

Cancer screening for people living with disability



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An invitation to consider:

- what attitudes and beliefs prevent people with disability from taking part in cancer screening?
- how can we improve the experience of cancer screening for people with disability?
- how can Yooralla support customers who live alone or with family to access cancer screening?
- how can Yooralla help customers to access health care when they have symptoms to watch out for?
- how can Yooralla facilitate informed decision-making about cancer screening and early detection using the customer's preferred communication methods?

Cancer rates and death among people with disability

Internationally, there is variation in the rates and risks of various types of cancer. Also, the profile, experience and life expectancy of people living with disability can be quite different across countries. Even within countries,

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such diversity can lead to differing interactions between certain types of disability and specific cancers. Reported cancer rates among people with intellectual disabilities are lower than¹⁻³, similar to⁴⁻⁶ or higher than⁷ those of the general population depending on which countries the studies examined. A recent study from the United States found that women who had difficulties with movement or complex activity have significantly higher rates of breast cancer and cervical cancer⁸. Death rates⁹⁻¹¹ and the likelihood of poorer outcomes¹² are higher among people with intellectual disabilities because their cancers may be diagnosed at a more advanced stage¹³. The key point is that cancer is a leading cause of death among people with disability in Australia, and population health measures to reduce the impact of cancer are just as relevant as they are for the general population.^{1, 5, 6, 12}



People with disability are more likely to be diagnosed with cancer at a more advanced stage leading to a higher risk of death.



Unequal access to Australia's national cancer screening programs

One reason for higher rates of cancer death experienced by people with disability is delayed diagnosis. A delay in diagnosis can be caused when cancer symptoms are incorrectly attributed to the person's disability.¹⁴ Cancer screening can detect cancers at an early, treatable stage, reducing the likelihood of poor outcomes, including early death.



BreastScreen Australia is a joint initiative of the Australian and state and territory governments and aims to reduce illness and death from breast cancer by detecting the disease early. Women over 40 can have a free mammogram every 2 years, and women aged 50 to 74 are actively invited to be screened. Breast cancer mortality has decreased since BreastScreen Australia began, dropping from 74 deaths per 100,000 women aged 50–74 in 1991 to 41 deaths per 100,000 women in 2019.¹⁵

In Australia, women with physical disabilities^{16–18} and intellectual disabilities^{19, 20} do not access mammography screening at the same rate as other women.



The National Cervical Screening Program (NCSP) reduces illness and death from cervical cancer. The introduction of the NCSP in 1991 led to falls in both cervical cancer rates and deaths due to the program's ability to detect pre-cancerous abnormalities that may progress to cancer if left untreated.²¹ Women and people with a cervix aged 25 to 74 are invited to have a cervical screening test every 5 years.

Cervical screening is underused by Australian women with intellectual disabilities.²⁰ From 1 July 2022, all women and people with a cervix will have the choice to self-collect their vaginal sample for Human papillomavirus (HPV) –

the cervical cancer screening test – using a swab. This is a much less invasive option than the speculum examination and will improve access to cervical screening for many people with disabilities.

The National Bowel Cancer Screening Program (NBCSP) aims to reduce deaths from bowel cancer by detecting the early signs of the disease. Since the NBCSP was introduced in 2006, the rate of colorectal cancer has declined by 22 per cent, and the death rate from colorectal cancer has decreased by 29 per cent²¹. Every 2 years, eligible Australians from 50 to 74 years of age are sent a free immunochemical faecal occult blood test (iFOBT) to be done at home. This test is used to check for blood in a person's poo, which can be an early sign of bowel cancer.



Among Australians with a range of disabilities, the uptake of bowel cancer screening was 91 per cent of the broader community's rate.²²

Population screening for other cancers is not recommended. Specifically:

- Cancer Council Australia does not recommend mass or population-based screening for melanoma or non-melanoma skin cancer.²³
- Men thinking of getting tested for prostate cancer should talk to their doctor about the benefits and harms of prostate-specific antigen (PSA) testing.²⁴ Current evidence shows that the PSA test should not be used for population screening,²⁵ as the risks outweigh the benefits. Only a prostate biopsy can definitively diagnose prostate cancer.

Under-screening of people with disability is an international issue

The underuse of screening programs for breast, cervical and bowel cancer among people with physical and or intellectual disabilities appears to be a common finding everywhere it has been studied.^{26–36} Generally, the more severe the disability, the lower the screening rate compared to the broader population.^{8, 37–43}

Overseas research has shown that GPs mostly accept their role as primary health care providers for people with

intellectual disability. However, more than one in four GPs were less willing to accept their responsibility for health promotion and health screening initiatives for people with intellectual disability because of feelings of discomfort, lack of assistance and workload pressures.^{44–46}

Where people live is a factor

Women who live in supervised group homes are more likely to be up-to-date with their cancer screening.^{31, 36} On the other hand, women with disability who live alone or with family have lower screening rates and are more likely to be diagnosed with late breast cancer.¹¹

Yooralla operates a cancer screening register for every customer in its residential services. Each customer has an individualised screening program recorded centrally, including the dates of screens completed and due, and evidence-based information resources that provide guidance about the required tests and intervals based on the customer's age, gender and history.



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Health assessment for people with a disability

The Comprehensive Health Assessment Program (CHAP) is a health assessment proven to increase health actions, compared with usual care, for people with intellectual disability.^{47, 48} Health assessments for people with an intellectual disability are available through GPs, including longer consultations for people with complex needs. A health assessment can be done once every 12 months for eligible patients with an intellectual disability.

The National Roadmap for Improving the Health of People with Intellectual Disability⁴⁹ recommends more use of annual health assessments and other existing MBS items to improve health outcomes for people with intellectual disability. Evidence-based tools that support regular health assessments, such as the CHAP, should be readily available and accessible to GPs, practice nurses, disability service providers and support workers, families and carers. The Roadmap identifies cancer screening among the desired outcomes from the more widespread use of comprehensive health plans for people with intellectual disability.

The Australian Commission on Safety and Quality in Health Care and the National Disability Insurance Scheme Quality and Safeguards Commission recently published a Practice Alert⁵⁰ for people with disability – not only those with an intellectual disability – to take part in an annual health assessment where the “GP will also recommend and refer the participant for relevant preventative health care such as regular screening for serious conditions. For example: skin cancer checks; breast and/or bowel cancer screening.”

General practice plays a vital role in helping people with disability access cancer screening.⁵¹ According to Cancer Council Victoria,⁵² all three cancer screening programs should:

- consider other screening options such as the self-collected Cervical Screening Test
- include cancer screening in the patient's health care plan
- encourage talking directly to the patient (where possible) rather than to their carer or support person
- provide resources in plain language and other accessible formats, such as large print or text-to-talk platforms.



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Focus on early detection

Cancer screening programs are designed to detect cancers at an early, treatable stage. However, the three cancer types for which Australia has national screening programs – bowel, breast and cervical cancers – only account for roughly one in ten cancers diagnosed among men and one-quarter of cancers among women. So the early detection of cancer requires attention beyond cancer screening. There is evidence that people with disability may be at increased risk of several cancers that occur at a relatively early age.⁷ Unfortunately, people with disability are more likely to be diagnosed with cancer at a more advanced stage leading to a higher risk of death. Clinicians must consciously avoid attributing signs and symptoms that may indicate cancer to the patient's disability. Such misdiagnosis can delay correct treatment. Support staff who have long-term relationships with clients have a role in overcoming barriers to proper care where communication and behavioural issues interfere.

Responding to people's beliefs, attitudes and information needs

The experience for people with disability must meet their expectations to be informed, involved, and treated with respect. Providers must be alert to the preferences and choices of people with disability. Support staff need to be confident and competent in cancer screening to ensure it is safe, pain-free and non-discriminatory. Critically, the experience must be one where the person feels it is personally relevant and worth repeating.^{16–18, 53–55}

Collaboration between GPs, patients with intellectual disability and the patients' trusted caregivers and support people is essential in a rights-based approach to communication and supported decision making. Patients must have the opportunity to indicate their wants, needs and feelings, including through visual and behavioural cues or access to augmentative and alternative communication strategies.^{56–59} Support staff who have long-term relationships with clients have a role in overcoming communication and behavioural barriers to proper care. Disability support services can promote

discussion at adult day programs about cancer screening and promote positive attitudes.⁶⁰ Disability support workers can assist with system navigation⁶¹ and help make appointments (including for longer consultations to allow full involvement of the patient, family carer(s) and support worker).

Implications for practice

- **People with disability share the community's risk of cancer.**
- **People with disability face a higher risk of late diagnosis of cancer.**
- **Taking part in national cancer screening programs is vital for people with disability to reduce their risk of dying from cancer.**
- **There are a number of actions that support staff and health care professionals can take to support timely and person-centred access to cancer screening for people with disability.**

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