledge alone did not necessarily translate into participation in cancer screening Programmes. This suggested that barriers beyond health literacy continue to influence access to preventive healthcare. Practical difficulties, communication barriers, service accessibility and the need for appropriate support may all contribute to lower uptake of screening among people with intellectual disabilities despite relatively good awareness among family members.

A further issue identified during the presentation was the lack of comprehensive epidemiological data relating to cancer prevention and outcomes for people with intellectual disabilities. This absence of reliable data limits the ability of healthcare systems and policymakers to accurately assess health inequalities, monitor outcomes and develop targeted interventions. The presentation therefore highlighted the need for systematic data collection to support evidence-based policy development and service planning.

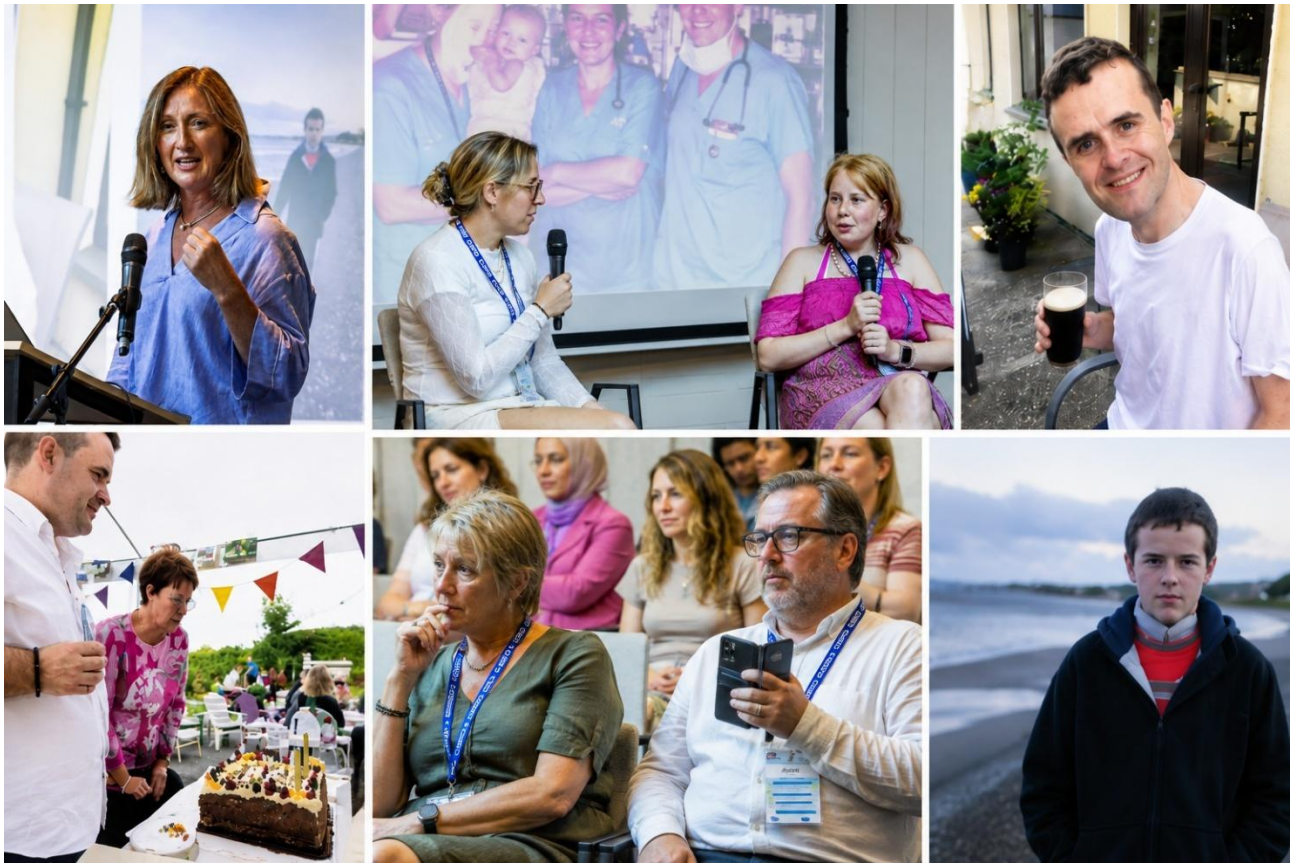
The findings also demonstrated how research can be translated into practical improvements in healthcare delivery. Recommendations included adapting information materials into accessible formats, improving communication between healthcare professionals, people with intellectual disabilities and their families, strengthening family involvement throughout prevention Programmes and increasing awareness of available screening services. These measures have the potential to reduce barriers and improve participation in preventive healthcare.

The presentation further reflected on the practical lessons learned from conducting research with people with intellectual disabilities. Successful research requires accessible communication, flexibility in research methods, trust-building with participants and families, careful attention to ethical considerations and meaningful participation by people with intellectual disabilities throughout the research process. These principles not only improve research quality but also ensure that the resulting evidence is relevant to the needs and experiences of those most affected.

The presentation concluded by identifying several priority actions for improving cancer prevention among people with intellectual disabilities. These included strengthening systematic data collection, developing accessible screening Programmes, enhancing education and training for healthcare professionals, supporting collaborative European research and promoting active family involvement in cancer prevention initiatives. Collectively, these actions were presented as essential steps towards reducing health inequalities and ensuring equal access to prevention, diagnosis and treatment.

Overall, the presentation demonstrated that research plays a fundamental role in improving clinical practice and reducing inequalities in cancer prevention for people with intellectual disabilities. By generating evidence from both clinical experience and targeted research, healthcare services can become more accessible, inclusive and responsive to the needs of this population. The central message of the presentation was that every improvement in clinical practice begins by asking the right research questions and using evidence to guide meaningful change.

Presentations: Lived Experiences



Ms Daniela Bell & Dr Oliwia Bell

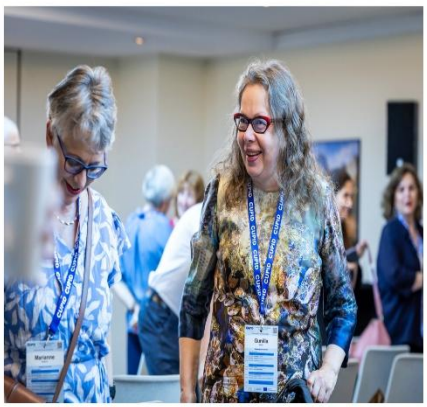
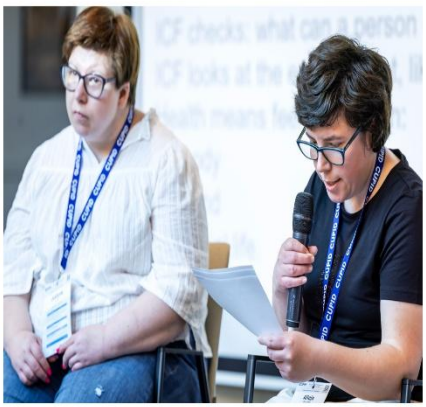
Raymond's Story- Presented by Dr Sinead Foran

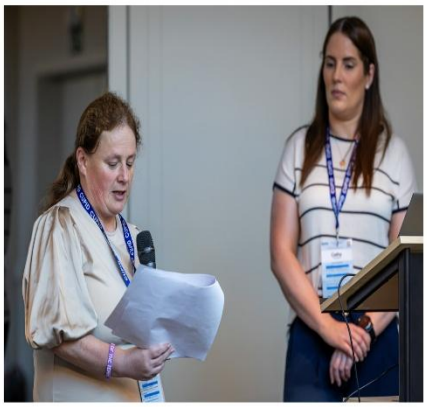
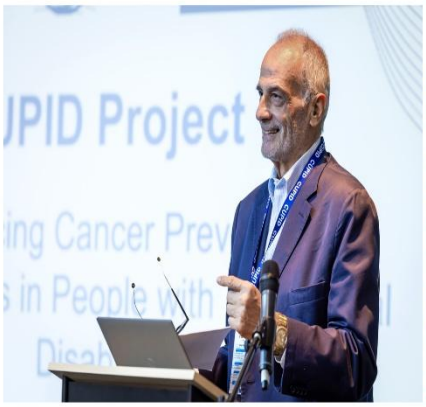
Background: People with intellectual disabilities experience significant inequalities in cancer prevention, screening, diagnosis and treatment. Lived experience provides important insights into barriers within healthcare systems and identifies practical strategies for improving equitable, person-centred care.

Methods: Two lived experience presentations were delivered as part of the CUPID COST Action Conference in Brussels. Daniela Bell, an advocate and expert by experience, shared her experiences of childhood brain cancer treatment and subsequent engagement with preventive healthcare through an interview with Dr Olivia Bell, her sister. Dr Sinéad Foran presented the story of Raymond, an Irish man with an intellectual disability diagnosed with advanced colorectal cancer, based on a narrative written by his family. Both presentations explored communication, healthcare experiences, diagnostic pathways and recommendations for improving cancer prevention and care.

Results:The presentations identified multiple barriers to equitable cancer care, including inaccessible communication, failure to engage directly with people with intellectual disabilities, inadequate preparation for medical procedures, diagnostic overshadowing and delayed recognition of cancer symptoms. Positive experiences were associated with healthcare professionals who established trusting relationships, communicated at an appropriate level, involved family members appropriately, and recognised individual strengths and support needs. Both narratives demonstrated that accessible communication, person-centred care, family involvement, reasonable adjustments and professional education are critical to improving uptake of cancer prevention initiatives and reducing inequalities in diagnosis and treatment.

Conclusions: The lived experiences of Daniela and Raymond demonstrate the urgent need to transform cancer services for people with intellectual disabilities through improved communication, inclusive healthcare practices and professional education. Embedding accessible, person-centred approaches throughout cancer prevention and care pathways has the potential to reduce health inequalities, facilitate earlier diagnosis and improve health outcomes for people with intellectual disabilities.



JPID Project


Oral Presentations

Working Group Leads Presentations

Denny[1] & Kowalczyk[2] - Working Group 1: Creating the CUPID Research Agenda

[1] Dr Margaret Denny, University of Maribor, Slovenia

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Background:The CUPID COST Action (CA21123) was established to improve cancer prevention and screening for people with intellectual disabilities through international collaboration, co-production, and knowledge exchange. Working Group 1 (WG1) played a central role in delivering the Action's objectives by bringing together researchers, clinicians, educators, advocacy organisations, policymakers, and people with intellectual disabilities to develop inclusive, evidence-informed approaches that promote equitable access to cancer prevention and screening across Europe.
Methods: WG1 adopted a collaborative and participatory approach throughout the four-year COST Action. Activities focused on establishing an interdisciplinary European network, engaging stakeholders through co-production methodologies, developing accessible resources, implementing an international Training School, supporting Short-Term Scientific Missions (STSMs), and fostering early-career researcher development. Knowledge exchange was facilitated through stakeholder engagement initiatives, pilot implementation activities, conference presentations, scholarly publications, and collaborative dissemination. A rights-based framework underpinned all activities, ensuring that the voices of people with intellectual disabilities informed the design, implementation, and evaluation of project outputs.

Results: WG1 successfully achieved the objectives and deliverables assigned within the CUPID COST Action. Key achievements included establishing a strong interdisciplinary European network and developing accessible educational and research resources. The group co-produced a rights-based Evaluation Protocol, accompanied by an Easy-Read version, to support inclusive cancer prevention and screening practices. Extensive stakeholder engagement activities were conducted across Europe, alongside pilot implementation initiatives and STSMs that strengthened international collaboration and knowledge exchange. WG1 also delivered Programmes supporting early-career researchers, contributed substantially to conference presentations, peer-reviewed publications, and the CUPID Training School book, and generated empirical evidence to inform policy and practice. These activities strengthened international partnerships and promoted inclusive research methodologies across participating countries.

Conclusions: WG1 made a substantial contribution to the successful delivery of the CUPID COST Action by advancing collaborative research, capacity building, and inclusive practice in cancer prevention and screening for people with intellectual disabilities. The outputs generated provide a sustainable foundation for future research, education, policy development, and service delivery. Through co-production, international collaboration, and stakeholder engagement, WG1 has helped establish an enduring framework that supports equitable access to cancer prevention and screening for people with intellectual disabilities across Europe.

McMahon[1] & Vuković [2]- Working Group 2: Auditing European Cancer Prevention and Screening Policies for People with Intellectual Disabilities

Professor Martin McMahon[1] and Dr Vladimir Vokovic[2]

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Background: Working Group 2 (WG2) focuses on auditing and evaluating European cancer prevention and screening policies for people with intellectual disabilities. Its core aim is to identify national and regional policy documents, examine where intellectual disability is explicitly addressed, and translate these findings into recommendations that support equitable access to cancer prevention and screening across Europe.

Methods: WG2 developed a standardised protocol for searching academic databases, grey literature and relevant organisations across participating countries. The review identified 16 policy, guideline, recommendation and information documents. Most focused on breast, cervical and colorectal cancer screening, while prevention, clinical monitoring and treatment received substantially less attention.

Results: The review identified a range of recommended reasonable adjustments, including accessible invitations and information, flexible appointments, pre-visit preparation, involvement of support persons, and supported decision-making that respects autonomy and the right to refuse. To date, WG2 has brought together more than 125 members, with 40 contributors from 25 organisations across 18 countries participating in the review. Activities have included a joint WG2 and WG3 Training School at Trinity College Dublin, webinars, workshops, knowledge exchange initiatives and a Short-Term Scientific Mission. At the final conference, the group explored the potential use of a discrete choice experiment to rank reasonable adjustments according to their importance and feasibility within cancer screening services.

Conclusions: Next steps include publishing the policy review, developing a European report with evidence-informed recommendations, and refining methods to prioritise reasonable adjustments in partnership with people with intellectual disabilities, supporters, healthcare professionals and policymakers. Collectively, this work provides a strong foundation for more consistent, inclusive and equitable cancer prevention and screening policy across Europe.

Additional resource

A short video summarising the work of Working Groups 2 and 3 is available on YouTube: **CUPID COST Action WG2 & WG3** CUPID COST Action WG 2&3

Sykes -Working Group 3: Creating the CUPID Research Agenda

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Working Group 3's main deliverable is to develop a Europe-wide cancer prevention and screening strategy for people with intellectual disabilities, led by Dr Kate Sykes (Northumbria University). Its core aim is to build a research agenda for EU-wide cancer prevention guidelines, drawing on findings from WG1 and WG2 to ensure fair, lasting access to prevention and screening Programmes, alongside guidance on the knowledge and skills healthcare workers need and how to measure whether their care is effective. To date, WG3 has completed a Training School at Trinity College Dublin (May 2025, attended by 48 people in person and 20 online) on health system approaches to screening and prevention, run cancer prevention workshops in Ireland and Turkey (paper published on this work), and currently carrying out a systematic review of reviews to identify barriers and facilitators to prevention and screening for this population. These sources, combined with CUPID publication, and WG2 policy review, are being used to structure a research agenda covering recommendations, workforce skills/competencies, and research questions on uptake, acceptability and interventions. Next steps involve finishing the systematic review and agenda analysis for publication, and consulting carers, healthcare professionals, and people with intellectual disabilities themselves to prioritise and validate the final agenda.

Trajkovski - Dissemination, Communication, and Knowledge Translation: Achievements and Impact of Working Group 4 within the COST Action CUPID

Professor. Dr Vladimir Trajkovski

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Background: Effective dissemination and communication are fundamental to maximizing the impact of international research collaborations. Within the COST Action CUPID (Cancer – Understanding Prevention in Intellectual Disability), Working Group 4 (WG4) was established to develop and implement dissemination strategies that promote accessible communication, stakeholder engagement, and knowledge translation in the field of cancer prevention for people with intellectual disabilities. Objective: To present the principal activities, scientific outputs, and impact of WG4 during the implementation of the COST Action CUPID.

Methods: WG4 developed and implemented a comprehensive dissemination and communication strategy targeting researchers, healthcare professionals, policymakers, advocacy organisations, people with intellectual disabilities, and their carers. Activities included the development of an accessible project website, dissemination through social media platforms, newsletters, webinars, scientific conferences, training schools, open-access publications, Easy Read materials, promotional resources, and policy-oriented communication.

Results: WG4 successfully established a sustainable dissemination infrastructure, including an accessible project website, annual newsletters, open-access educational resources, promotional materials, and multimedia content. The group organized webinars and contributed to scientific meetings, supporting collaboration among Working Groups and increasing stakeholder engagement across Europe. Dissemination activities enhanced awareness of cancer prevention inequalities affecting people with intellectual disabilities, promoted inclusive health communication, and strengthened international networking. The Action also contributed to the development of policy roadmaps and supported the dissemination of scientific outputs produced across the CUPID network.

Conclusions: WG4 played a central role in increasing the visibility, accessibility, and societal impact of the COST Action CUPID. Through coordinated dissemination, accessible communication, and stakeholder engagement, the group contributed to sustainable knowledge translation, promoted equitable cancer prevention, and established a foundation for future international collaborations and policy development beyond the lifetime of the Action.

Insights from the Training Schools

Golubović[1] & Milutinović[2] - Making Sun Protection Understandable: A Multimodal Workshop for Persons with Intellectual Disabilities

Professor Špela Golubović1, Professor Dragana Milutinović2
[1] Department of Special education and Rehabilitation, Faculty of Medicine, Universiti of Novi Sad, Serbia
[2] Department of Nursing, Faculty of Medicine, Universiti of Novi Sad, Serbia

Background: Persons with intellectual disabilities (PwID) often experience difficulties understanding conventional health information, which can limit their adoption of effective sun-protection behaviours. This project aimed to show how an accessible, multimodal workshop on ultraviolet (UV) radiation, skin changes, and sun protection was developed and delivered for PwID.

Methods: Workshop design followed eight didactic principles: simplicity and clarity, step-by-step learning, multimodal presentation, repetition of key messages, hands-on activities, social/collaborative learning, everyday-life application, and accessibility for PwID, delivered through an explicit-instruction approach. Content was organised around three guiding questions — what the Sun is and why it can be harmful, what happens to the skin, and how to protect oneself — moving from a familiar, positive everyday scenario (sunny days, the beach) rather than a fear-based opening. Information was presented through an accessible slideshow, oral explanation, and posters, paired with five sequential hands-on activities: (1) interpreting the UV index (low to very high); (2) exploring the three skin layers and locating sweat/sebaceous glands; (3) creating moles with modelling clay on a body drawing; (4) identifying unusual moles in photographs, introduced through a simplified message based on the ABCDE criteria (change, pain, itching, bleeding, or unusual appearance = ask for help); and (5) dressing a beach scenario drawing with stickers to select protective items. An easy-read take-home document reinforced key messages for use with carers after the session.

Results: The workshop yielded a complete accessible learning package: an adapted slideshow, a UV-index activity sheet, a skin-layer drawing, modelling-clay materials, mole-recognition photographs, a beach poster with sticker set, and an easy-read document. Through this approach, participants practised reading the UV index, recognising normal versus unusual moles, applying sunscreen correctly across body areas, selecting protective clothing, hats and UV-blocking sunglasses, seeking shade, avoiding peak sun hours (10 a.m. – 4 p.m.), staying hydrated, remembering winter sun exposure risks, and knowing when to consult a doctor or trusted support person.

Conclusion: Accessible sun-protection education for PwID benefits from going beyond simplified text. Combining clear language, visual and tactile materials, repetition, hands-on activities, and easy-read take-home resources helped connect abstract health information with everyday decisions and practical self-protection skills.

Kowalczyk - Co-designing Accessible Breast Awareness Education for Women with Intellectual Disabilities

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Co-designing Accessible Breast Awareness Education for Women with Intellectual Disabilities:

Women with intellectual disabilities (ID) continue to experience profound inequalities in breast cancer prevention, reflected in lower participation in screening programmes, delayed diagnosis, and poorer health outcomes. Despite these disparities, structured breast awareness education tailored to the communication and learning needs of people with ID remains largely absent across Europe. Within the framework of the COST Action CUPID (CA21123), an innovative breast awareness educational session was developed and implemented during the international Training School in Prague to address this unmet need through an evidence-informed and co-designed educational approach.

The intervention was informed by principles of accessible health communication, Easy-to-Read methodology, and participatory co-design involving researchers, healthcare professionals, people with intellectual disabilities, and carers. The educational framework integrated six interconnected components: plain language, visual communication, repetition with comprehension checks, active involvement of carers, personalisation of health messages, and clear behavioural guidance. Rather than relying on traditional knowledge transmission, the session employed experiential and interactive learning strategies that encouraged active participation, reflection, and practical application of accessible communication principles.

A distinctive element of the programme was the dual educational perspective, whereby participants first experienced the learning process using the same accessible methods designed for people with ID and subsequently engaged in collaborative exercises translating conventional medical information into Easy-to-Read materials. This approach illustrated that accessibility is not achieved through simplification alone but through intentional instructional design that combines linguistic adaptation, visual support, user involvement, and iterative feedback.

The Training School demonstrated the feasibility of integrating co-production and inclusive communication strategies into cancer prevention education. The developed framework offers a transferable model for designing accessible educational interventions that promote health literacy, support informed decision-making, and contribute to reducing health inequalities among people with intellectual disabilities. More broadly, this work illustrates how participatory educational design can facilitate the implementation of equitable, person-centred approaches to cancer prevention across diverse healthcare settings.

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Developing Accessible Cancer Prevention Information for People with Intellectual Disabilities: Lessons from a COST Action Training School

People with intellectual disabilities experience significant health inequalities, including lower participation in cancer prevention and screening programmes. One important barrier is the availability of health information that is accessible, understandable, and meaningful. This presentation is based on a session delivered as part of the COST Action CA21123 Training School and explored the principles and practical application of developing accessible health information, with a particular focus on Easy Read resources.

The session introduced participants to the concept of accessible information, highlighting the importance of health literacy and the need to provide information in formats that meet diverse communication needs. Current standards, including the Accessible Information Standard in England, were discussed alongside broader approaches such as large print, audio, Braille and Makaton. Participants examined the fundamental principles of Easy Read design, including page layout, language, font selection, image use and writing style, emphasising that effective Easy Read materials require more than simply adding pictures to text.

A central theme of the workshop was the importance of co-production, recognising people with intellectual disabilities as experts in their own communication needs and essential partners in developing accessible resources. Interactive activities enabled participants to apply Easy Read principles by adapting cancer prevention information on topics such as sun safety and obesity, encouraging reflection on how complex health messages can be communicated more effectively. The presentation concludes that embedding accessible communication standards and co-production into routine healthcare practice has the potential to improve health literacy, promote equitable access to cancer prevention information, and contribute to reducing health inequalities experienced by people with intellectual disabilities.

10-Minute Oral Presentations

Gil et al. -‘I’m fighting my case all the time’: Experiences of the cancer care pathway: adults with intellectual disability and their supporters

Natalie M Gil[1], Anna Cox[1], Katriina L. Whitaker[1], Emily McBride[2], Robert S. Kerrison[1]

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Abstract

Background: People with intellectual disability experience substantial inequities in cancer outcomes, including higher rates of emergency presentation and later-stage diagnosis. Although these disparities are increasingly documented, less is known about the social and institutional processes through which they are produced. This study explored lived experiences of navigating the cancer care pathway among adults with intellectual disability and their supporters. **Methods:** Semi-structured interviews were conducted with five adults with intellectual disability and five supporters between August 2024 and September 2025. Flexible and inclusive methods were used to support participation. Interviews explored experiences of recognising symptoms, seeking help, and navigating healthcare encounters. Data were analysed using reflexive thematic analysis, followed by abductive interpretation drawing on Candidacy; Health Stigma and Discrimination Frameworks. **Results:** Participants described an ongoing process of negotiating recognition as a legitimate candidate for investigation and care. Intellectual disability-related stigma operated upstream of clinical decision-making, shaping whether bodily changes were taken seriously, whose accounts were treated as credible, and how quickly concerns were acted upon. Participants described fragmented systems, inaccessible communication, and repeated adjudication of legitimacy across encounters, requiring sustained labour to remain visible within services. Advocacy functioned both as a route through the system and a marker of system failure, with access frequently dependent on supporters. **Conclusions:** We extend Candidacy theory by conceptualising “advocated candidacy,” whereby access becomes contingent on supporters’ ability to negotiate legitimacy on the person’s behalf. These findings highlight the need for cancer pathways that are inclusive by default to ensure equitable and timely diagnosis and care.

Keywords: intellectual disability; cancer care; stigma; candidacy; patient experience

Sykes et al.- Understanding Cancer Prevention and Screening in People with Intellectual Disabilities: A review of systematic reviews

Kate Sykes[1], Martin McMahon, Vladimir Vuković , Adela Popa, Emine Ef, Dragana Milutinović, Ruveyde Aydin, Aysegul Ilgaz, Soner Dogan, Trine Allerslev Horsbøl, Dusanka Tadic, Bahar Aksoy, Bilge Güvenç Tuna, Deniz Harputlu, Damla Altin, Edanur Tar Bolacali, Eda Sahin, Lau Caspar Thygesen, Elif Saraç, Vera Dimitrievska

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Abstract

Background: People with intellectual disabilities are more likely to receive a cancer diagnosis at advanced stages. Barriers to cancer prevention and screening contribute to persistent health inequalities. **Aim:** To identify the barriers and facilitators to cancer prevention initiatives and screening, and to inform policies and practices by highlighting research gaps. **Methods:** A review of systematic reviews was conducted in accordance with PRISMA guidelines. Nine electronic databases were searched including forwards and backwards citation searching. Reviews focusing on cancer prevention and/or screening involving or focused on people with intellectual disabilities. De-duplication and screening were undertaken using Covidence. Methodological quality assessed using AMSTAR-2. Data synthesised using framework analysis guided by the Social Ecological Model (individual, interpersonal, organisational, community, policy levels). **Results:** To date, 3615 records have been identified, with 187 full texts being screened. Currently there are 21 included systematic reviews, of which 68 unique primary studies are included. Preliminary findings specifically focus on cancer screening and highlight that people with intellectual disabilities face significant barriers. This includes psychological, cognitive, and systemic factors. Tailored strategies such as a need for carer support, accessible information, and healthcare professional training can improve uptake. **Conclusion:** Initial findings highlight the importance of personalised approaches and reasonable adjustments to ensure meaningful participation in cancer prevention and screening initiatives. The framework will identify potential interventions to improve engagement at the individual level, while also informing the policy changes needed to support co-produced, equitable early detection strategies for people with intellectual disabilities across Europe.

Keywords: intellectual disabilities; cancer prevention; cancer screening; review of reviews; health inequalities

Karabiyik & Ilgaz - Effects of interventions to increase cancer screening and prevention among individuals with intellectual disabilities: A systematic review of randomized controlled trials

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Abstract

Background: People with intellectual disabilities are unable to fully benefit from cancer screening and prevention Programmemes because of the many barriers they face when attempting to access healthcare services; this reduces opportunities for early diagnosis and exacerbates health disparities. **Objective:** The aim of this study was to explore the effectiveness of interventions aimed at increasing cancer screening and prevention in individuals with intellectual disabilities. **Methods:** A comprehensive literature search was conducted across PubMed, Scopus, Web of Science, CINAHL, MEDLINE, and the Cochrane Library, as well as grey literature sources. Following study selection and eligibility assessment, randomized controlled trials published without time restrictions were included in the review. **Results:** A total of 71 randomized controlled trials were included in this review, most of which concentrated on promoting healthy eating, weight control, and increased physical activity. Most of the interventions examined were multi-component, incorporating family, school, community, and care institution-based practices, as well as technology-supported approaches such as mobile health, active video gaming, and virtual reality. Studies has indicated that interventions targeted at managing weight, preventing substance abuse, improving diet and physical activity, or increasing physical activity are generally beneficial. Additionally, the Programmemes have raised awareness of cancer screenings for people with intellectual disabilities, particularly with regard to screenings for women's health. **Conclusion:** The results show that interventions that emphasize physical activity, nutrition, weight control, and drug abuse prevention are generally helpful for people with intellectual disabilities. These Programmemes have also raised awareness of cancer screenings, especially in the context of women's health. Health Programmemes for people with intellectual disabilities should incorporate accessible and modified cancer screening education along with integrated lifestyle modification interventions.

Keywords: intellectual disability; cancer screening; cancer prevention; randomized controlled trial

Karadag Arli - Nurse-Led Approaches to Promote Cancer Prevention in Individuals with Intellectual and Developmental Disabilities

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Background: Individuals with intellectual and developmental disabilities (IDD) face significant health inequities, including reduced access to cancer prevention and screening services. Systemic barriers, low health literacy, and limited awareness of cancer risk factors contribute to delayed detection and poorer outcomes. Nurses, as primary healthcare providers in continuous contact with this population, are uniquely positioned to lead interventions that promote cancer prevention and health equity. **Aim:** This review aims to synthesize current evidence on nurse-led strategies supporting cancer prevention among individuals with IDD. **Methods:** A narrative review was conducted using recent international literature focusing on cancer prevention in adults with IDD. Key studies examining awareness of cancer risk factors, symptom recognition, caregiver perspectives, and healthcare disparities were included to highlight implications for nursing practice and leadership. **Results:** Evidence indicates that individuals with IDD have lower awareness of cancer risk factors and symptoms compared to the general population, and caregivers' knowledge significantly affects preventive behaviours. Systematic reviews report consistent inequalities in cancer prevention access, with nurses playing a central role in bridging these gaps through education, advocacy, and individualized care planning. Caregiver-focused interventions, supported by nursing leadership, improve engagement in preventive services and facilitate communication between patients, families, and healthcare systems. **Conclusion:** Nurses are essential in promoting cancer prevention among individuals with IDD through education, advocacy, and coordinated care. Nurse-led Programmemes that address awareness, access barriers, and caregiver support can reduce health disparities and enhance preventive care uptake in this vulnerable population.

Keywords: Intellectual disability; developmental disability; nursing leadership; cancer prevention; health equity

Efe et al. - The Impact of Parental Caregiver Burden on Cancer Screening Behaviours of Children with Special Needs: A Regression Analysis Study

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Abstract

Background: Caring for children with special needs places substantial emotional, psychological, and physical demands on parents, which can negatively affect their health awareness and behaviours. **Aim:** This study aimed to assess the caregiver burden of parents with children who have special needs and examine its impact on their cancer screening behaviours. Methods: A descriptive, relational, cross-sectional study was conducted between October 1, 2025, and March 15, 2026. Parents of children aged 0–18 years attending Special Education Schools affiliated with the Ministry of National Education in Turkey were included (n = 113). Data were collected using the Parent Demographic Information Form, the Attitude Scale Toward Cancer Screening – Short Form (ASCS), and the Zarit Burden Interview – Short Form (ZBI-SF). Statistical analyses were performed using SPSS 24, including descriptive statistics, correlation, and linear regression. **Results:** Most participants were female (65.5%), and 95.6% had no cancer diagnosis. A moderate negative correlation was found between ZBI-SF and ASCS ($r = -0.46$, $p=0.001$, 95% CI [−0.60, −0.31]), indicating that higher caregiver burden was associated with lower attitudes toward cancer screening. Linear regression confirmed that ZBI-SF significantly predicted ASCS ($B = -0.31$, $p=0.001$, $R^2 = 0.22$), meaning each one-unit increase in caregiver burden corresponded to a 0.31-unit decrease in cancer screening attitudes. **Conclusion:** Increased caregiver burden is linked to reduced attitudes toward cancer screening, suggesting that parents experiencing higher burden may be less likely to engage in preventive screening behaviours. These findings highlight the need to consider caregiver burden when designing interventions aimed at improving cancer screening attitudes and promoting preventive health behaviours among parents of children with special needs.

Keywords: Caregiver burden; cancer screening; children with special needs; parental stress; preventive health behaviour

5-minute Presentations

Banda - Understanding decision-making in cancer screening for people with intellectual disabilities

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Abstract

Background: Participation in cancer screening Programmemes is significantly lower among people with intellectual disabilities (ID). Previous research has identified barriers such as limited accessible information, low health literacy, and reliance on caregivers. However, less is known about how decisions about participation are made. Understanding this process is important to identify opportunities to improve decision-making and increase screening participation among people with ID. **Aim:** This study explores the information and decision-making process regarding cancer screening participation among people with ID living in long-term care organisations in the Netherlands. **Methods:** Data were collected using a system dynamics approach through two group model building (GMB) workshops with caregivers and ID healthcare professionals. Participants identified key factors influencing screening participation. In addition, semi-structured interviews were conducted with support workers, healthcare professionals, and people with ID to explore experiences with the screening pathway. These perspectives were used to map how organisational processes and support structures influence decision-making. **Results:** GMB outcomes were summarized in a causal loop diagram showing the complexity of the screening process and the involvement of multiple stakeholders. Decision-making emerged as a key phase, influenced by (1) awareness of screening invitations, (2) the ability to make an informed decision, and (3) the availability of tailored support. Collaboration between healthcare professionals, support workers, caregivers, and people with ID was essential. **Conclusion:** Understanding how decisions about cancer screening are made within healthcare organisations can help identify opportunities to better support informed decision-making and improve accessibility and participation in screening Programmemes for people with ID.

Keywords: cancer screening; informed decision-making

Koko et al. - Cancer screening for people with intellectual disabilities: Evidence from a global scoping review

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Abstract

Background: Equitable access to cancer screening is a central objective of population-based screening Programmes. However, people with intellectual disabilities (ID) experience lower screening participation and face multiple barriers across the screening pathway. Objectives: This scoping review synthesises international evidence on cancer screening for people with ID to examine screening participation rates, map barriers and facilitators, and identify interventions to improve screening access. **Methods:** A scoping review was conducted within the EUCanScreen Joint Action following Joanna Briggs Institute methodology and PRISMA-ScR guidelines. MEDLINE, Embase, and Web of Science were searched for studies published between 2013 and 2024, complemented by targeted grey literature searches. Eligible studies included qualitative, quantitative, and mixed-methods research addressing screening participation, barriers and facilitators, or interventions among people with ID. Barriers and facilitators were mapped along the WHO cancer screening pathway. **Results:** Seventy-eight studies met the inclusion criteria. Most addressed breast, cervical, and colorectal cancer screening. Across countries and study designs, people with ID showed lower screening participation than the general population. Barriers included inaccessible information, limited provider training, fear or discomfort during procedures, and structural barriers such as insufficient identification of support needs. Facilitators included accessible communication, trusted accompaniment, flexible examination settings, and trained healthcare professionals. Only few studies evaluated interventions to improve screening participation. **Conclusion:** Persistent inequalities in cancer screening highlight the need for more inclusive screening pathways, improved professional training, and stronger health system data structures to support equitable participation among people with ID.

Keywords: intellectual disability; cancer screening; health equity; screening participation; prevention

Hedlund et al. - Early Interventions and Cancer Preventive Care for Persons with Intellectual Disabilities in the Norwegian Healthcare System: A Scoping Review

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Abstract

Background: People with intellectual disabilities (ID) experience disproportionate barriers in accessing early interventions and cancer preventive care, despite Norway's universal healthcare framework. Evidence shows that adults with ID face significantly lower participation rates in cancer screening Programmes, including breast, cervical, and colorectal screening, compared with the general population. This literature-based study aims to synthesise recent international and Norwegian-relevant research to explore structural, professional, and individual factors influencing preventive cancer services for this population. **Preliminary results:** Studies identify persistent challenges, including communication barriers, limited health literacy, insufficient provider competence in disability-sensitive care, and inadequate implementation of reasonable adjustments in healthcare settings. Caregivers—both professional and familial—play a critical role in facilitating access to preventive services, yet report gaps in training, support, and resources that hinder effective cancer prevention efforts. Although Norway's health system is built on principles of universal access and decentralisation, research highlights ongoing disparities in the availability and uptake of preventive health measures for people with ID, underscoring a need for strengthened cross-sector coordination and targeted interventions within primary care. **Conclusion:** This review emphasises the urgent need for improved knowledge-based strategies to ensure equitable early intervention and cancer-preventive care for individuals with ID, and calls for further Norway-specific empirical studies to guide policy and practice.

Keywords: cancer; intellectual disability; preventive care and services

Żyta et al.- Personal experiences with preventive cancer screening in people with intellectual disabilities – participatory qualitative research

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Background: People with intellectual disabilities (ID) experience persistent health inequalities, including reduced access to preventive healthcare and poorer health outcomes. Although cancer screening Programmemes are effective in early detection and reducing mortality, individuals with ID participate less frequently than the general population. Barriers may include limited health literacy, communication challenges, reliance on caregivers, and healthcare systems that are insufficiently adapted to their needs. Importantly, the perspectives of people with ID themselves remain underrepresented in research. Understanding their lived experiences is essential for identifying meaningful strategies to promote equitable access to cancer prevention. **Aim:** This participatory study aimed to explore the knowledge, experiences, and perspectives of adults with ID regarding preventive cancer screening in Poland. **Methods:** A participatory qualitative design was used. The study involved 44 adults with ID from northern and southeastern Poland who attended occupational therapy workshops. Individual semi-structured interviews were co-conducted by academic researchers and trained co- researchers with ID to enhance accessibility and empowerment. Data were analysed using thematic analysis. **Results:** Four main themes were identified: (1) knowledge about screening Programmemes and procedures; (2) attitudes toward participation in screening Programmemes; (3) varied personal experiences; (4) barriers to accessing and using screening tests. **Conclusion:** Adults with ID face interconnected individual and systemic barriers to cancer screening. Co-designed interventions - such as easy-read materials, inclusive communication training for healthcare professionals, and structured support - are needed to improve participation. Participatory approaches are crucial to ensure services align with the needs and preferences of people with ID.

Keywords: intellectual disability; cancer screening; participatory research; experience

Knapp et al.- Uptake of the HPV vaccine in boys and girls with an intellectual disability (ID): a scoping review

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Abstract

Background: Most cervical cancer cases are associated with persistent infection with high- risk HPV. By 2025 76% WHO member states were vaccinating girls against HPV; many were also vaccinating boys. Girls and boys with ID may be less likely to receive the vaccine. Aims: To collate evidence on HPV vaccine uptake in adolescents with ID, and the factors that influence it. **Methods:** Scoping review. Databases were searched to January 2026 for studies in ID or, in mixed-disability samples, when >50% sample had ID. Quantitative, qualitative and mixed- methods studies published since 2000 were identified, without language limits. Findings were reported through narrative synthesis. **Results:** We included 20 studies from USA (7), Australia (6), UK (4), Canada (1), Denmark (1), Sweden (1). Vaccination rates were reported in 14 studies of females and/or males with ID, of which 11 studies compared rates in the general population. In all 11 studies rates were lower in ID. In ID, non-vaccination was predicted by language impairment, material deprivation and non-receipt of other childhood vaccines. Barriers and facilitators of vaccination were reported in 10 studies; participants were people with ID, parents, and healthcare and educational practitioners. Prominent influences on vaccination (or not) were: not having it offered; strength of parental feeling; vaccine safety; scepticism in relation to non-sexually active people; and balancing safeguarding concerns with promotion of sexual rights. **Conclusions:** Girls and boys with ID are less likely to receive HPV vaccines. Some reasons for non-vaccination are similar to those in the general population, but many are ID-specific.

Keywords: HPV vaccine; cervical cancer

Nur Pehlivan - Cancer Prevention Awareness and Training Needs among Staff Working with Individuals with Intellectual Disabilities in Turkey: A Preliminary Study

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Abstract

Background: Individuals with intellectual disabilities often experience inequalities in access to health information and preventive healthcare services, including cancer prevention and screening. Staff working with individuals with intellectual disabilities play a key role in promoting health awareness and facilitating access to preventive health services. However, their level of awareness regarding cancer prevention and their training needs remain underexplored, particularly in the Turkish context. **Aim:** This study aimed to examine cancer prevention awareness and training needs among staff working with individuals with intellectual disabilities in Çorum, Turkey. **Methods:** A cross-sectional preliminary study was conducted using an online questionnaire distributed to staff working with individuals with intellectual disabilities in Turkey. The questionnaire included items on demographic characteristics, cancer prevention awareness, health-related practices, and training needs. Data were analysed using descriptive statistics. **Results:** A total of 68 staff members participated in the study. Most participants were female (79.4%) and held a bachelor's degree (61.8%). Over half (52.9%) were disability care personnel, and 60.3% had 1–5 years of experience working with individuals with intellectual disabilities. Although participants recognized the importance of cancer prevention, 58.8% reported not receiving prior training on this topic. Approximately 63% agreed that staff play an important role in promoting cancer prevention, and 66% indicated that more awareness activities are needed in their institutions. A large proportion (83.8%) expressed a need for additional training, particularly in healthy lifestyle behaviours (57.4%), cancer risk factors (52.9%), and cancer screening (51.5%). **Conclusion:** These findings highlight the need to strengthen cancer prevention awareness and provide targeted training Programmemes for staff working with individuals with intellectual disabilities. Developing accessible and tailored health education resources may contribute to improving preventive health practices and reducing health inequalities for this population.

Keywords: intellectual disability; cancer prevention; awareness; training needs; health education

Lima et al.- Factors Associated with Cervical and Breast Screening Attendance in Women with Intellectual Disabilities

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Abstract

Background: Women with intellectual disabilities experience disparities in access to cervical and breast screening. Identifying factors associated with attendance is essential to improve uptake. Aim: To examine whether access to technology, literacy level, social inclusion, and social support are associated with screening attendance, and to identify reasons for non-attendance. **Method:** This study analysed data from 275 women with intellectual disabilities eligible for cervical screening and 254 eligible for breast screening from the IDS-TILDA study. Sociodemographic variables included residential circumstances, level and cause of intellectual disability, age, and education. Associations were assessed using chi-square or Fisher's exact tests, while independent samples t-tests and Mann–Whitney U tests were used to compare continuous score variables between attendees and non-attendees. **Results:** Participants eligible for cervical screening had a mean age of 54.2 years (SD = 6.80). Nearly half lived in community group homes (48.4%). Moderate (41.7%) and mild (34.0%) levels of intellectual disability were prevalent, and primary-level education was the most represented category (48.8%). No significant association was found between receiving an invitation for cervical screening and sociodemographic characteristics. However, cause of intellectual disability was significantly associated with screening attendance ($p = .020$). Women who attended screening had significantly higher self-choice scores ($p = .042$) and lower literacy difficulties ($p = .039$) than non-attendees. Personal reasons (fear and lack of understanding) were the most common barriers (61.9%), followed by lack of professional recommendation (22.7%). **Conclusion:** Improving screening uptake requires interventions that enhance decision-making support and address literacy-related barriers.

Keywords: intellectual disabilities; cancer screening; social determinants

Korukcu & Ozkaya - Participation in Cervical Cancer Screening Among Women with Intellectual Disabilities: What Do We Know?

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Abstract

Background: Women with intellectual disabilities experience substantial inequalities in cervical cancer screening compared with the general population. Evidence from several countries indicates that screening participation rates among women with intellectual disabilities are considerably lower, often reported to be 20–50% below those of the general population. These disparities are further compounded by lower uptake of human papillomavirus (HPV) vaccination and challenges in follow-up after abnormal results. **Aim:** This review aims to synthesize current evidence on participation in cervical cancer screening among women with intellectual disabilities, with a particular focus on barriers and facilitators influencing screening uptake. **Methods:** A scoping review was conducted following the Arksey and O'Malley framework. Literature published between 2015 and 2025 was searched in PubMed and Embase, alongside key journals focusing on intellectual disability research. Studies examining cervical cancer screening participation among women with intellectual disabilities were included and thematically analysed. **Results:** The literature consistently reports multiple barriers to screening participation, including communication difficulties, consent and decision-making complexities, limited accessibility of services, and insufficient provider training. Facilitators identified across studies include the use of accessible health information (e.g., Easy Read materials), caregiver support and advocacy, and the availability of adapted or specialized screening services. Evidence also suggests lower attendance at follow-up procedures such as colposcopy after abnormal cytology results. **Conclusion:** Current evidence highlights persistent inequalities in cervical cancer screening participation among women with intellectual disabilities. Addressing these disparities requires inclusive and accessible screening strategies, improved HPV-related education, and collaborative approaches involving individuals with intellectual disabilities, caregivers, and healthcare professionals.

Keywords: cervical cancer screening; intellectual disabilities; HPV; health inequalities; participation

Breau - Self-advocates with learning disabilities sharing their feedback on a cancer screening study with learning disability nurses

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Abstract

Background: We conducted interviews with learning disabilities nurses across the UK on how they support patients with learning disabilities with accessing cancer screening. As part of a larger knowledge dissemination project, we shared the findings from this study with self-advocates with learning disabilities who were part of a self-advocacy group at a local service provider. **Aim:** To elicit feedback from self-advocates on the relevance of study findings to their experience and those of their peers from a study of learning disability nurses on how they support patients with accessing cancer screening. **Methods:** We held a 1.5-hour feedback session with 12 self-advocates with learning disabilities from a local self-advocacy group. The study author gave a brief presentation of the study findings, and a learning disabilities nurse facilitated the discussion of the study findings. **Results:** Self-advocates demonstrated three main themes for their feedback: (1) seeking information from the session co-facilitator (who was a learning disability nurse) on cancer screening; (2) describing their personal experience with cancer screening, and (3) suggesting reasonable adjustments to screening that may make it easier for them and their peers to access screening. **Conclusion:** We concluded that while our earlier study with nurses had methodological rigour, our findings were less relevant to the lived experience of people with learning disabilities. Future studies should adopt an inclusive research approach and include coresearchers with learning disabilities at all stages of the research process to ensure the study findings are relevant to their lived experience.

Keywords: learning disabilities; cancer screening; learning disabilities nurses; inclusive research; knowledge dissemination

E-poster Presentations

Tyner et al.- Mapping the evidence on cancer care for adults with intellectual disabilities: an evidence gap map protocol

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Abstract

Background: Existing reviews document significant cancer disparities for adults with intellectual disabilities, including lower screening uptake, later-stage diagnosis, and elevated mortality, yet none spans the full continuum from prevention to palliative care. An evidence gap map (EGM) systematically identifies where evidence exists and where gaps remain. **Aim:** This EGM will map research on cancer care for adults with intellectual disabilities across the WHO cancer continuum, characterise evidence coverage by severity, study design, geography, and identify gaps. **Methods:** Following Campbell Collaboration guidance, six databases (MEDLINE, Embase, CINAHL, PsycINFO, Web of Science, Cochrane Library) will be searched from year 2000, supplemented by grey literature and citation searching. Two reviewers will independently screen and map data to a matrix of cancer continuum stage by intellectual disability severity, with secondary coding of outcome type. Evidence gaps, defined as cells with fewer than three primary studies, will be classified by type (absolute, synthesis, or contextual). The protocol follows PRISMA-P and will be pre-registered on the Open Science Framework. **Results:** Initial scoping across 10 eligible systematic and scoping reviews suggests evidence is concentrated on screening and cancer biology, with survivorship identified as an absolute gap. However, whether previously identified gaps reflect true evidence absences or artefacts of narrower search strategies in earlier reviews remains to be established. Preliminary results and draft maps will be presented. **Conclusion:** This will be the first EGM in this field. The conference offers an opportunity for COST Action members to review the interactive map and discuss whether identified gaps align with their national priorities.

Keywords: evidence gap map; intellectual disability; cancer; cancer care continuum; scoping review

Aksoy et al. - Addressing Inequities in Cancer Care for Individuals with Intellectual Disabilities: Insights from a Bibliometric Analysis

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Abstract

Background: Individuals with intellectual disabilities often face substantial barriers across the cancer care continuum. **Aim:** This study aims to examine the structure of scientific production related to cancer care in individuals with intellectual disabilities and to analyze research trends, and thematic focus areas through bibliometric analysis. **Methods:** A descriptive bibliometric study design was employed. A comprehensive search was conducted in the Web of Science Core Collection on March 23, 2026, which identified 598 publications. The inclusion criteria were peer-reviewed articles focusing on cancer care in individuals with intellectual disabilities. Meeting abstracts, early access publications, letters, proceeding papers, book reviews, corrections, and retracted publications were excluded from the analysis. Bibliometric analyses were conducted using R Studio (bibliometrix package) software. **Results:** A total of 432 articles published between 1992 and 2026 were analysed bibliometrically. The highest number of publications on cancer care in individuals with intellectual disabilities was recorded in 2025 (n=38, 8.8%). The journal publishing the greatest number of articles on the subject was Journal of Applied Research in Intellectual Disabilities (n=31, 14.7%). The most productive author was Tuffrey-Wijne. The United states (n=102), the United Kingdom (n=67), and Netherlands (n=40) were the most productive countries. The most frequently used author's keywords were intellectual disability (n=103), palliative care (n=95), and Down syndrome (n=47). The thematic map indicated that the literature mainly focused on communication, children, and palliative care, indicating that supportive care needs and access-related challenges are the most prominent research areas in cancer care for individuals with intellectual disabilities. **Conclusion:** Publications on cancer care for individuals with intellectual disabilities have increased over the years; however, the literature appears to be concentrated on certain topics, particularly communication, children, and palliative care. This suggests that the field has largely developed around supportive care needs and access-related challenges, while further research is needed on diagnosis, treatment experiences, and comprehensive cancer care.

Keywords: bibliometric analysis, cancer care, intellectual disabilities, research trends.

Hansford - Breast cancer screening among adults with and without intellectual and/or developmental disabilities: A population-based cohort study

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Abstract

Background: Adults with intellectual or developmental disabilities (IDD) are more likely to have metastatic breast cancer compared to non-disabled adults. Following Canadian findings that adults with IDD were less likely to be screened for cancer, screening recommendations were added to the 2018 Canadian consensus guidelines for the primary care of this population. To examine guideline effectiveness, we will compare breast cancer screening rates among adults with and without IDD from 2015 to 2024 before and after the guideline introduction. **Methods:** We are conducting a quasi-experimental study design study using Ontario administrative health data. Screen-eligible females with IDD will be identified using algorithms and matched 5:1 on birth year to non-disabled females. Annual receipt of mammography will be captured. Breast cancer screening rates will be compared using Andersen-Gill models. We will examine whether breast cancer screening rates between each group (with and without IDD) changed before and after the 2018 guidelines using a difference in differences analysis. We are recruiting two advisors with lived experience of cancer screening and IDD to help guide our project, including informing our interpretation and knowledge sharing. **Results:** Cohort construction is underway. Analyses will be completed by May 2026. **Conclusion:** These findings could be used to inform primary care guidelines for adults with IDD. Such high-quality data will underscore the importance of advocating for changes in how breast cancer screening is offered to adults with IDD, including a focus on developing inclusive strategies to improve the accessibility of cancer screening for adults with IDD.

Keywords: breast cancer screening; population-based research; intellectual and/or developmental disability

Štefková et al. - Bridging data gaps in inclusive cancer prevention for people with intellectual disabilities: A Slovak policy and systems analysis

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Abstract

Background: People with intellectual disabilities (PwID) experience persistent health inequalities across Europe, including lower participation in cancer prevention and screening. The European COST Action CUPID project CA21123 (Cancer Understanding, Prevention and Improved Detection for People with Intellectual Disabilities), research shows earlier symptom – drive diagnoses and markedly higher premature mortality, while EUCanScreen's Annual National Inquiry (2025) highlights a pan-European lack of disability-disaggregated monitoring. In Slovakia, organized screening Programmemes exist, but PwID needs are not systematically integrated. **Aim:** To identify policy and system-level gaps in inclusive cancer prevention for PwID in Slovakia and propose measure aligned with CUPID benchmarks and European public health priorities. **Methods:** A policy and systems analysis of national strategic documents and screening reports, triangulated with international frameworks (EU, WHO, CRPD) and recent evidence from CUPID and EUCanScreen. Key domains: accessibility, workforce preparedness, supported decision-making, and disability-disaggregated monitoring. **Results:** Four systemic barriers emerged: 1. Data invisibility – no routine monitoring of PwID participation in screening; 2. Low participation – national colorectal screening remains ~30–35%, likely lower for PwID due to communication barriers; 3. Prevention gaps – HPV vaccination coverage remains 30 – 40% despite full reimbursement; 4. Clinical barriers – absence of standardized reasonable accommodations and limited training in inclusive communications; Easy-to-Read materials are not routine. **Conclusion:** To meet EU cancer control goals, Slovakia should embed inclusive standards into national Programmemes: mandatory workforce training, Easy-to-Read materials, supported decision-making pathways, and disability-disaggregated monitoring. Aligning EUCanScreen's implementation focus with CUPID´s evidence on barriers can provide a feasible roadmap to reduce avoidable disparities in cancer outcomes for PwID.

Keywords: intellectual disability, cancer screening, cancer prevention, health equity, Slovakia, CUPID

Chełchowska - Strategies and Challenges in Communication with Individuals with Intellectual Disabilities: A Literature Review

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Abstract

Background: Relationship-based and person-centered communication constitutes a key element of social, educational, and therapeutic functioning among individuals with intellectual disabilities. Due to cognitive and social difficulties, the communication process should be adapted to the abilities and needs of these individuals. It is therefore necessary to apply appropriate strategies and tools that support effective communication, enhance independence, and improve overall quality of life. **Aim:** The aim of this review is to present the key concepts that support communication with individuals with intellectual disabilities. **Methods:** A review of the scientific literature was conducted, including empirical articles, review papers, and guidelines published by organisations supporting individuals with intellectual disabilities. The following databases were used for this purpose: PubMed, Scopus, and Web of Science. **Results:** The analysis of the available literature made it possible to identify key areas influencing effective communication with individuals with intellectual disabilities. Interpersonal strategies, as well as visual and multimodal methods, enhance message comprehension and enable active participation in social interactions. However, effective communication also requires adequate staff preparation and the creation of an empathetic and open communicative environment. **Conclusion:** The review of the available literature indicates that the use of appropriate communication strategies and techniques based on augmentative and alternative communication (AAC) significantly improves the functioning of individuals with intellectual disabilities. At the same time, the need for further development and wider dissemination of supportive methods is emphasized, particularly in the context of participatory research involving the active engagement of individuals with intellectual disabilities.

Keywords: communication; intellectual disability; communication strategies

Güneş - The experience of the primary caregiver of a child with cancer and intellectual disability

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Abstract

Background: Having a child with a dual diagnosis has a significant impact on a family. **Aim**: The purpose of this phenomenological study was to explore the perspective of a caregiver with a child with cancer and intellectual disability. **Methods:** A family systems theoretical framework and phenomenological research method were used. Data was collected using purposive sampling and semi-structured in-depth interviews. **Results:** Children with cancer and intellectual disability are a relatively understudied patient population, and this study offers valuable insight into their families' lives. Dynamics and role changes within the family when a child is diagnosed with cancer and has an intellectual disability bring extra challenges. This could be seen as an additional burden that has an impact on the parents in relation to their exhaustion in dealing with the added complexities of their child's cancer diagnosis. The caregiver indicated that experiencing stigma, anxiety, social isolation, and a decrease in quality of life related to intellectual disability and cancer. **Conclusion:** Primary caregivers in paediatric cancer and disability contexts face complex challenges that appear under-reported. This study emphasises the importance of support for these caregivers and offers insights on how healthcare services can be improved to meet their specific needs.

Keywords: childhood cancer; intellectual disability; primary caregivers; qualitative

Siklaroglu et al.- Mapping Global Research on Cancer Screening in People with Disabilities: A Bibliometric Analysis of Trends and Evidence Gaps (2015–2025)

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Background: Cancer screening is a key public health strategy for early detection and mortality reduction. However, people with disabilities—particularly those with intellectual disabilities—face persistent inequities in access due to physical, communication, and system-level barriers. Despite growing interest, comprehensive analyses mapping global trends and identifying evidence gaps remain limited. **Aim:** To map global research trends, key contributors, and thematic developments in cancer screening among people with disabilities, focusing on gaps relevant to equitable care. **Methods:** Data were retrieved from the Web of Science Core Collection on March 13, 2026. English-language articles and reviews published between 2015 and 2025 were included. A total of 1,418 publications were analysed using Bibliometrix (R) and VOSviewer. Publication and citation trends, along with author, country, and journal productivity, were examined, as well as keyword co-occurrence and thematic structures. **Results:** Publications increased steadily, with a marked rise after 2020. Earlier studies had higher citation impact, while recent studies have fewer citations. The most productive authors were Park JH, Rezaei N, and Kuper H. The United States led in output, followed by China and the United Kingdom. Research focused mainly on screening, disability, and early detection, with a predominance of descriptive studies. Intervention-based research remains limited. Emerging topics include artificial intelligence, health inequities, and access barriers. **Conclusion:** Although research output has increased, the field remains largely descriptive. From a nursing perspective, accessible and person-centered screening services are essential. Greater focus is needed on equity-driven and intervention-based approaches, particularly for individuals with intellectual disabilities.

Keywords: bibliometric analysis; cancer screening; disability; health equity; nursing

Sahin & Akciger - Understanding Health Inequalities: Family Experiences in Access to Cancer Screening Programmemes for Adults with Intellectual Disabilities

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Abstract

Background: Adults with intellectual disabilities face significant health inequalities, particularly in accessing preventive services such as cancer screening. Family caregivers play a critical role in facilitating healthcare access, yet their experiences remain underexplored. **Aim:** This study aimed to explore family caregivers' experiences regarding barriers and facilitators to cancer screening participation among adults with intellectual disabilities. **Methods:** This phenomenological qualitative study included 15 family caregivers recruited using snowball sampling. Data were collected through semi-structured in-depth interviews and analysed using thematic analysis. **Results:** The mean age of caregivers was 49.3±14.8 years, and 73.3% were female. Adults with intellectual disabilities had a mean age of 40.7±11.8 years; 60% were female, with 46.7% mild, 26.7% moderate, and 26.7% severe disability. None of the participants reported prior participation in breast, cervical, or colorectal cancer screening, and all were unaware of national screening services. Despite recognizing the importance of early detection, caregivers identified multiple barriers. Three main themes emerged: (1) lack of knowledge and awareness, (2) structural and system-level barriers, including lack of guidance and inaccessible services, and (3) individual and caregiving-related challenges, such as communication difficulties and caregiving burden. Additionally, 40% of individuals had comorbid chronic conditions, further complicating access. **Conclusion:** Substantial inequalities persist in access to cancer screening among adults with intellectual disabilities. Strengthening primary care engagement, improving caregiver awareness, and developing inclusive, accessible screening Programmemes are essential.

Keywords: intellectual disability; cancer screening; health inequalities; access to care; qualitative research

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Abstract

Background: This study aimed to examine the relationship between health literacy and cancer screening knowledge and attitudes among caregivers of individuals with intellectual disabilities. **Methods:** This descriptive cross-sectional study was conducted with caregivers of individuals with intellectual disabilities receiving services from a rehabilitation and care center in Ankara, Türkiye. Data were collected using a Sociodemographic Information Form, the Health Literacy Scale, the Cancer Screening Knowledge Scale, and the Short Form of the Attitude toward Cancer Screening Scale. Data were analysed using descriptive statistics, group comparison tests, and correlation analysis. **Results:** The mean age of caregivers was 45.25 ± 15.06 years, and 61.1% were female. Only 2.6% of individuals with intellectual disabilities had been taken for cancer screening. The mean Cancer Screening Knowledge Scale score was 15.71 ± 6.16, indicating a moderate level of knowledge. The mean Attitude toward Cancer Screening score was 61.06 ± 11.30, reflecting generally positive attitudes toward screening. The mean Health Literacy Scale score was 32.41 ± 11.79, suggesting a moderate level of health literacy. Significant positive correlations were found between health literacy and cancer screening knowledge ($\rho = 0.376$, $p = 0.001$), health literacy and attitudes toward screening ($\rho = 0.374$, $p = 0.001$), and knowledge and attitudes toward screening ($r = 0.354$, $p = 0.001$). **Conclusions:** Health literacy was positively associated with caregivers' knowledge and attitudes toward cancer screening. Interventions aimed at improving caregivers' health literacy may help enhance cancer screening awareness and promote more positive attitudes toward screening among individuals with intellectual disabilities.

Keywords: intellectual disability; caregivers; health literacy; cancer screening; attitude to health

van den Hout et al. - Project Design: Improved Informed Decision-Making on Cancer Screening for People With Intellectual Disabilities

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Abstract

Introduction: Participation in Dutch population-based cancer screening is significantly lower among people with intellectual disabilities, although trends and subpopulation differences remain unclear. The information currently provided with the invitation letter to participate is not tailored to the needs of people with intellectual disabilities. However, it is unknown which support needs people with intellectual disabilities and their supportive network have, and how to address these to improve informed decision-making about cancer screening. Aim: This PhD project aims to identify: (1) which needs people with intellectual disabilities and their support networks have when making an informed decision about cancer screening; (2) how to support decisions about cancer screening; (3) whether using such support approach improves perceived informed decision-making, and (4) trends in cancer screening participation among people with intellectual disabilities. Each aim is addressed through its own separate study. **Methods:** The research design consists of primarily qualitative methods for the first three studies and a quantitative approach to examine trends in study four. Data collection methods include: (1) a mixed-methods questionnaire; (2) focus groups; (3) semi-structured interviews; and (4) population-based analysis. **Results & Conclusion:** We will present the rationale and design of an PhD project which aims to generate evidence on informational needs, decision-support strategies, and participation trends to develop and pilot a new support approach in cancer screening among people with intellectual disabilities and their support network. Ultimately it will enable accessible screening and support equitable participation.

Keywords: informed decision-making; cancer screening; intellectual disability; study design

Aydin et al.- Are Individuals with Intellectual Disabilities Included in Oncology Research? An Example of a Qualitative Study

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Abstract

Aim/Objectives: Individuals with intellectual disabilities are not included in studies conducted in the field of oncology. However, the literature does not clearly explain why individuals with intellectual disabilities are excluded from these studies. This study aims to investigate the reasons why individuals with intellectual disabilities are excluded from research in the field of oncology. **Methods:** This study is a phenomenological study, a type of qualitative research. The COREQ guide served as the basis for conducting the study. Data will be collected between January and May 2026 using the snowball sampling method from researchers working in the field of oncology, in accordance with the principle of maximum diversity. An introductory information form and a semi-structured interview form are used for data collection. Thematic analysis will be employed for data analysis. The necessary ethical committee approval for the study has been obtained. **Results:** The data collection process is ongoing, and the analysis of the collected data has not yet been completed. Therefore, no findings have been reported at this stage. **Conclusion:** It is anticipated that the findings from the data analysis will contribute to the literature on the representation and level of inclusion of individuals with intellectual disabilities in oncology research.

Keywords: cancer nursing; inclusion; individuals with intellectual disabilities; researchers working in the field of oncology; qualitative research

Sahin & Sahin - Special Education Teachers' Knowledge and Behaviours Regarding Cancer Screenings for Individuals with Intellectual Developmental Disabilities

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Abstract

Background/Introduction: Individuals with intellectual developmental disabilities (IDD) face elevated cancer risks yet encounter significant barriers to cancer screening. Special education teachers interact closely with this population and may play a key role in promoting cancer awareness and preventive behaviours, but their knowledge in this area remains largely unexplored. **Aim/Objectives:** This study aimed to determine the knowledge and behaviours of special education teachers regarding cancer screenings for individuals with IDD, and to raise awareness on the subject. **Methods:** A qualitative, descriptive design was employed using semi-structured individual interviews with a purposive sample of 15 teachers (7 female, 8 male; age range: 29–55 years), comprising 9 special education, 2 physical education, 1 ceramics, 1 religious education, 1 IT, and 1 nutrition teacher, with 8–35 years of professional experience and 1–27 years working with individuals with IDD. Data were analysed using qualitative content analysis. **Results:** Teachers demonstrated limited knowledge about cancer screening, similar to that of the general population. Significant gaps were identified in awareness of risk and protective factors for breast, bowel, cervical, and testicular cancers, as well as IDD-specific symptom presentations. Teachers lacked identity-specific cancer information and reported not implementing risk-reduction measures. The majority had received no training on health promotion or cancer awareness for individuals with IDD, and expressed a strong desire for such training. **Conclusion:** Special education teachers' knowledge and behaviours regarding cancer screening for individuals with IDD are inadequate. Educational interventions targeting this group are essential to improve cancer awareness and support preventive practices for individuals with mild/moderate IDD.

Keywords: intellectual developmental disability; cancer screening; special education teachers; health promotion; cancer awareness

Ozcelik et al.- Programmeme to Promote Cancer Prevention Health Behaviours for Intellectual Disabilities Children's Mothers: Non-Randomized Controlled Trial

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Abstract

Background: Nearly half of all cancers can be prevented if recommended preventive behaviours are followed. This study aimed to evaluate the effectiveness of the Programmeme to Promote Cancer Prevention Health Behaviours (PROCAP) among a disadvantaged population: mothers of children with intellectual disabilities. **Methods:** This single-site, non-randomized controlled experimental study included. The PROCAP group received multiple interventions—education, guidance, counselling, and case management—based on the 12 recommendations of the European Code Against Cancer. The study included 24 mother–child pairs in the PROCAP group and 23 in the control group. Interventions were delivered over eight weeks, consisting of two face-to-face sessions and three telephone interviews. Active control group: The parents in the control group were referred to national cancer screening Programmemes and received leaflets. **Results:** In the PROCAP group, one mother applied to a smoking cessation clinic, two underwent cervical cancer screening, four breast cancer screening, and one colorectal cancer screening. Additionally, three mothers reported that their child had stopped smoking. Improvements were observed in mothers' physical activity, dietary habits, and sun protection behaviours. In the control group, three mothers stopped smoking and discontinued hormonal treatment, and three underwent breast cancer screening. Three mothers in the PROCAP group reported quitting smoking, while one mother in the control group reported having her child vaccinated for HPV. However, these behavioural changes did not result in statistically significant differences between the groups. **Conclusions:** These findings highlight the need for diverse and sustained interventions to promote cancer prevention behaviours in this vulnerable population.

Keywords: intellectual disabilities; cancer screening; cancer prevention; vulnerable population; disadvantage; mother; parent

Carneiro et al.- Managing Depression in Cancer Patients: Opportunities for Artificial Intelligence–Based Interventions

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Abstract

Artificial intelligence is transforming mental health and cancer care, opening new horizons for integrated treatment approaches. This paper examines how AI technologies can enhance the detection, diagnosis, and management of depression in cancer patients while addressing critical ethical considerations and implementation challenges. We highlight key recommendations for responsible AI integration in clinical practice. **Background/Introduction:** Depression is highly prevalent among cancer patients and significantly affects morbidity, mortality, and quality of life. Artificial intelligence (AI) is rapidly transforming oncology and mental health care by improving early detection, risk prediction, and personalised treatment strategies. **Aim/Objectives:** This editorial discusses the emerging role of AI in the integrated management of cancer and depression, highlighting clinical opportunities, ethical considerations, and implementation challenges. **Methods:** This editorial synthesises current evidence and recent developments in AI applications in psycho-oncology, including machine learning for early diagnosis, predictive modelling for mental health service utilisation, and AI-driven decision support systems, alongside discussion of regulatory and ethical frameworks. **Results:** AI demonstrates strong potential in identifying high-risk patients, predicting psychiatric referrals with over 70% accuracy, and supporting personalised treatment planning. Advanced systems integrate imaging, genomic, clinical, and patient-reported data to optimise oncological and psychological care. However, concerns regarding privacy, informed consent, bias, transparency, and accountability remain significant barriers to responsible implementation. **Conclusion:** AI offers substantial opportunities to enhance integrated cancer and depression care. Its successful adoption requires interdisciplinary collaboration, ethical governance, regulatory oversight, and a balanced approach that complements human expertise while safeguarding patient rights.

Keywords: artificial intelligence; cancer; depression; machine learning

Aydin Acar - Pan-Cancer In Silico Analysis of PTEN: Insights from an Intellectual Disability-Associated Tumor Suppressor Gene

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Abstract

Background: A significant proportion of intellectual disabilities are associated with genetic syndromes. The PTEN gene plays a key role in PTEN Hamartoma Tumor Syndrome (PHTS), a genetic disorder characterized by developmental abnormalities, macrocephaly, and, in some individuals, intellectual disability. PTEN is also a crucial tumor suppressor regulating cellular proliferation, growth, and apoptosis. Mutations or dysregulation of PTEN have been implicated in a variety of cancers. Aim: This study aims to investigate the expression patterns and potential cancer-related roles of PTEN, a gene associated with intellectual disability, across multiple cancer types using bioinformatic approaches. Methods: Pan-cancer analyses of PTEN expression were conducted using publicly available cancer genomics datasets. Gene expression profiles were analysed through GEPIA and UALCAN platforms. The relationship between PTEN expression and the tumor microenvironment was evaluated using TIMER2, examining correlations with immune cell infiltration. Additionally, STRINGdb was employed to identify PTEN-associated protein–protein interaction networks and related biological pathways. Results: Analyses reveal that PTEN exhibits altered expression across multiple cancer types. Dysregulation of PTEN may affect cell proliferation, growth, and signaling pathways and is likely associated with tumorigenesis. Moreover, PTEN expression correlates with immune cell infiltration and participates in diverse cellular pathways relevant to cancer biology. Conclusion: PTEN, a gene linked to neurodevelopmental disorders and intellectual disability, plays a critical role as a tumor suppressor in cancer. Pan-cancer in silico analyses provide insights into the molecular mechanisms connecting intellectual disability-associated genes with cancer, highlighting the broader biological significance of PTEN in tumorigenesis.

Keywords: intellectual disability; PTEN; cancer genetics; pan-cancer analysis; gene expression; bioinformatics

Aydin & Karakisla - Understanding Cancer Prevention and Screening in People with Intellectual Disabilities: A Bibliometric Analysis

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Abstract

Background: Individuals with intellectual disabilities benefit less from cancer screening and prevention Programmemes compared to the general population due to the structural and cognitive barriers they face. This leads to later diagnosis of cancer and the emergence of health disparities. **Aim:** The aim of this study is to present a map of cancer prevention and screening behaviours among individuals with intellectual disabilities by examining them using bibliometric analysis. **Methods:** This study is a bibliometric review. The Web of Science database was used to search for the keywords “cancer screening*” OR “cancer prevention*” and “intellectual disability*” OR “learning disability*” OR “developmental disability*” in the topic search field. As a result of the search, 87 articles published between 1999 and 2026 were analysed using the R Studio Programmeme. **Results:** Bibliometric analysis revealed that between 1999 and 2026, 87 articles were published in 51 sources with 368 different authors. The annual growth rate of publications was 6.14%, while the average citations per doctor was 23.86. The journal with the most publications was Journal of Intellectual Disability Research (n=7), the most prolific author was Park JH (n=8), and the most prolific country was the USA. The most frequently used keywords in the studies examined were intellectual disability (31), breast cancer (13), cancer screening (13), and mammography (12). According to trend topic analysis, mortality, breast, and cancer keywords have come to the forefront in recent years. **Conclusions:** The number of studies aimed at understanding cancer prevention and screening behaviours among individuals with intellectual disabilities has increased in recent years.

Keywords: Intellectual disability; cancer screening; cancer prevention; bibliometric analysis

Kart - An Overlooked Inequality: Co-Producing Accessible Cancer Prevention Education for Individuals with Intellectual Disabilities

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Abstract

Individuals with intellectual disabilities remain an overlooked population in cancer prevention efforts, despite well-documented health inequalities, including delayed diagnosis, lower participation in screening Programmemes, and reduced access to understandable health information. This disparity is compounded by the fact that most cancer prevention strategies are designed for the general population and rarely adapted to meet the cognitive and communication needs of individuals with intellectual disabilities. This review aims to critically examine existing literature on cancer prevention in individuals with intellectual disabilities, with a particular focus on accessibility and the role of co-production in health education. Current evidence indicates that while some initiatives have attempted to simplify health information, these efforts are often limited in scope and rarely involve individuals with intellectual disabilities in the development process. The lack of co-produced interventions represents a significant gap, as it overlooks the value of lived experiences in shaping effective and inclusive health strategies. Moreover, studies consistently highlight barriers such as low health literacy, inadequate communication strategies, and limited involvement of caregivers and healthcare professionals in tailored education Programmemes. Emerging evidence suggests that co-production approaches—bringing together individuals with intellectual disabilities, caregivers, and healthcare providers—have the potential to improve the relevance, accessibility, and impact of cancer prevention interventions. In this study integrating co-production into cancer prevention is essential to addressing persistent health inequalities. It proposes a community-based, nurse-led framework for developing accessible educational interventions. By emphasizing inclusivity and participation, this approach offers a pathway for more equitable and effective cancer prevention strategies and contributes to ongoing discussions in inclusive public health.

Keywords: intellectual disability; cancer prevention; health inequalities

Asi et al. - Smoking Parents' Beliefs and Attitudes Toward Secondhand Smoke Exposure in Children with Intellectual Disabilities: A Qualitative Study Based on the Health Belief Model

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Abstract

Aim: This study aimed to explore the beliefs and attitudes? children with intellectual disabilities of smoking parents regarding passive smoke exposure, based on the Health Belief Model (HBM). **Method:** A qualitative study design was adopted in Türkiye, involving semi-structured, in-depth interviews with 15 parents of children with intellectual disabilities who smoke. Interviews were designed according to HBM domains to determine beliefs and attitudes toward secondhand smoke exposure. All interviews were recorded and transcribed. Data were analysed using a content approach by mapping the identified topics to the components of the HBM. **Results:** Smoking Parents' Beliefs and Attitudes Regarding Passive Tobacco Smoke Exposure in Children with Intellectual Disabilities were categorized within the HBM. Smoking parents believe that their children with intellectual disabilities are susceptible to secondhand smoke and at significant health risk (perceived susceptibility). While stating that reducing exposure would provide significant benefits for children's health (perceived benefits), they cited factors such as smoking addiction, stress, caregiver burden, and social environment as key barriers (perceived barriers). Participants indicated that passive tobacco smoke could lead to serious respiratory and health problems in their children (perceived severity). The possibility of children becoming ill, especially experiencing breathing problems, has influenced parents to reconsider their smoking behaviour (health motivation). Furthermore, parents indicated that concerns about their children's health triggered behavioural change, but most believed they could reduce exposure rather than completely prevent it (self-efficacy). **Conclusion:** Parents are aware that secondhand smoke can harm their children, but they are frequently unable to fully shield them from exposure due to addiction and societal circumstances. Programmemes for parenting education and counseling should be created, with an emphasis on lowering exposure to smoking both indoors and outdoors, as well as providing cessation assistance.

Keywords: secondhand smoking; children; intellectual disability; health belief model; qualitative study

Aydin et al.- Experiences of Family Caregivers of Individuals with Intellectual Disabilities Regarding Participation in Cancer Screenings: A Qualitative Study in a Turkish Sample

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Abstract

Aim/Objectives: Participation in cancer screening among individuals with intellectual disabilities may be limited due to various barriers encountered in accessing healthcare services. In this process, family caregivers play a critical role in ensuring access to healthcare, maintaining screening processes, and providing emotional support. This study aims to examine the experiences of family caregivers regarding the participation of individuals with intellectual disabilities in cancer screening in Türkiye. **Methods:** This study is a phenomenological study, a type of qualitative research. The COREQ guide served as the basis for conducting the study. Data will be collected from family caregivers of individuals with intellectual disabilities using the snowball sampling method between April and May 2026. An introductory information form and a semi-structured interview form will be used to collect data. Thematic analysis will be employed for data analysis. The data collection process will continue until data saturation is achieved. **Results:** The data collection process is ongoing, and the data obtained has not yet been analysed. Therefore, no findings are presented at this stage. **Conclusion:** The findings to be obtained from this study are expected to reveal caregivers' experiences in the process of participation of individuals with intellectual disabilities in cancer screenings and to guide the development of interventions in this field.

Keywords: cancer screening; cancer prevention; caregivers; person with intellectual disability; qualitative research

Topkaya & Avci -Pink Shield : Accessible Web-Based Platform Supporting Early Detection of Breast Cancer in Individuals with Intellectual Disabilities

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Abstract

Introduction: Breast cancer is one of the most common cancers among women, and an early diagnosis can significantly improve outcomes. However, participation in screening Programmes for cancer is lower among individuals with intellectual disabilities than in the general population. Participation rates in cervical, breast and colorectal screenings are reported to be 20–25% lower (1). Despite facing similar risks, women with intellectual disabilities often receive a diagnosis at a more advanced stage due to low awareness and limited health literacy (2, 3). **Objective:** This study aims to develop a user-centred, accessible web-based platform to reduce health disparities and raise early breast cancer detection awareness among adults with mild-to-moderate intellectual disabilities. **Methods:** A literature-based design approach was adopted, drawing on research into cancer awareness, accessible health communication and digital health. Content was grounded in WHO, CDC, and NHS guidelines. An HTML5 platform compliant with WCAG 2.2 AA standards was developed, incorporating Easy-Read language, visual storytelling, audio narration, and caregiver integration. **Results:** The developed platform includes animations explaining the symptoms of breast cancer, visuals illustrating the screening process step by step, and educational modules to guide users. Caregiver support and an accessible interface design enhance the user experience. **Conclusion:** Accessible web-based solutions can increase early diagnosis awareness among underserved populations. This study presents a preliminary design; development and user testing are ongoing.

Keywords: breast cancer; intellectual disability; early detection; web-based healthcare

Simin et al.- Mapping Nursing Contributions to Cancer Prevention and Screening for Individuals with Intellectual Disabilities: A Preliminary Bibliometric Analysis

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Abstract

Background: Individuals with intellectual disabilities (PwID) face significant inequalities in access to cancer prevention and screening. Although nursing plays a pivotal role in reducing these inequalities, its contribution remains underexplored. This study addresses a critical gap, as nursing is central in practice but largely invisible in research. **Aim:** To explore current research trends and examine the positioning of nursing in cancer prevention and screening for PwID through a preliminary bibliometric approach. **Methods:** A literature search was conducted using the Scopus database to identify publications on intellectual disabilities, cancer prevention or screening, and nursing-related concepts. No time restrictions were applied to ensure comprehensive coverage, and only English-language peer-reviewed articles were included. Preliminary bibliometric mapping was performed using Bibliometrix and VOSviewer to explore publication patterns, collaboration networks, and thematic structures. **Results:** Preliminary analysis indicates an expanding body of literature, mainly from high-income countries. The research landscape is predominantly shaped by public health perspectives, emphasising barriers to screening and access to care. Nursing contributions, including competencies, communication strategies, and care-based interventions, are limited and underdeveloped. Network analyses reveal moderate collaboration, with evident fragmentation across research groups. These patterns highlight a critical gap between the recognised importance of nursing in preventive care and its limited visibility within the current research landscape. **Conclusion:** While research in this field is increasing, the role of nursing remains insufficiently articulated. Further research is needed to strengthen nursing contributions and promote equitable access to cancer prevention and screening. This study provides a foundation for advancing nursing-led approaches to reduce health inequalities in PwID.

Keywords: intellectual disability; mass screening; oncology nursing; health services accessibility; bibliometrics

Bayafers - Enhancing Sexual Health and Reproductive Justice for Adolescents and Youth with Disabilities: Insights from the SRH+ Project in Ethiopia

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Abstract

Background: This study examines the impact of the SRH+ project implemented by the Ethiopian Center for Disability and Development (ECDD) in collaboration with UNFPA. The project focuses on improving sexual and reproductive health (SRH) services for adolescents and youth with disabilities (AYWDs) in Ethiopia, addressing the barriers they face in accessing quality health services. Objectives: The primary objective of this research is to evaluate the effectiveness of various interventions aimed at enhancing the knowledge, skills, and access to SRH services among AYWDs. The study seeks to identify the outcomes associated with educational, advocacy, and health service modifications facilitated through the project. **Methods:** A mixed-methods approach was employed, utilizing quantitative data from call logs of the MINCH platform, surveys from peer-to-peer educational sessions, and qualitative data from training workshops and advocacy meetings. Key activities included the establishment of an interactive voice response platform, accessibility modifications in health centers, training for health professionals in disability inclusive care, and peer education workshops. **Results:** From January to June 2025, the SRH+ project generated over 23,000 calls to the MINCH platform, indicating a substantial increase in awareness among AYWDs. Accessibility modifications were completed in three health facilities, and 151 health service providers received training on disability-inclusive practices. Advocacy workshops engaged 34 government stakeholders, emphasizing the need for inclusive health policies. Budget utilization was high, achieving 99.23% of the planned expenditures. **Challenges:** The research identifies challenges such as political instability and administrative delays in payment processes. Strategies to overcome these challenges included reallocating resources and enhancing collaboration among team members. **Conclusions:** The findings suggest that the SRH+ project significantly contributes to advancing sexual health and reproductive justice for AYWDs in Ethiopia. Ongoing advocacy and stakeholder engagement are essential for sustaining improvements in health service inclusivity and ensuring equitable access.

Keywords: sexual health; reproductive justice; disabilities; adolescents; health ınterventions; advocacy; inclusive health services; Ethiopia

İyi Altınışık & İşler - Global Trends and Research Hotspots in Cancer Prevention among Children with Intellectual Disabilities: A 40-Year Bibliometric Analysis

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Abstract

Background/Introduction: Although cancer prevention has received increasing global attention, research trends focusing on children with intellectual disabilities have not been comprehensively examined. **Aim/Objectives:** This study aims to systematically map and analyze the global evolution of research on cancer prevention among children with intellectual disabilities over the past 40 years using a bibliometric approach. **Methods:** A bibliometric analysis covering 1985–2025 was conducted in February 2026 using the Web of Science Core Collection database. A comprehensive Boolean search strategy was applied to titles, abstracts, and keywords, including terms related to intellectual disabilities, cancer, prevention, and children. Document types (articles and reviews), SCI- Expanded and SSCI indexing, and English language filters were applied, resulting in a total of 121 studies included in the final analysis. Data analysis and visualization were performed using the Bibliometrix package in R and VOSviewer software. **Results:** Trend analysis using linear regression revealed a steady and moderately strong increase in annual publications over time (R^2=0.696). The United States (n=39), the French National Institute of Health and Medical Research (n=10), Thierry Frébourg (n=2), Jin-Ding Lin (n=2), and the American Journal of Medical Genetics Part A (n=6) were identified as the most productive country, institution, authors, and journal, respectively. The most frequent keywords were “children,” “cancer,” and “intellectual disability.” **Conclusion:** The findings indicate that research in this field is increasing; however, underexplored areas, particularly genetic factors, represent promising directions for future research.

Keywords: intellectual disabilities; cancer; prevention; children; bibliometric analysis

Ibrahim - Advancing Inclusive Cancer Prevention for People with Intellectual Disabilities: Insights from CUPID Working Group 2

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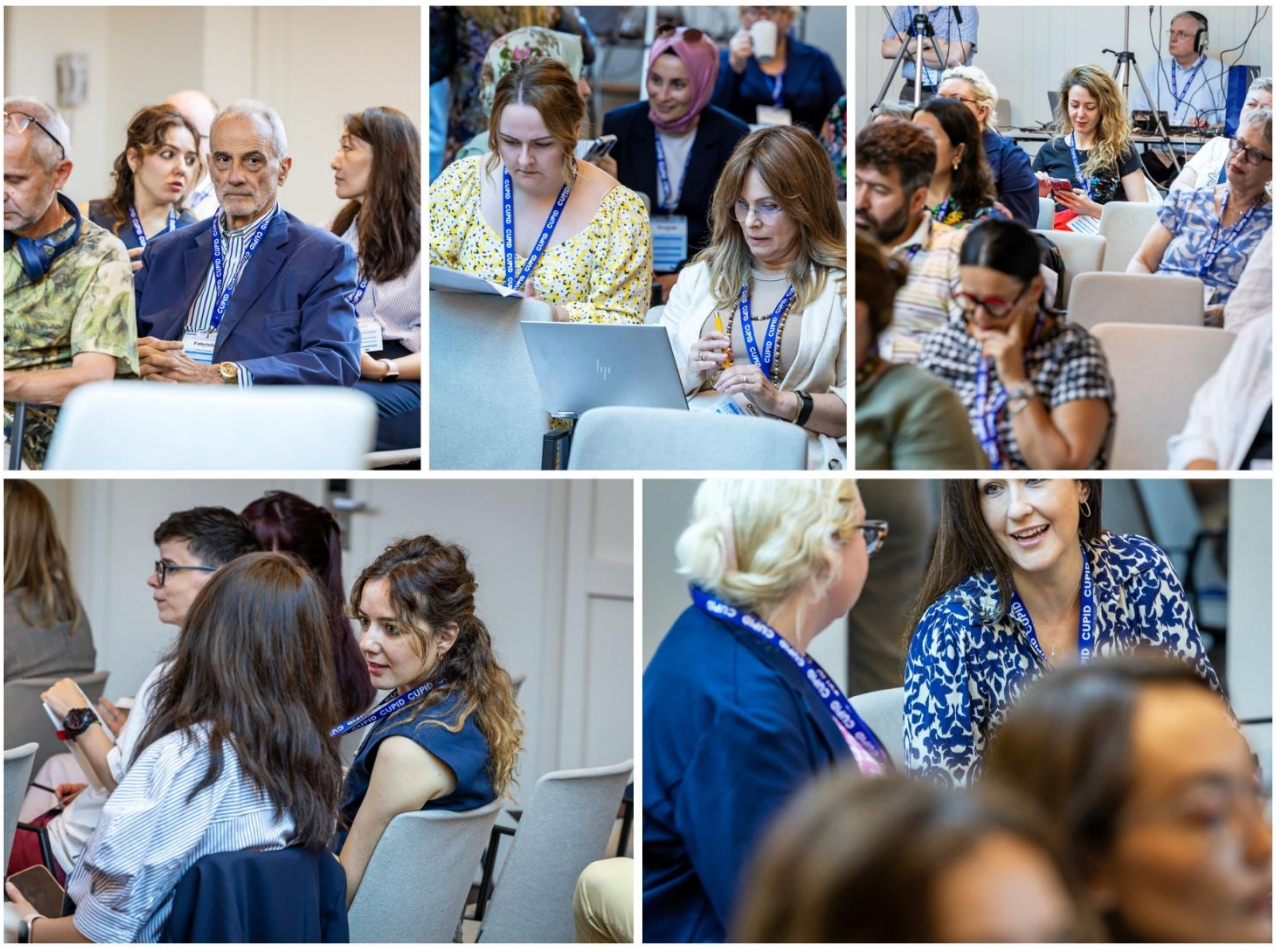
Abstract

Background: People with intellectual disabilities (ID) experience persistent inequities across the cancer prevention continuum, including limited inclusion in national policies and inadequate access to health communication. The CUPID COST Action addresses these gaps by advancing collaborative research and inclusive practices, with Working Group 2 focusing on developing a knowledge base to define minimum policy standards for inclusive cancer prevention for people with intellectual disabilities across Europe, alongside capacity-building and dissemination to support implementation and knowledge exchange. **Aim:** To present contributions of Working Group 2 within CUPID to accessible communication, capacity building, and policy development. **Methods**: A qualitative, practice-based approach was used, drawing on engagement in multiple CUPID ctivities. This included contribution to a cross-national policy paper (Martin McMahon et al., 2026), participation in a Training School at Trinity College Dublin and completion of a Short-Term Scientific Mission (STSM) to the Collegium Medicum at the University of Nicolaus Copernicus in Torun. **Results:** Working Group 2 activities demonstrated practical approaches to improving accessibility, including simplified communication, and calls for inclusive policy actions. These collaborative initiatives strengthened research capacity, facilitated international knowledge exchange, and identified limited inclusion of people with ID in cancer prevention strategies across countries. **Conclusion:** CUPID, through Working Group 2, effectively links policy evidence with accessible communication practices. WG2 integrated approach supports inclusive cancer prevention systems and contributes to global efforts to reduce health inequities for people with ID. These experiences also provided insights into transferability beyond European contexts.

Keywords: intellectual disabilities; cancer prevention; health inequities; accessible communication; policy development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These Proceedings contain the peer-reviewed papers and summaries of the keynote speakers' and working group leads' presentations from the Final Conference of the CUPID COST Action:

Cancer – Understanding Prevention in Intellectual Disability: Partnering to Support Co-produced Change

held in Brussels, Belgium, from 23 to 24 June 2026.

The Conference brought together project partners, researchers, practitioners, policymakers, and key stakeholders to present the key outcomes of the CUPID COST Action, share best practices, and explore future directions for research, policy, and practice.

The Conference provided a valuable platform for collaboration, knowledge exchange, and continued progress in addressing inequalities in cancer prevention for people with intellectual disabilities.

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COST (European Cooperation in Science and Technology) is a funding agency for research and innovation networks. Our Actions help connect research initiatives across Europe and enable scientists to grow their ideas by sharing them with their peers. This boosts their research, career and innovation.

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