

# Research priorities to improve cancer care for people with intellectual disabilities across the cancer continuum

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Significant deficits in cancer care persist for people with intellectual disabilities (ID).<sup>1</sup> National cancer control policies, screening recommendations and oncological guidelines rarely address the differential care needs of people with ID. We currently lack an understanding of how to tailor oncology care to meet the unique needs of this population. We identify research priorities to address this injustice.

The demographic profile of people with ID differs significantly from the general population, with an overrepresentation of males and fewer people reaching an older age when cancer is more common. Divergent patterns also appear in risk factors such as smoking, obesity, physical activity, diet, alcohol consumption, sun exposure, human papillomavirus vaccine uptake and overall frailty.<sup>2</sup> Population and cancer registries rarely record ID.<sup>3</sup> Therefore, a first priority is to enhance the recording of ID. This would facilitate research with larger cohorts and linkage to other databases. Machine learning and predictive modelling can help analyse causal pathways exclusive to ID subgroups and be used to develop targeted interventions (eg, alerts) more effectively.

A better understanding of cancer epidemiology among people with ID will also inform tailored strategies for cancer prevention and screening. This concerns who to target, as the relevant ages and types of cancer to screen for may be different, and screening methods (eg, mammograms where people are unable to stand or stay still) may require consideration of alternative methods (eg, ultrasound) rather than no screening. Research on shared decision-making throughout the screening pathway is a priority, supported by easy-to-understand educational materials and tools that are able to balance the evidence-based risks and benefits of screening for people with ID. Implementation research focused

on removing existing barriers to screening is essential and needs to be prioritised.<sup>4</sup>

Cancer diagnoses in people with ID are made at later stages than in the general population.<sup>5</sup> Research priorities include understanding the natural history of cancer in people with ID and identifying potential factors associated with delayed diagnoses.<sup>6</sup> What symptoms are most likely to be misinterpreted or overlooked, and in what circumstances? Preferably, this requires longitudinal studies with linkage to medical records. This may help raise awareness of cancer risks and improve the training of healthcare providers and caregivers in recognising cancer symptoms in individuals with ID.

Treating cancer in patients with ID often necessitates deviations from standard protocols, as factors like tolerated doses and safety procedures can vary based on the level of disability and underlying aetiology.<sup>7</sup> Existing oncological guidelines lack specific detail, leaving treatment adaptations to the interpretation of the oncology team, with expertise from ID specialists rarely incorporated. Existing literature guidance primarily comprises case reports on specific combinations of cancer types and ID syndromes, but there is a need for systematic collection, review and analysis to consolidate existing evidence and inform treatment guidelines and reasonable adjustments. Research is also required to tailor approaches to involve people with ID meaningfully in treatment decision-making processes and take legal frameworks related to consent and decision-making capacity into account.

Significant progress has been made in understanding and addressing the unique needs of individuals with ID in palliative care settings,<sup>8</sup> although this knowledge has yet to be fully integrated into oncology care. Moreover, research on cancer survivorship among individuals with ID remains scarce.<sup>9</sup>



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Understanding the long-term effects of cancer treatment, psychosocial support needs and health outcomes post-treatment is an urgent research priority for developing comprehensive survivorship care programmes tailored to the needs of this population.

Bridging research gaps necessitates a multidisciplinary and international approach, fostering collaborations to obtain larger datasets and align methodologies across studies. Buy-in from funders is crucial, with international initiatives such as the UN Convention on the Rights of Persons with Disabilities and the EU Beat Cancer Plan providing frameworks for future research design. However, while these initiatives offer broad opportunities, they do not fully address the unique challenges in oncology care for individuals with ID. There is a need for greater advocacy to ensure that the divergent oncological care needs of this population are adequately addressed within funding programmes. Additionally, community engagement and the inclusion of people with ID in research design and implementation are paramount.<sup>10</sup> Their perspectives and experiences are invaluable in shaping research priorities and ensuring that interventions are relevant and effective for this population.

We are failing to address the disparities in cancer care for people with ID. As an oncological community, there is a need for collective action from researchers, clinicians, policymakers and advocacy groups to advance research and improve cancer outcomes for this vulnerable population.

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