



Cancer screening for people with disabilities

A guide for general practice

Cancer screening for people with disabilities

A guide for general practice

International and Australian data indicates that people with disabilities are under-screened for cancer¹.

General practice plays an important role in enabling people with disabilities and their carers to participate in cancer screening. This resource card offers recommendations for addressing barriers to cancer screening and considerations when determining suitability for cancer screening pathways.

Cancer risk factors

- Age
- Family history
- Lifestyle behaviours and modifiable risk factors
- Previous cancers
- Under screened or never screened
- Other illnesses
(e.g. Crohn's disease, ulcerative colitis)

After you have assessed the patient's cancer risk, consider whether the benefit of screening outweighs the potentially negative experience for the individual and if further procedures on the clinical pathway would be possible.

“...by asking me questions, telling me what was going on, asking if I was ok and if I understood - it made me feel like I knew what was happening. I found the examination so much more comfortable, and I felt much more in control.”

FRANCESCA ON HER LIVED EXPERIENCE OF CERVICAL SCREENING WITH A DISABILITY.

Talking point:
Are you aware of some of the risks for developing certain cancers?

Part One - Overcoming barriers and enhancing access

Barriers	Enhancing access
Identifying the need for care tailored to a disability	<ul style="list-style-type: none"> • Include a tick box on new patient forms to identify a pre-existing disability. • Posters for waiting rooms encouraging people to disclose their disability. • Include disability status on referral forms.
Accessibility of GP clinics	<ul style="list-style-type: none"> • Make changes that improve physical accessibility, including wheelchair accessibility in screening rooms. • Consider other screening options e.g. self-collected Cervical Screening Test or colonoscopy. • Consider the room set-up for a patient with a disability e.g. bed with a hoist. • Ensure staffing resources are sufficient e.g. a female chaperone can be present if needed.
Competing health needs and time pressure	<ul style="list-style-type: none"> • Provide longer appointments or consider dividing the appointment into two parts - one to discuss other health-related issues/fears related to screening, and the other for screening clinical pathways. • Include cancer screening in the patient's health care plan.
Communication barriers	<ul style="list-style-type: none"> • Provide resources in plain language and other accessible formats, such as large print or text-to-talk platforms. • Involve the patient in the decision to screen—is this the right decision? Are there other options? • Ensure translators and/or professional support workers are present. • Talk directly to the patient (where possible), rather than to their carer or support person. • Encourage people with hearing or speech impairments to make appointments using the National Relay Service (see links and resources).

Talking point:
Have you ever been
screened for bowel,
breast or cervical
cancer?

Barriers to cancer screening (cont)

Barriers	Enhancing access
Fear/embarrassment of the procedure	<ul style="list-style-type: none">• Prior to the appointment, inform the patient of the people involved in the screening process.• Explain the procedure, using resources in accessible formats such as large print/plain language.• Women with intellectual disabilities are at an increased risk of sexual assault² and may be reminded of the experience by procedures such as cervical screening. Additional support and sensitive communication is required.• Cervical screening can be a confronting experience and the presence of a support person can help alleviate stress and anxiety.• Consider whether the patient would feel more at ease with a staff member of the same gender. Provide a female chaperone for the duration of the appointment (all BreastScreen radiographers are women).• Encourage patients to make a familiarisation visit prior to the screen.
Pain/discomfort (discomfort during screening can be distressing for people with intellectual disabilities, or can be severely painful for people with certain physical disabilities)	<ul style="list-style-type: none">• Establish whether the benefit of screening outweighs the potentially negative experience the individual may encounter and, if necessary, discuss alternative screening options.• If screening, communicate with the patient clearly and continually about what is going to happen next in the procedure.• Explain that the patient can stop the procedure at any time and agree on a signal.
GP apprehension around obtaining informed consent/medical power of attorney consent	<ul style="list-style-type: none">• Provide information about the benefits and harms of cancer screening and the procedure so the patient can make an empowered decision to take part.• Identify who has medical power of attorney (if applicable).

Part Two - Cancer Screening Pathways: considerations

	Bowel screening	Breast screening	Cervical screening
Program overview	<p>The National Bowel Cancer Screening Program (NBCSP) invites people aged 50 to 74 to screen for bowel cancer.</p> <p>The NBCSP sends a free immunochemical faecal occult blood test (FOBT) to eligible patients every two years.</p> <p>The FOBT is an at-home test that detects miniscule amounts of blood in bowel motions.</p>	<p>The National Breast Cancer Screening Program (BreastScreen Australia) recommends that women aged 50–74 years attend free two-yearly mammograms.</p> <p>People (women, trans women and gender diverse people) are eligible from 40 years.</p> <p>This program is for asymptomatic people.</p> <p>Patients with symptoms should be referred to a diagnostic service for quicker and more targeted results.</p>	<p>The National Cervical Screening Program recommends people with a cervix aged 25–74 to have a Cervical Screening Test every 5 years.</p> <p>There may be assumptions that people with disabilities are not sexually active—ask all people with a cervix if they are due for screening.</p> <p><i>*HPV vaccination should be given to adolescents with disabilities as a preventative measure for cervical cancer. It should not be assumed that all patients receive the vaccination through their school and their vaccination status should be checked.</i></p>
Screening	<ul style="list-style-type: none"> The patient must be able to understand and follow the steps involved in doing the FOBT including taking the two samples, completing the necessary label on the collection tube and completing the participant details form. The patient's carer can assist if required. It's important to consider before screening that if an FOBT returns a positive result, the individual is informed and able to undergo colonoscopy. Some people may not be suitable to conduct the test at home if they are a high falls risk. 	<ul style="list-style-type: none"> The patient must be able to hold position and stay still during the screen. The patient must be able to hold their arms above shoulder height. To find out about wheelchair accessibility call 13 20 50. People who use a wheelchair are advised to come in a wheelchair which has removable arms. A small amount of radiation is involved. 	<ul style="list-style-type: none"> Check if the patient is familiar with the procedure and who is involved to obtain informed consent. The physical nature of the exam may require the use of an adjustable bed or hoist—consider the patient's ability to lie on their back or side and move their legs apart to insert the speculum. <div> <p>Talking point: Do you have any concerns about what will happen during the screen?</p> </div>

	Bowel screening	Breast screening	Cervical screening
Considerations	<p>If unable to complete an FOBT by themselves, with the patient's consent, a carer or support person is able to assist. For example, a disability support worker who assists with toileting and hygiene.</p> <div> <p>Talking point: Do you feel able to do the test on your own or would you like some help?</p> </div>	<p>Some people with limited mobility are unable to be positioned appropriately for a complete breast screen. This is due to the limitations of the equipment, meaning that radiographers may not be able to obtain an image of the entire breast. For these people, other tests such as ultrasound may be helpful but still have limitations and barriers. BreastScreen Victoria may be able to organise a familiarisation visit before the breast screen appointment.</p>	<p>For those who are unable to have a Cervical Screening Test another option is:</p> <ul style="list-style-type: none"> • A self-collected Cervical Screening Test where an individual can take a vaginal swab themselves (see eligibility below). <p>It's important to consider that if a self-collected Cervical Screening Test returns a positive result, the next step is a speculum examination or colposcopy. Therefore, ensure an individual is informed and able to undergo these procedures.</p> <p>A self-collected Cervical Screening Test is only available to people who:</p> <ul style="list-style-type: none"> - are aged 30 and over; and - are at least 2 years overdue or have never been screened. <p>Self-collection must be completed at the GP practice/Health Centre.</p> <p>From 1 July 2022, the above eligibility criteria will be removed and all people with a cervix will be eligible for self-collection.</p>

	Bowel screening	Breast screening	Cervical screening
Results and pathways	<p>If the FOBT returns a positive result the GP will be notified.</p> <p>A follow up appointment is needed to discuss further testing. Colonoscopy may be required.</p> <p>Preparation for colonoscopy is the main barrier for people with disabilities moving through the bowel cancer screening pathway. Things to consider:</p> <ul style="list-style-type: none"> - Ability to undergo preparation for colonoscopy (consider admitting patient one day prior). - Colonoscopy preparation includes; fasting, consuming only liquids and frequent and urgent bowel movements. <p>If colonoscopy is necessary GPs are recommended to provide details about the disability and their needs in the referral to the specialist.</p>	<p>If there is an area on the mammogram that needs further investigation, the person may be recalled for further tests such as extra mammograms, breast ultrasound, breast examination or needle biopsy. Consider physical and emotional impacts that these tests may have as well as the consent needed for medical procedures.</p> <div> <p>Talking point: Would having an interpreter, friend or support worker come to an appointment help you to feel more comfortable?</p> </div>	<p>Should the GP be unable to complete the Cervical Screening Test for any reason, or the results are inconclusive, the GP can refer the patient to a GP Liaison Officer, a Gynaecologist or a Women's Health Clinic for an opinion.</p>
Links and resources	<p>NBCSP for Health Professionals: http://bowelcancer.org.au/for-health-professionals.php</p>	<p>BreastScreen for people with a disability: www.breastscreen.org.au/community-support/disability</p>	<p>Toolkit for engaging Under-screened and Never-screened women in the National Cervical Screening Program: www.cancerscreening.gov.au/internet/screening/publishing.nsf/Content/cervical-toolkit-engaging-under-and-never-to-c</p> <p>Cervical Screening Information for women with disabilities: www.cancer.org.au/cervicalscreening/over-25/disabilities</p>

Contact

Cancer Council Victoria on 13 11 20

BreastScreen Victoria on 13 20 50

National Cancer Screening Register 1800 627 701

Contact the National Cancer Screening Register for more information about accessing your patient's bowel and cervical screening results and histories

To access plain language resources

visit screeningresources.cancervic.org.au/

The National Relay Service (NRS) allows people who are deaf, hard of hearing and/or have a speech impairment to make and receive phone calls. Visit communications.gov.au/what-we-do/phone/services-people-disability/accesshub/national-relay-service

Non-English speakers can call through TIS (Translating and Interpreting Service) by calling 13 14 50 and being connected to the appropriate screening program



**BreastScreen
Victoria**



**Cancer
Council
Victoria**

September 2019

1. Floud S, Barnes I, Verfürden M, Kuper H, Gathani T, Blanks RG, Alison R, Patnick J, Beral V, Green J et al. Disability and participation in breast and bowel cancer screening in England: a large prospective study. Br. J. Cancer (Internet) 2017 (cited 2019 Aug 16);117(11):1711. Available from: <https://www.nature.com/articles/bjc2017331> / DOI: 10.1038/bjc.2017.331
2. Nixon M, Thomas SDM, Daffern M, Ogloff JRP. Estimating the risk of crime and victimisation in people with intellectual disability: a data-linkage study. SOC PSYCH PSYCH EPID (Internet) 2017 (cited 2019 Aug 16); 52(5):617. Available from: <https://link.springer.com/article/10.1007%2Fs00127-017-1371-3> / DOI: 10.1007/s00127-017-1371-3