Toolkit for engaging under-screened and never-screened women in the National Cervical Screening Program

November 2017
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Introduction

This toolkit has been developed to assist healthcare providers to engage under-screened and never-screened women in cervical screening, and to support them should they choose to participate.

70% of Australian women who develop cervical cancer are under screeners or have never screened.

With the Renewal of the National Cervical Screening Program (NCSP) there is an increased focus on engaging under-screened and never-screened women.

Professor Ian Hammond, Chair of the National Cervical Screening Program Renewal Committee, explains the key components of the renewed National Cervical Screening Program and the rationale for the changes in our video about the changes to the program.

This toolkit has been developed to assist healthcare providers to engage under-screened and never-screened women in cervical screening, and to support them should they choose to participate.

It includes information relevant to:

- GPs
- Nurses
- Sexual Health Nurses
- Disability Support Workers
- Aboriginal Health Workers
- Bilingual Health Workers, and
- Practice Managers.

Each section provides information, a range of resources and links to further information.

We encourage all healthcare providers involved in cervical screening to make use of this Toolkit, particularly those working with women from population groups that are often under-screened. You might choose to spend some time familiarising yourself with the range of resources available and then save a shortcut to the Toolkit for later reference.

Related information

- Cervical screening test
- National Cervical Screening Policy
- National Cervical Screening Program online training modules – six accredited modules about cervical screening.
- National Cervical Screening Program: Guidelines for the management of screen-detected abnormalities, screening in specific population and investigation of abnormal vaginal bleeding
- The renewal of the National Cervical Screening Program – Medical Journal of Australia Editorial, October 2016.
- National Cancer Screening Register - a single national register for cervical screening results and patient history – please call 1800 627 701.
Section 1: Addressing the barriers to screening
Under-screened and never-screened women

Under the renewed NCSP, cervical screening is recommended for all women aged 25 to 74 who have ever been sexually active, HPV vaccinated or unvaccinated. Women will be invited by the National Cancer Screening Program to screen every five years. Women already participating in the Program will have their first Cervical Screening Test two years after their last Pap test.

Under-screened women are those who are overdue for cervical screening by at least two years. During the early years of transition to the renewed NCSP, this will mean greater than four years since a woman’s last conventional Pap test or greater than seven years since her last Cervical Screening Test.

Encouraging under-screened and never-screened women to participate in cervical screening is an important task for healthcare providers, as these women are most at risk of cervical cancer.

There are specific sub-population groups in Australia who are less likely to engage in cervical screening. These include, but are not limited to, Aboriginal and Torres Strait Islander women, women from culturally and linguistically diverse backgrounds, women with disabilities, women who experience socio-economic disadvantage and women who have experienced sexual assault.

It is important to remember that these sub-groups are not homogenous, and each woman’s individual circumstances will influence her participation in cervical screening.

Barriers to screening

There are many potential barriers that may influence a woman in her decision or ability to participate in cervical screening. Studies into barriers have typically focused on barriers to having a Pap test. Barriers may be related to the patient, healthcare provider or the health system.

Patient-related barriers

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<thead>
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<th>Lack of knowledge about -</th>
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<td>Reluctance to screen after a negative past experience such as previous pain or discomfort</td>
<td>The risks of cervical cancer</td>
<td>Limited previous experience of prevention or screening programs</td>
<td>Concerns about cost</td>
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<td>Past history of sexual abuse or sexual violence</td>
<td>Who needs to be tested</td>
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<td>The accuracy of the test</td>
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<td>Lack of transport</td>
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<td>Cultural issues (related to circumstances, beliefs, background and inequities in society)</td>
<td>Cancer and/or a belief that cancer = death</td>
<td>Perception that screening is not required for women who have sex with women, or for transgender men</td>
<td>Physical, social or practical barriers associated with a disability</td>
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<td>Weight-related barriers (obesity)</td>
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<td>Personal preference for choice of healthcare provider</td>
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**Healthcare provider and system-related barriers**

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<tr>
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<th>System-related barriers</th>
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<tr>
<td>Time constraints and pressure to restrict consultation times</td>
<td>Accessibility of the health service</td>
</tr>
<tr>
<td>Availability of female healthcare providers</td>
<td>Availability of convenient appointment times</td>
</tr>
<tr>
<td>Lack of practical training in cervical screening (e.g. for international medical graduates who have never performed cervical screening)</td>
<td>Availability of bulk billing</td>
</tr>
<tr>
<td>The patient knowing the healthcare provider personally</td>
<td>Services without a culturally sensitive environment</td>
</tr>
<tr>
<td>Interpersonal and communication skills</td>
<td>Availability of female healthcare providers or any healthcare provider who is a cervical screener</td>
</tr>
</tbody>
</table>
Healthcare provider-related barriers | System-related barriers
--- | ---
Age and/or cultural background of the healthcare provider | Availability of local language resources and patient information

General tips for discussing cervical screening

When discussing cervical screening with your patients, particularly under-screened or never-screened women, it’s important to be mindful of these considerations:

- Building trust and rapport is vital. Creating a sense of safety and security will go a long way towards allaying a woman’s concerns or fears. E.g. Quiet voice, respectful tone
- Demonstrate respect and inclusivity through the language you use when talking to women and by creating an inclusive atmosphere of your health service e.g. waiting room displays and consumer resources in various languages.
- Ensure women understand that their Cervical Screening Test results will remain confidential.
- Reassure women that the procedure will be undertaken carefully and respectfully, and that they will be able to undress in private and given a sheet to cover their lower body.
- Use visual aids where appropriate, particularly with women with low literacy levels and women who may be embarrassed discussing sexual activity or their genitalia.
- Give women time to feel comfortable with new information, to ask questions and make informed decisions.
- Don’t make assumptions about women’s cultural background, sexual history, sexual preferences, literacy levels or knowledge of their bodies.
- Use face-to-face or telephone interpreters if language is a barrier.

Engagement strategies

There are several evidence-based strategies that healthcare providers can use to engage under-screened and never-screened women in cervical screening.

<table>
<thead>
<tr>
<th>Strategy</th>
<th>Details</th>
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</table>
| Education and support | Women view healthcare providers as an important source of information about cervical screening. It is important for healthcare providers to engage patients in a conversation about cervical screening to help patients understand:  
- What cervical screening involves  
- Why it is important i.e. *because regular cervical screening is one of the main methods to prevent cervical cancer*  
- Why it is relevant to them, and  
- What their test results mean. |
<table>
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| Toolkit for engaging under-screened and never-screened women in the National Cervical Screening Program | Healthcare providers also have an important role in supporting their patient to undertake cervical screening and counselling them about any perceived barriers. Open communication will assist in creating a safe and secure environment that enables women to feel comfortable to have the test performed. Include local women in the promotion of programs in their communities e.g. Where it is appropriate to advertise an event esp. women's business in remote/Aboriginal community. Although a healthcare provider may view the Cervical Screening Test as routine, it is important to remember that for women the experience is generally something that is out of the ordinary. Healthcare providers should acknowledge that cervical screening is a personal and potentially difficult experience for some women. This might include:  
- Encouraging patients to express their concerns  
- Acknowledging and addressing the patient's feelings of embarrassment and/or anxiety  
- Before the procedure begins, always give the woman the power and permission to stop you at any time  
- Being aware of and sensitive to any cultural issues  
- Reassuring the patient about the procedure, and  
- Offering the patient an opportunity to ask questions. |
| Making the screening experience as comfortable as possible | Some patients may prefer to insert their own speculum, and it can be helpful to offer this option. Providing instructions on calming and deep breathing techniques can also help the woman to relax. A prescription of vaginal oestrogen cream can be effective in decreasing pain or discomfort for post-menopausal women. Provide a mirror in case women want to view their own cervix |
| Invitation, recall and reminder letters | Healthcare providers can either manually or electronically (using their practice’s clinical software) identify which patients have no record of screening, which are due for screening and which are overdue. These women can then be targeted individually with a personalised invitation, a phone call or reminder letter. Letters are particularly effective when they include an endorsement from a healthcare provider. Consult with local women about how this would happen |
| Educational resources | Education resources may include printed or audio-visual materials. These materials work best when combined with other strategies (for example, when provided in the context of a healthcare consultation). Locally designed developed and owned resources always work best.  
- e.g. Something designed in Top End NT doesn’t necessarily work in Central Australia |
<p>| Healthcare providers reminders | A note or flag identifying each patient’s cervical screening status can be added to the patient’s electronic record to prompt healthcare providers to discuss cervical screening when the patient next attends the health service. |</p>
<table>
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<tr>
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<tr>
<td>Audit and feedback activity</td>
<td>Clinical audits involve assessing performance in delivering and/or offering screening to patients (using patient record management software), either at a practitioner or health service level. Healthcare providers are then presented with information/feedback about their performance. Results may be compared with a benchmark screening rate. It is expected that this activity will then prompt healthcare providers to improve their performance.</td>
</tr>
</tbody>
</table>

**Engaging with particular groups**

There are specific population groups in Australia who are less likely to engage in cervical screening. The below mentioned links provide tailored information and resources to assist you to engage and support particular groups who may face specific barriers to participation:

**Aboriginal and Torres Strait Islander women**

Aboriginal and Torres Strait Islander women are more likely to develop invasive cervical cancer and are more likely to die from cervical cancer than non-Aboriginal and Torres Strait Islander women.

Although there is limited data on the cervical screening participation of Aboriginal and Torres Strait Islander women, studies suggest overall participation in cervical screening is 18% lower for Indigenous women than for non-Indigenous women. It is likely that the higher incidence and mortality from cervical cancer amongst Aboriginal women is linked to under-screening and late detection of pre-cancerous lesions and infection with HPV.

**Barriers to screening**

In addition to the general barriers women may face in participating in cervical screening, the following barriers have been identified as common for Aboriginal and Torres Strait Islander women.

**Barriers for Aboriginal and Torres Strait Islander women:**

- Shame, fear and embarrassment about cervical screening and cancer
- Distrust of healthcare providers, mainstream providers and government services
- Lack of culturally sensitive and appropriate health services
- Lack of Indigenous and female healthcare providers
- Negative cultural perceptions about cancer – for example fatalistic and superstitious attitudes. This may leave some to perceive cervical screening as unnecessary
- Lack of access to health services due to distance/remoteness and transport
- Low knowledge/awareness of the importance and benefits of cancer screening
- Women’s prioritisation of family needs before their own health
- Lack of Indigenous-specific, culturally relevant educational resources e.g speaking posters, as very few local Central Australian languages are written or read.
- History of sexual assault
- Language and literacy barriers.
Engagement strategies

The following strategies have been shown to be effective in engaging Aboriginal and Torres Strait Islander women in cervical screening.

<table>
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<tr>
<td>Cultural safety training</td>
<td>Cultural safety training for healthcare providers and practice staff will help to build an understanding of culturally-based attitudes towards disease, the importance of culture and tradition and women’s business.</td>
</tr>
<tr>
<td>Culturally safe environment</td>
<td>Ensure that your health service is culturally safe – including culturally appropriate, easy to understand resources and Indigenous art. Employ Indigenous staff, especially females, as doctors, health workers, nurses, receptionists or liaison officers.</td>
</tr>
<tr>
<td>Service flexibility</td>
<td>Offer mobile screening services to Aboriginal communities, flexible appointments, group transportation and/or transportation assistance. Offer opportunistic screening where possible.</td>
</tr>
<tr>
<td>Choice of provider</td>
<td>Provide opportunities for women to choose between male/female, doctor/nurse, Indigenous/non-Indigenous cervical screening providers. If necessary, healthcare providers should refer patients to a health service which may be more acceptable to perform cervical screening (for example, an Aboriginal medical service).</td>
</tr>
<tr>
<td>Appropriate communication</td>
<td>Healthcare providers should communicate in clear and respectful language. Disseminate information in the Indigenous community about services offered.</td>
</tr>
</tbody>
</table>

Healthcare provider resources

- [An introduction to Aboriginal and Torres Strait Islander health cultural protocols and perspectives](#) – a guide to appropriate and respectful behaviour with Aboriginal and Torres Strait Islander people. Includes core principles for working with Aboriginal and Torres Strait Islander people (page 20), protocols for culturally respectful engagement of Aboriginal and Torres Strait Islander people (page 25) and advice on culturally appropriate communication (page 28). (62 pages) Royal Australian College of General Practice (RACGP)

Recording information on Aboriginal and Torres Strait Islander status

Health services should work toward identifying and recording the Aboriginal and Torres Strait Islander status of all patients.

Collecting data on the cervical screening participation of Aboriginal and Torres Strait Islander women will enable a greater understanding of their screening behaviour and inform targeted strategies to increase their participation in screening at a local, state and national level.
• **National best practice guidelines for collecting Indigenous status in health data sets** – includes information on asking the question, recording responses and putting the guidelines into practice (25 pages, Australian Institute of Health and Welfare).

• **Identification of Aboriginal and Torres Strait Islander people in Australian General Practice** – background and advice for GPs and practice teams, as well as standard questions and data recording advice (13 pages, RACGP).

• **Collecting self-identified status data from Aboriginal and/or Torres Strait Islander patients and patients from culturally and linguistically diverse (CALD) backgrounds** – explains why and how to collect self-identified status data (3 pages).

• See [Health literacy](#) for strategies to help improve patients' health literacy.

### Healthcare provider training

Cultural safety, cultural awareness and cultural competency training is available for healthcare providers working with Aboriginal and Torres Strait Islander communities.

National options include:

- **Aboriginal and Torres Strait Islander Cultural Awareness in General Practice** – 6-hour Active Learning Module accredited for 40 Category 1 QI & CPD points. Free for Royal Australian College of General Practice (RACGP) members and participants in the PIP Indigenous Health Incentive (RACGP).

- **Aboriginal and Torres Strait Islander Cultural Competence Course** – Free, 10-hour on-line learning module. TAFE accredited (Centre for Cultural Competence Australia).

- **Cultural Safety Learning Module** – short, free, on-line module with case studies and interactive exercises (Services for Australian Rural and Remote Allied Health).

- **Online cultural orientation plan for healthcare providers** – short, free, on-line course (Western Australian Centre for Rural Health).

Visit [Australian Indigenous HealthInfoNet](#) for a listing of additional courses available nationally and in each state/territory.

### Training tool

**Staff knowledge training tool for Indigenous identification** – A downloadable 12 question quiz to assess knowledge and promote best practice (Australian Institute of Health and Welfare).

### Consumer resources

**Section 5: Consumer resources** includes a range of downloadable resources to support conversations about cervical screening.

- **National Cervical Screening Program – Brochure** – A new and better test for women (Aboriginal and Torres Strait Islander languages)

- **National Cervical Screening Program – Poster** – A new and better test for women (Aboriginal and Torres Strait Islander languages)
Women from CALD backgrounds, including women who have experienced female genital cutting

Watch our videos on working with women from CALD backgrounds:

- How to engage women from culturally and linguistically diverse backgrounds about cervical screening
- Working with an interpreter
- Discussing cervical cancer and screening
- Explaining the screening pathway

Barriers to screening

In addition to the general barriers women may face in participating in cervical screening, the following barriers have been identified as common for women from CALD backgrounds.

Barriers for women from CALD backgrounds

- Lack of knowledge of the availability, purpose, importance and benefits of cervical screening
- Belief that cervical screening is unnecessary without symptoms
- Misunderstandings in regards to causes of cancer (i.e. cancer is contagious, cancer is a punishment for past behaviour/moral conduct, cervical cancer is caused by promiscuity, cancer = death)
- Negative cultural perceptions about cancer – for example fatalistic and superstitious attitudes (i.e. cancer is the will of God, cancer is incurable, cancer is predetermined). This may leave some women to perceive cervical screening as unnecessary
- Beliefs in traditional, non-western medicine
- Stigma and taboos around discussing sexual topics
- Fear, shame and stigma associated with cancer
- Fear, modesty and embarrassment around the test
- Language, communication and literacy difficulties
- Availability of female healthcare providers
- Availability of female interpreters
- Availability of a healthcare provider who speaks their language
- Women may have difficulties accessing and navigating the Australian healthcare system (particularly, newly arrived women)
• Women may have other competing priorities such as employment, housing and family (particularly, newly arrived women)
• Women may have multiple complex health problems such as chronic diseases and/or physical and mental health consequences of trauma, violence and sexual abuse (particularly, women who have newly arrived as refugees)
• Distrust of healthcare providers due to experiences from their originating country
• Resistance to usage of local health systems due to perceptions or experiences of culturally insensitive services
• Logistical concerns – lack of transport, difficulties getting to the appointment, organising childcare if necessary
• Cost to see a healthcare provider if bulk-billing is not available

Women from CALD backgrounds are less likely than women from the general population to participate in cervical screening. The reasons for this are related to cultural beliefs, a lack of understanding of the screening program and the Australian health system and language barriers.

Women who have experienced female genital cutting (FGC) may face additional barriers to screening associated with psychological trauma, pain (real or anticipated) and embarrassment. Women who have experienced type 3 FGC (where the labia have been sewn together to make the vaginal opening smaller) may physically be unable to have a speculum examination and may be eligible for self-collection. (See Self-collection section) also who have genetic abnormally/dysmorphia of vagina where the opening is too small to introduce smallest speculum.

As women from CALD backgrounds come from diverse cultures and have diverse beliefs, it is important for healthcare providers to deliver culturally safe, appropriate and inclusive services.

**Cross-cultural understanding**

When working with women from CALD backgrounds, it’s important to consider their linguistic and cultural needs when discussing cervical screening.

Assessing your patient’s individual culture is necessary to assist you in caring for her in a culturally sensitive way. Cultural factors can be dynamic and are specific to each person. Factors include race, gender, religion and ethnicity.

It’s important to recognise the complexity of your patient’s cultural background in addition to other issues that may impact on her life, such as migration, settlement and socioeconomic status. If you need to know more about a woman’s beliefs or values, just ask.

If you are working in a mainstream health service, collaborating with women’s ethno-specific/multicultural health and welfare agencies will help you to share information and best practice ideas and to link your client to these services for further multilingual information about their health. Bilingual and bicultural health educators have expertise and skills in providing education for migrant and refugee women, and in promoting health services in general.
### Engagement strategies

The following strategies have been shown to be effective in engaging women from CALD backgrounds in cervical screening.

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<td>Physical, social or practical barriers associated with a disability</td>
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### Questions to ask yourself

Before a consultation about cervical screening with women from a culturally diverse background, ask yourself:

- Do I need a qualified interpreter? Do I need to access a female interpreter?
• Has my patient understood the procedure of cervical screening? Should I ask her to repeat to me what I have explained before she gives consent?
• Are flexible, longer and multiple appointment times available for my patient? If this is not possible, do I know where to refer my patient for outreach sexual and reproductive health education and information?
• Do I know where to access multilingual health information (such as written information, DVDs, CDs, posters, charts and 3D models) to give my patient more information?
• Consider what information is necessary to guide your consultation:
  • Country of birth and time of arrival to Australia
  • Previous cervical screening experiences
  • Is the woman from a country with prevalent practices of female genital cutting?
  • Would the woman prefer a female practitioner?
  • Should I explain the concept of confidentiality to the woman who may be concerned about her husband or family knowing why she has visited the doctor?

Barriers to cervical screening for women who have experienced female genital cutting

In addition to the general barriers women may face in participating in cervical screening, and those faced by women from CALD backgrounds, the following barriers have been identified as common for women who have experienced female genital cutting.

• Psychological trauma of female genital cutting
• Pain due to scar tissue and infection. Women may anticipate that the Cervical Screening Test will be painful/uncomfortable/difficult
• Lack of knowledge of the availability, importance and benefits of cancer screening
• Negative cultural perceptions about cancer – for example fatalistic and superstitious attitudes (i.e. cancer is the will of God). These attitudes may lead some women to perceive cervical screening as unnecessary
• Embarrassment associated with female genital cutting (i.e. anticipating the healthcare provider to have a shocked reaction)
• Language, communication and literacy difficulties
• Fear of the test
• Availability of female healthcare providers
• Women may have difficulties accessing and navigating the Australian healthcare system (particularly, newly arrived women)
• Women may have other competing priorities such as employment, housing and family (particularly, newly arrived women)

Female genital cutting is practiced in 29 countries around the world and is most prevalent in Africa (particularly Somalia, Guinea, Djibouti, Egypt, Eritrea, Mali, Sierra Leone, and Sudan), although it is also practiced in some parts of the Middle East and Asia.

Women are increasingly migrating to Australia from countries where female genital cutting is practiced. It is estimated that there are approximately 120,000 migrant women in Australia who have undergone the practice in their countries of birth. Often these countries do not have organised cervical screening programs.

In Australia, there is a low uptake of preventative health services by African women and it is known that women from culturally and linguistically backgrounds are less likely to participate in cervical screening.

**Strategies to engage women who have experienced female genital cutting**

The following strategies have been shown to be effective in engaging women who have experienced female genital cutting in cervical screening.

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<td>Appropriate communication</td>
<td>Provide time to explain the procedure and allow women to ask any questions, including that they have the right to request a female provider. Use simple language and pictures where appropriate/available. Women may not be familiar with basic health topics and concepts. Provide written information in simple plain language (English or other language), but be aware that not all women are literate and/or may prefer to receive information in oral form. Use a telephone interpreter if required. Be non-judgemental and empathetic to the women’s situation. Many women are proud to have undergone FGC, but are aware that in Australia it is a judged procedure. Offer culturally-appropriate resources such as translated fact sheets for women. Provide suitable, trained female interpreters, as it may not be appropriate to use a family member, friend, or even an interpreter from the same community.</td>
</tr>
<tr>
<td>Cultural training</td>
<td>Offer cultural safety training for all health service staff. Provide specific training for healthcare providers around how and when to ask about female genital cutting (i.e. country of birth is a good indicator; use simple language; be sensitive; use value neutral non-judgemental language).</td>
</tr>
<tr>
<td>Strategy</td>
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<tr>
<td><strong>Make the procedure as comfortable as possible</strong></td>
<td>Offer women the opportunity to perform the test in a different position (e.g. on their side rather than their back). Consider use of a smaller speculum. In some cases it may be appropriate to offer <em>self-collection</em>.</td>
</tr>
<tr>
<td><strong>Patient records</strong></td>
<td>Record interpreter requirements and female genital cutting status in medical records for future consultations.</td>
</tr>
<tr>
<td><strong>Choice or cervical screening provider</strong></td>
<td>Ensure female cervical screening providers are available. Refer patients to a cervical screening provider who speaks their language (preferably female) or to a service that may be more acceptable (i.e. a healthcare service for migrant and refugee women).</td>
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**Working with interpreters**

These resources will help you to assess whether an interpreter is required, and to book and brief interpreters.

*Assessing the need for an interpreter* provides practical information on when and how to offer an interpreter (2 pages, Centre for Culture, Ethnicity & Health).

Engaging an interpreter is recommended when a patient:

- Requests one
- Speaks English as a second language and is in a stressful, complex or unfamiliar situation
- Is difficult to understand
- Responds only in a limited way
- Relies on family or friends to interpret
- Wishes to communicate in his or her preferred language, or
- Cannot grasp or respond to questions in English.

*Booking and briefing an interpreter* provides basic information about engaging and briefing interpreters. Includes administrative information and questions to consider (2 pages, Centre for Culture, Ethnicity & Health).

Additional time should be allowed for consultations with interpreters and female interpreters should be engaged for cervical screening consultations. Please ensure there is a space for the interpreter to position themselves behind a screen or curtain while the Cervical Screening Test is being performed.
Although working with professional interpreters is advised, if none are available in the required language, women may wish to have a trusted friend or family member who can speak English at their consultation/s, or a phone interpreter could be arranged.

**Healthcare provider resources**

**Speaking with clients who have low English proficiency** – tip sheet. Includes information on preparing for your conversation, issues to be conscious of during the conversation and how to check information has been understood (2 pages, Centre for Culture, Ethnicity & Health).

**Using the teach-back technique** – advice for communicating with clients with low health literacy (2 pages, Centre for Culture, Ethnicity & Health).

Basic steps involve:

1. Explaining one concept of a diagnosis or treatment plan to the client
2. Assessing the client’s recall and understanding by asking the client to explain what you said
3. Repeating the process until the client can demonstrate they have satisfactorily understood the information
4. Introducing the next concept

**Female genital cutting and cervical screening resource card** – a guide for practitioners – includes descriptions and diagrams of the types of FGC and gives suggestions for supporting women and sample questions you could include in a consultation (2 pages).

See Health literacy for strategies to help improve patients’ health literacy.

If you require an interpreter please contact the Translating and Interpreter Service (TIS) on 131 450 or visit their website.

**Recording information on country of birth and language preference**

Health services should work toward systematically identifying and recording both the country of birth and language preference of all patients. This background information can be an important indication of clinical risk factors and can assist healthcare providers in providing relevant care.

Asking and recording a patient’s preferred language and whether an interpreter is required will assist health services to plan for consultations and in making accessible health information available.

Collecting data on the cervical screening participation of women from CALD backgrounds will enable a greater understanding of their screening behaviour and inform targeted strategies to increase their participation in screening at a local, state and national level.

**Collecting self-identified status data**

Collecting self-identified status data from Aboriginal and/or Torres Strait Islander patients and patients from culturally and linguistically diverse (CALD) backgrounds (PDF, 70KB) explains
why and how to collect self-identified status data. Includes key questions to ask of every patient (3 pages).

Healthcare provider training

Various training programs are available to assist healthcare providers working with CALD communities to improve their cultural competency. Topics include improving cultural awareness and understanding and working with interpreters.

National options include:

- Introduction to Cultural Competence – introductory online learning module (Centre for Culture, Ethnicity and Health).

Contact the relevant peak bodies in your state/territory for additional training options.

Consumer resources

Section 5: Consumer resources includes a range of downloadable resources that can support conversations about cervical screening.

Women with disabilities

Watch our videos on working with women with disabilities:

- How to engage with women with intellectual disabilities about cervical screening
- Explaining the cervical screening process
- Conducting the cervical screening test

Women with disabilities are another group that are less likely to participate in cervical screening. Barriers to their participation are often related to the accessibility of health services, healthcare providers’ perceptions of the priority of cervical screening for women with disabilities and women’s reliance on carers.

In addition to the general barriers women may face in participating in cervical screening, the following barriers have been identified as common for women with disabilities.

Barriers to cervical screening for women with disabilities

- Healthcare provider, caregiver and/or family assumptions that screening is unnecessary because women with a disability are not sexually active
- The assumption that women with disabilities, particularly intellectual disabilities, may not be able to tolerate the procedure
- Lack of suitable screening equipment such as adjustable beds and hoists
- Inaccessible transport and cervical screening facilities
- Short appointment times – additional time is often needed for a healthcare provider to support women to understand and undertake the procedure
- Capacity to provide informed consent
- Availability of accessible plain English information and resources in other formats (e.g. video and audio). This includes invitation and recall/reminder letters.
- Low awareness/comprehension of the importance and benefits of cancer screening
• Women may be unable or unwilling to disclose their sexual history because of fear of stigma
• Fear or embarrassment of the test
• History of sexual assault
• Healthcare providers’ lack of training or knowledge related to women with disabilities and how to provide appropriate support
• Caregivers and/or families with low awareness of the importance and benefits of cancer screening for women with disabilities
• Physical, sensory and communication barriers
• Healthcare providers may prioritise a patient’s disability needs and healthcare concerns over preventative health measures
• Reliance on family and carers when going to medical appointments
• The Cervical Screening Test may be painful and/or traumatic for some women due to their disability
• Bad experiences with healthcare providers in the past

**Engagement strategies**

The following strategies have been shown to be effective in engaging women with disabilities who have ever been sexually active in cervical screening.

<table>
<thead>
<tr>
<th>Strategy</th>
<th>Detail</th>
</tr>
</thead>
<tbody>
<tr>
<td>Staff training</td>
<td>Encourage staff to complete education and training to raise awareness of the importance of cervical screening for women with disabilities and develop effective communication skills.</td>
</tr>
<tr>
<td>Appropriate</td>
<td>Make materials available with information designed for women with disabilities (i.e. plain English, Braille, diagrams, large print materials, videos). This should include invitations and recall/reminded letters as well as materials available in the waiting room. Use a modified communication style appropriate for each client (i.e. using clear, short, direct language). Build rapport and trust. Allow time to support women to understand and undertake the procedure (e.g. allow the woman to visit the clinic before the appointment to view the rooms, see the equipment and ask questions; offer longer consultations). Time is also often needed to build trust with women around these sensitive issues. Acknowledge the woman’s expertise about her own disability as this will contribute to building a positive interaction. It will also reinforce the woman’s role as an agent of her own healthcare management, which will facilitate communication and comfort during examinations. Include questions about sexual activity in medical histories of women with disability.</td>
</tr>
<tr>
<td>informed consent</td>
<td>Support women to provide consent. Explain the procedure using appropriate language and visual cues, revisiting points where necessary. If the woman does not have the capacity to consent, include the ‘person responsible’ in the consultation. (See Office of the Public Advocate/Guardian/Trustee in your state/territory)</td>
</tr>
<tr>
<td>Strategy</td>
<td>Detail</td>
</tr>
<tr>
<td>---------------------------------------------------</td>
<td>--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Accessibility</td>
<td>Ensure the clinic is wheel chair accessible and that height adjustable exam tables and equipment is available.</td>
</tr>
<tr>
<td>Patient records</td>
<td>Identify women with disabilities who are under-screened or never-screened and flag them in the practice database.</td>
</tr>
<tr>
<td>Choice of cervical screening provider</td>
<td>Most health services have experience supporting women with disabilities, but if necessary, healthcare providers could refer patients to services that may be better able to cater for women’s particular needs in relation to cervical screening. For example, a clinic with rooms and/or equipment designed to be accessible for people with disabilities, or to specialised health services for women with disabilities.</td>
</tr>
</tbody>
</table>

**Communication tips that may help when talking with someone with a disability**

1. Ensure you have the person’s attention
   - Address the person by name, use eye contact

2. Be aware of known communication difficulties
   - Receptive difficulties (e.g. deafness, cognitive impairment, autism spectrum disorder) and/or
   - Expressive difficulties (e.g. cerebral palsy, autism spectrum disorder)

3. If unsure of ability to understand, assume competence and adjust accordingly
   - It is more appropriate and respectful to ‘assume competence’ than assume a lack of understanding

4. If uncertain, ASK about communication preferences/style/techniques
   - How does s/he say ‘Yes/ No’?
   - Does s/he use a communication device or aid?
   - Check if an interpreter is required

5. Be appropriate and respectful in your choice of:
   - Language: simple, clear words & short uncomplicated sentences
   - Visual information: pictures, diagrams, signs, gestures
   - Tone & volume: a respectful approach reflects your degree of familiarity with the person, their age and the context of your interaction

6. Wait for a response
   - Allow the person time to listen, process what you say and respond. DONT RUSH!
   - Check that you have their permission before starting the procedure

7. Check understanding in the person’s own words
   - DO NOT simply ask ‘Do you understand?’ Most people will say ‘Yes!’) Remember that receptive language may be better than expressive language (or vice versa).
8. Be honest and take responsibility for communication breakdowns
   - e.g. ‘I’m sorry, I don’t understand you.’ NEVER PRETEND to understand!
9. If they don’t understand you – KEEP TRYING.
   - Repeat the information using clear simple words and concepts. Say it in a different way with different words and try to use pictures.
10. KEEP TRYING if you don’t understand. Try alternative strategies like:
   - Would you say that again please?
   - Is there another way you can think of saying it?
   - Could you use another word?
   - Could you show me?
   - Is there someone who could help us?
   - ASK a family member/carer/support worker if appropriate if they can assist you.

(Included with thanks to the Centre for Developmental Disability Health Victoria)

**Healthcare provider resources**

[Working with people with intellectual disabilities in healthcare settings](#) discusses barriers and strategies for providing good healthcare. Includes information on attitude, communication, working with carers and for providing proactive healthcare (6 pages, includes summary above; Centre for Developmental Disability Health).

See [Health literacy](#) for strategies to help improve patients’ health literacy.

**Consumer resources**

[Section 5: Consumer resources](#) includes a range of downloadable resources to support conversations about cervical screening.
Women who identify as lesbian, gay, bisexual, transgender or intersex (LGBTI) and have a cervix

Watch our case study video on overcoming the LGBTI barriers.

LGBTI people experience higher rates of discrimination and poorer health outcomes than other Australian women, and may be less likely to participate in regular cervical screening than heterosexual women. This is particularly the case for women who have never had sex with men.

Transgender men who still have a cervix are also at risk of cervical cancer. They are less likely to have regular cervical screening than the general population, and more likely to have an unsatisfactory result. They are also less likely to be offered screening by healthcare providers.

Barriers to screening

In addition to the general barriers women may face in participating in cervical screening, the following barriers have been identified as common for women who identify as lesbian, bisexual or are same-sex attracted, and people who identify as transgender and have a cervix.

Barriers to cervical screening for LGBTI people

- Misconception that lesbian, bisexual and same-sex attracted women, and transgender men who have a cervix, are not at risk of cervical cancer (i.e. belief that cervical screening is not necessary)
- Healthcare providers’ misconception that lesbian, bisexual and same-sex attracted women, and transgender men who have a cervix are not at risk of cervical cancer (i.e. incorrectly advising patients not to participate in screening)
- Misconception that HPV is only spread through heterosexual intercourse (i.e. incorrect belief that women who have not had sex with men are not at risk of cervical cancer)
- Discrimination and social stigma
- Fear of negative attitudes of healthcare providers
- High levels of psychological distress, experiences of trauma and abuse
- Healthcare providers’ lack of understanding about sexual and gender diversity
- Heterosexual assumptions by healthcare providers
- Difficulty finding a suitable healthcare provider (i.e. accepting, empathetic, non-judgemental)
- Previous negative experiences with healthcare providers/healthcare services
- Reluctance to disclose sexual orientation/identity
- Potential distress for transgender patients caused by the conflict between their sex assigned at birth (i.e. female) and their gender identity (i.e. male)
Transgender men with a cervix may find speculum examinations painful.

**Engagement strategies**

The following evidence-based strategies have been shown to be effective in engaging women who identify as LGBTI and have a cervix in cervical screening.

<table>
<thead>
<tr>
<th>Strategy</th>
<th>Detail</th>
</tr>
</thead>
<tbody>
<tr>
<td>Staff training</td>
<td>Encourage all health service staff to undertake Lesbian, Gay, Bisexual, Transgender, and Intersex (LGBTI) -specific cultural sensitivity training.</td>
</tr>
<tr>
<td>Appropriate communication</td>
<td>When discussing cervical screening with patients, healthcare provider should employ a nonjudgmental and open-minded approach (e.g. avoiding the assumption that everyone is heterosexual). Use terminology that encompasses all sexual orientations (e.g., asking about a patient’s partner/significant other instead of their husband), and acknowledging the patient’s same-sex partner and including them in conversations. Advise lesbian, bisexual and same-sex attracted women, and transgender men who have a cervix, that they are at risk of cervical cancer and recommend that screening is appropriate for them. When communicating with patients, reflect their use of language and self-identification. If in doubt, ask what terms they prefer. Use gender-neutral language on intake forms and give patients ample choices when documenting next of kin, relationship status and sexual orientation.</td>
</tr>
<tr>
<td>Avoid making assumptions</td>
<td>If a female patient identifies a female partner, do not assume that she has never had a male sexual partner or been pregnant.</td>
</tr>
<tr>
<td>Supportive environment</td>
<td>Provide a safe, supportive, sensitive and welcoming environment for the LGBTI community. Make the waiting room welcoming, with posters and resources directed to the LGBTI community. Prominently display your health service’s policy of non-discrimination and confidentiality. Signal your health service’s willingness to provide quality services to all patients and your openness to disclosures about sexuality e.g. through messages on your website.</td>
</tr>
</tbody>
</table>

**Healthcare provider resources**

*Guide to sensitive care of lesbian, gay and bisexual people attending general practice* – This guide has been designed to assist GPs, practice nurses and practice staff to be inclusive of and sensitive to LGBTQI people. It includes definitions for minority sexual orientations and the specific health issues faced by LGB people, as well as a range of suggestions for improving communication and practice (4 pages, the University of Melbourne).
Healthcare provider training

Various training programs are available to assist healthcare providers working with LGBTI communities to improve their practice:

- LGBTI Professional Development, Education and Training – information on training opportunities available across Australia – National LGBTI Health Alliance
- Victoria - HOW2 create a lesbian, gay, bisexual, transgender and intersex (LGBTI) inclusive service – interactive training program with 4 x 4.5 hour sessions held 6 to 8 weeks apart. Conducted by Gay and Lesbian Health Victoria (GLHV).

Consumer resources

Section 5: Consumer resources includes a range of downloadable resources about to support conversations about cervical screening.

Women who have experienced sexual assault

Sexual assault is common in Australia, with 19% of women having experienced some form of sexual violence since the age of 15.

Sexual assault includes any unwanted sexual act or behaviour which is threatening, violent, forced or coercive, and to which a person has not given consent or was not able to give consent.

Women who have experienced sexual assault are often reminded of the experience by gynaecological procedures and are less likely to attend for cervical screening. If they do screen, they are more likely to have a negative experience during the procedure.

Women who have experienced sexual assault are also more likely to have higher levels of gynaecological problems and cervical neoplasia.

Barriers to screening

In addition to the general barriers women may face in participating in cervical screening, the following barriers have been identified as common for women who have experienced sexual assault.

Barriers to screening for women who have experienced sexual assault

- Feelings of anxiety, shame, embarrassment, fear and vulnerability
- Avoidance as a way to cope with trauma (i.e. avoiding a gynaecological examination as a way to control or avoiding triggers of trauma response)
- Reluctance to disclose sexual assault to a healthcare provider
- Parallels with the abuse situation/reminder of the sexual assault – for example, perceived loss of control, the power disparity between healthcare providers and patients, feeling exposed and the physical sensation of the examination. The gynaecological procedure may feel threatening and re-traumatising.
- Lack of trust, feeling unsafe
- Availability of a female doctor or nurse
- Physical pain/discomfort during examination
- Healthcare providers’ lack of knowledge about the impact of sexual assault
- Insensitivity of healthcare providers

**Engagement strategies**

The following strategies have been shown to be effective in engaging women who have experienced sexual assault in cervical screening.

<table>
<thead>
<tr>
<th>Strategy</th>
<th>Detail</th>
</tr>
</thead>
<tbody>
<tr>
<td>Staff training</td>
<td>Encourage all healthcare providers to undertake training about sexual assault, supporting women to participate in cervical screening, managing disclosure and making referrals to specially trained cervical screening providers. This training should build knowledge and skills in order to feel more confident to meet the needs of women.</td>
</tr>
<tr>
<td>Appropriate communication</td>
<td>Present opportunities for disclosure of sexual assault (e.g. including questions during history taking).</td>
</tr>
<tr>
<td></td>
<td>Offer more than one appointment and/or longer appointment times (e.g. the first visit to familiarise the women with healthcare providers, procedure and instruments and the second for the test itself). This strategy will also help build rapport and trust.</td>
</tr>
<tr>
<td></td>
<td>Ask women for their consent before undertaking the procedure.</td>
</tr>
<tr>
<td></td>
<td>Acknowledge the difficulties that screening poses for these women and your willingness to support these women through the procedure.</td>
</tr>
<tr>
<td></td>
<td>Provide women with control over their appointment (e.g. they are able ask to stop the procedure at any time).</td>
</tr>
<tr>
<td>Make the procedure as comfortable as possible</td>
<td>Offer women the opportunity to perform the test in a different position (e.g. on their side rather than their back, letting them have their hands and arms free during the examination).</td>
</tr>
<tr>
<td></td>
<td>Consider use of a smaller speculum.</td>
</tr>
<tr>
<td></td>
<td>In some cases it may be appropriate to offer self-collection.</td>
</tr>
<tr>
<td>Supportive environment</td>
<td>Place relevant posters or pamphlets in your practice to indicate an awareness and willingness to discuss sexual assault and support women to undertake cervical screening.</td>
</tr>
<tr>
<td></td>
<td>Encourage the woman to bring a friend or support person to the appointment.</td>
</tr>
<tr>
<td></td>
<td>Offer and/or advertise the availability of counsellors and provide contact details.</td>
</tr>
<tr>
<td>Patient records</td>
<td>If sexual assault is disclosed, flag this in medical records so healthcare providers are aware for future visits.</td>
</tr>
<tr>
<td>Choice of cervical screening provider</td>
<td>Ensure female cervical screening providers are available.</td>
</tr>
<tr>
<td></td>
<td>Refer women to a cervical screening provider who is experienced in working with women who have experience sexual assault.</td>
</tr>
<tr>
<td></td>
<td>If sexual assault is disclosed, provide additional support and referrals as required.</td>
</tr>
</tbody>
</table>
Healthcare provider resources

**Sexual assault and cervical screening – resource card** – discusses the impact of sexual assault on cervical screening and provides suggestions for supporting victims/survivors (2 pages).

Consumer resources

**Section 5: Consumer resources** includes a range of downloadable resources to support conversations about cervical screening.

Women from remote areas

Women who live in remote areas of Australia have generally poorer health and wellbeing than women in urban areas. There is a higher incidence of cervical cancer in remote and very remote areas, which is likely to be related to the proportionally high number of Aboriginal and Torres Strait Islander women living in these areas.

Although the cervical screening participation rates in remote areas are only slightly lower than those in regional and urban areas, women in remote areas face particular barriers to participation. These barriers are related to access to health services, socioeconomic disparities and privacy issues.

Barriers to screening

In addition to the [general barriers](#) women may face in participating in cervical screening, the following barriers have been identified as common for women from remote areas.

**Barriers to screening for women from remote areas**

- Less access to health services compared to those living in major cities – for example, fewer GPs, fewer female GPs, fewer GPs who bulk-bill, fewer after-hours services, fewer hours when GPs are available and greater waiting times for appointments.
- Geographical remoteness – greater distance to services.
- Socioeconomic disparities (i.e. lower education and income).
- In rural and remote towns women may develop a personal relationship with their healthcare provider. Not all women want to have a close relationship with their cervical screening provider. The lack of social distance in a small town may lead to the lack of privacy.
- Out of pocket costs for health services.

Engagement strategies

Strategies for engaging women from remote areas in cervical screening relate to improving access to screening and to addressing privacy concerns.

- Mobile and outreach services have been effective in engaging women from remote areas in cervical screening.
- Consider flexible appointments, group transportation and/or transportation assistance.
- Offer opportunistic screening where possible.
• Reduce or eliminate fees for women with a healthcare card.
• Ensure women understand that their privacy and confidentiality will be maintained.

See Engagement strategies for Aboriginal and Torres Strait Islander women for further ideas.

Consumer resources

Section 5: Consumer resources includes a range of downloadable resources that can support conversations about cervical screening.

Older women

Older women may still be at risk of cervical cancer. Although not necessarily under-screened, some older women may face particular barriers to participating in cervical screening. It may be more difficult for a practitioner to collect a cervical screening sample as the transformation zone moves higher up the vaginal canal as women age. Post-menopausal women may be reluctant to have a Cervical Screening Test as changes to oestrogen levels can cause vaginal atrophy and dryness, which can make the procedure uncomfortable.

Woman aged between 70 and 74 years of age can safely exit the National Cervical Screening Program if their last Cervical Screening Test indicates oncogenic HPV has not been detected, as they have a low risk of developing cervical cancer.

Woman aged 75 years or older who have never had a Cervical Screening Test or has not had one in the previous five years, may request a Cervical Screening Test and be screened.

Barriers to screening

In addition to the general barriers women may face in participating in cervical screening, the following barriers have been identified as common for older women.

Barriers to cervical screening for older women

• Pain and/or discomfort associated with speculum insertion.
• Misconception that women who have been in a monogamous relationship for many years do not require cervical screening.
• Misconception that if you have gotten to this age and never had a screen that there is no need to have one now
• Misconception that women who are no longer sexually active do not require cervical screening.
• Misconception that women who have had a hysterectomy do not require cervical screening.

Engagement strategies

The following strategies may be effective in engaging older women in cervical screening.
<table>
<thead>
<tr>
<th>Strategy</th>
<th>Detail</th>
</tr>
</thead>
<tbody>
<tr>
<td>Explain that HPV may lay dormant</td>
<td>It is important to convey to older women that HPV is common and may lay dormant for many years, even decades. Reinforce that no matter how long it has been since a woman was last sexually active, cervical screening is still important to help prevent cervical cancer.</td>
</tr>
<tr>
<td>Determine type and reason for hysterectomies</td>
<td>Women who have had a hysterectomy should discuss whether vaginal screening is required with their healthcare provider. The answer will depend on the type of hysterectomy performed (i.e. whether the woman still has a cervix) and the reasons why it was needed.</td>
</tr>
<tr>
<td>Making the Cervical Screening Test more comfortable</td>
<td>With a loss of oestrogen after menopause there is a natural decline in vaginal lubrication and the vaginal walls can become thinner and dryer, contributing to pain or discomfort during vaginal examinations. Discuss cervical screening and determine whether your patient finds the Cervical Screening Test painful. A short-course of vaginal oestrogen cream can be effective in preparing the vagina temporarily for a more comfortable Cervical Screening Test as it reduces vaginal atrophy and dryness.</td>
</tr>
</tbody>
</table>

**Consumer resources**

Section 5: Consumer resources includes a range of downloadable resources that can support conversations about cervical screening.

**Women who experience socio-economic disadvantage**

NCSP participation data from 2014–15 showed 51% participation for the lowest socio-economic group compared to 63% for the highest socio-economic group (AIHW 2017).

**Barriers to screening**

In addition to the general barriers women may face in participating in cervical screening, the following barriers have been identified as common for women who experience socio-economic disadvantage.

**Barriers to cervical screening for women who experience socio-economic disadvantage**

- Cost: out-of-pocket expenses associated with going to the GP unless bulk billing is available, and pathology costs if laboratories charge higher than the MBS fee
- Low education levels
- Literacy barriers
- Competing priorities, such as employment, access to food etc.
Engagement strategies

The following strategies may be effective in engaging women who experience socio-economic disadvantage in cervical screening.

<table>
<thead>
<tr>
<th>Strategy</th>
<th>Detail</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reduce out-of-pocket costs</td>
<td>Reduce or eliminate fees for women with a healthcare card</td>
</tr>
<tr>
<td>Service flexibility</td>
<td>Offer screening opportunistically</td>
</tr>
<tr>
<td>Appropriate communication</td>
<td>Provide resources explaining the importance of cervical screening that have been written in plain English.</td>
</tr>
</tbody>
</table>

Health literacy

‘Health literacy’ refers to how people understand information about health and healthcare, and how they apply that information to their lives.

In Australia, it has been estimated that almost 60% of adults have a low level of individual health literacy. The proportion of people with low individual health literacy is even higher for people who speak English as a second language.

Low health literacy is a barrier to good health and healthcare. The following diagram provides an overview of some of the steps health services can take to help improve the health literacy of their patients.
Strategies include:

- Asking the patient to repeat the instructions/information they have just been told
- Expressing directions specificity, ‘you must take one week off work’ as opposed to ‘you need to rest’
- Using plain language rather than medical terms
- Sitting face-to-face with patients
- Using simple diagrams and pictures, and
- Repeating directions multiple times.

Healthcare provider resources

Health Literacy – a summary for clinicians – explains how clinicians can help their patients to better-understand health information (8 pages, Australian Commission on Quality and Safety in Health Care).

Supportive systems for health literacy – provides information on how to strengthen health literacy within health services by improving systems and practices. Strategies include implementing a Plain Language Policy and capacity building activities (2 pages, Centre for Culture, Ethnicity & Health).

Consumer resources

Section 5: Consumer resources includes a range of downloadable resources that can support conversations about cervical screening.

Women who have had the HPV vaccine

There has been an ongoing decline in cervical screening participation among younger women (20 to 29 years), which may reflect younger vaccinated women becoming complacent about the need for screening.

It is important to reinforce to women who have received the HPV vaccine that they should still have regular Cervical Screening Tests because the vaccine does not protect against all the types of HPV that are associated with cervical cancer.

Women who began sexual activity before being vaccinated may already have been exposed to HPV.
Informed consent for screening

Women should be supported to make an informed choice about participating in the NCSP. As with all medical testing, informed consent must be obtained before the Cervical Screening Test is undertaken.

Informed consent for screening can only be given if women:

- Have the capacity to give informed consent to the proposed procedure
- Have been given adequate information to enable them to make an informed decision
- Have been given a reasonable opportunity to make the decision
- Have given consent freely without undue pressure or coercion by any other person, and
- Have not withdrawn consent or indicated any intention to withdraw consent.

Involving women in the decision-making process helps to respect their autonomy, and includes acknowledging both the benefits and harms associated with screening.

<table>
<thead>
<tr>
<th>Benefits of cervical screening</th>
<th>Potential harms associated with cervical screening</th>
</tr>
</thead>
<tbody>
<tr>
<td>Regular cervical screening is one of the main methods to prevent cervical cancer.</td>
<td>Cervical screening can lead to treatment of cervical abnormalities that may go away on their own.</td>
</tr>
<tr>
<td>Cervical cancer has a long pre-cancerous stage, which provides an opportunity for the early detection of abnormalities through cervical screening.</td>
<td>There is an increased risk of pregnancy-related morbidity due to unnecessary excisional treatments. (Please note that the risk of treatment-related harm is minimised in the renewed NCSP as reflex LBC will be used to triage samples that have oncogenic HPV types detected.)</td>
</tr>
<tr>
<td>Treatment of cervical abnormalities is highly effective for preventing progression to cervical cancer.</td>
<td>False positive test results may cause anxiety.</td>
</tr>
</tbody>
</table>

Informed consent is particularly important when working with women with low English literacy and women with intellectual disabilities. Healthcare providers should take additional steps to ensure these patients have been given sufficient information, that they fully understand the procedure and that they freely consent.
Health literacy

‘Health literacy’ refers to how people understand information about health and healthcare, and how they apply that information to their lives.

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Low health literacy is a barrier to good health and healthcare. The following diagram provides an overview of some of the steps health services can take to help improve the health literacy of their patients.

Source: The Australian Commission on Safety and Quality in Health Care. Health Literacy for Clinicians

Strategies include:

- Asking the patient to repeat the instructions/information they have just been told
• Expressing directions specifically: ‘you must take one week off work’ as opposed to ‘you need to rest’
• Using plain language rather than medical terms
• Sitting face-to-face with patients
• Using simple diagrams and pictures
• Repeating directions multiple times, and
• Trying to embed all the above into your communication strategy – use plain language, along with graphic, as well as medical terminology (take this is a teaching opportunity) to explain and then get feedback to ensure client understanding.

Healthcare provider resources – general

Discussing cervical screening with women who have never screened – tip sheet with points to include in a conversation about cervical screening (2 pages)

Explaining HPV to women – includes key messages and suggested phrases for explaining HPV to women (2 pages)

Health Literacy – a summary for clinicians – explains how clinicians can help their patients to better-understand health information (8 pages, Australian Commission on Quality and Safety in Health Care).

Healthcare provider training

Cervical Screening Online Training Modules – a series of six nationally accredited on-line training modules about cervical screening. Please refer to the online modules developed in partnership with National Prescribing Service and the Commonwealth Department of Health.

These have been developed to support healthcare providers when communicating with under screened women, the importance of cervical screening. Including videos focused on women from culturally and linguistically diverse communities and women with an intellectual disability.

Module 3 (Communicating the importance of cervical screening) focuses on engagement with under-screened and never-screened women.
Section 2: Self-collection
Aims of self-collection in cervical screening

The Self-Collection Policy of the National Cervical Screening Program aims to improve participation in screening by providing an alternative screening process for asymptomatic women who are under-screened or never-screened.

Patients with symptoms that suggest cervical cancer need diagnostic testing rather than screening. Diagnostic testing involves a co-test and a gynaecological assessment, and may require referral to a gynaecologist for specialist gynaecological assessment. Therefore self-collection is not appropriate.

Eligibility for self-collection

Self-collection HPV testing is now a cervical screening option for under-screened and never-screened women. It is only offered in a clinical setting to women who:

- have never had a Cervical Screening Test and are aged 30 years or over
- are under-screened - defined as overdue for cervical screening by two years or longer and are 30 years of age or over. During the early years of transition to the renewed NCSP, this will mean greater than four years since a woman’s last conventional Pap test or greater than seven years since her last Cervical Screening Test.

Self-collection may be considered during pregnancy in never-screened or under-screened women, following counselling by a healthcare professional regarding the risk of bleeding.

Additionally, women who have experienced Female Genital Mutilation (FGM) may physically be unable to have a speculum examination or a Cervical Screening Test taken by a practitioner. They are also eligible for self-collection.

Managing self-collection results

If the self-collected sample shows that high-risk HPV has been detected the woman will need to return to her healthcare provider for further testing and/or referral to a specialist and should be followed up in accordance with the NCSP: Guidelines for the management of screen-detected
abnormalities, screening women in specific populations and investigation of women with abnormal vaginal bleeding (2016 Guidelines).

Women who have HPV detected (not 16/18) and decline a follow-up test with a speculum examination should be offered a second self-collection HPV test in 12 months. This could be considered part of the same screening event because the women have not received a definite result. As this approach may delay diagnosis of abnormalities in under-screened women, it should only be an option for women who would otherwise be unlikely to complete the screening pathway, and who accept that they will need further testing if the second self-collection HPV test also shows oncogenic HPV detected (any type).

Practice-level considerations

A whole-of-practice approach to Renewal is recommended, with all staff adequately trained on the changes to the National Cervical Screening Program and self-collection. Services will need to determine which of their practitioners will provide self-collection consultations – nurse cervical screening providers, GPs or both, remembering that under-screened women are most likely to engage if they know and trust their health practitioners.

All health services should maintain comprehensive data on their patients’ screening history. Identifying under-screened and never-screened women and flagging them through patient records will help staff to opportunistically offer cervical screening, and potentially, offer self-collection to eligible women if they decline a Cervical Screening Test taken by a practitioner.

Self-collection must be requested and facilitated by a healthcare providers who also offers routine cervical screening services.

Self-collection must be offered and used appropriately.

Points to note when discussing self-collection

- Only offer self-collection to under-screened women aged 30 years or over who meet the eligibility criteria above and have declined a Cervical Screening Test taken by a practitioner. Screening that is not in-line with current recommendations will result in an out-of-pocket fee for patients.
- Be mindful of the barriers many under-screened women face in relation to cervical screening (See Addressing barriers to screening).
- As these women are under-screened or have never screened, you may need to allow a longer consultation time for questions and to address any concerns. Some women may need more time to consider the test and could be booked to return at a later date. These options need to be weighed up with the possibility of the woman not returning, or of her considering the cost of a longer appointment to be a barrier.
- Explain
  - What is HPV?
  - The importance of regular screening.
• What the self-collection Cervical Screening Test is, noting it is almost as accurate as a health practitioner administered Cervical Screening Test but a healthcare provider administered test is the preferred option.

• What different results indicate – it is important to prepare women for different possible results and the associated follow-up tests.

• Check that the woman understands how to complete the test. There have been cases where women have agreed to self-collection, but not taken a sample.

• Women should collect their sample whilst at your health service, either in the bathroom or behind a screen in the consulting room, and return it to you.

• Some women who are eligible for self-collection may not be confident to take a sample themselves. They may prefer for their healthcare provider to take the sample for them during the consultation. If the Cervical Screening Test is completed by the healthcare provider with a swab and no speculum is used, it would still classify as self-collection.

• Discussing results requires sensitivity. Consider how you will provide women with their results. Given these are under-screened women who may be anxious about screening, some health services make appointments for all women to return to receive their self-collection results, regardless of the result.

• All women who have HPV detected will require further testing. It is very important to tell your patients that if HPV is detected they will need to come back for a conventional Cervical Screening Test taken by a practitioner, or be referred for a colposcopy.

• Reinforce the need for regular cervical screening.

Healthcare provider resources


Consumer resources

How to take your own sample for a HPV test – visual step by step instructions (1 page).

Fact sheet: Self-collection and the cervical screening test – information for under-screened or never-screened women in plain English (1 page).


Fact sheet translations: Self-collection and the cervical screening test for Aboriginal and Torres Strait Islander women – available in multiple languages.

Consumer resources – includes a range of downloadable resources that can support conversations about cervical screening.
Section 3: Health service preparation
This section includes information to support health services to implement the renewed National Cervical Screening Program (NCSP).

Information is aimed at ensuring your service is able to provide all women with access to safe, cost effective and culturally sensitive cervical screening. We have included background reading as well as practical tips for improving service accessibility, recall and reminder systems, workforce readiness and quality practice.

Although the focus is on under-screened and never-screened women, much of the information will be applicable to cervical screening in general.

Service level actions to reduce barriers to cervical screening

There are several practical steps health services and cervical screening providers can take to reduce barriers to cervical screening. Options will depend on your service, its capacity and your local community. With the renewal of the NCSP, it is timely for services to consider the following suggestions:

- Reduce or eliminate any out-of-pocket costs for women with a healthcare card
- Reduce or eliminate out-of-pocket costs for women from marginalised groups, including those from under-screened populations as defined in Section 1- Addressing barriers to screening
- Send reminder letters to under-screened and never-screened women to promote attendance
- Encourage all clinical staff within your service to discuss cervical screening with patients even if they are attending for another reason
- Provide education sessions for women in the community
- Have an ‘open day’ so women can see where the Cervical Screening Test will be done and ask any questions
- Display posters in the waiting room reminding women of the importance of cervical screening
- Provide brochures in the waiting room so women can gain more information about cervical screening
- Provide childcare for women accessing your service
- Provide transport for women accessing your service
- Provide after-hours clinics
- Ensure you have equipment that can assist women with a disability accessing your service (consider electronic beds with adjustable height and/or a hoist)
- Promote your service within community groups
- Advertise when female cervical screening providers will be available
• Provide up-to-date program resources in waiting rooms (See Section 5 – Consumer resources).

Healthcare provider training

Ongoing training and professional development are important considerations for cervical screening providers as they help ensure competent, current patient care. For nurse cervical screening providers, continuing professional development is part of the requirements for national registration.

There are several accredited training courses available for general practice staff that may be relevant to cervical screening and/or to working with vulnerable communities. Training options include:

• Courses on Women’s Health, Sexual and Reproductive Health and Family Planning
• Cervical screening workshops
• Briefing / training on renewal of the NCSP
• Clinical audits, PDSA Cycles etc.

Visit RACGP – QI&CPD or contact your Primary Health Network for details on any local training about renewal of the NCSP.

Six interactive, accredited, on-line training modules on cervical screening are available for GPs, nurses and specialists:

• Cervical cancer
• Changes to the NCSP
• Communicating the importance of screening- this module includes information about engaging under-screened and never-screened women
• Screening in practice
• Understanding the screening clinical pathway
• Communicating test results and patient management.

There are many training options available for improving cultural competence and inclusive practices:

• Training for healthcare providers working with Aboriginal and Torres Strait Islander communities
• Training for healthcare providers working with CALD communities
• Cultural Respect Encompassing Simulation Training (CREST) – training to promote culturally sensitive healthcare and communication. Available nationally on-line or as face-to-face training in Victoria. The four modules cover:
  • Introduction to cultural diversity
  • Negotiating between different health beliefs
  • Effective communication when English proficiency is low
  • Communicating culturally sensitive issues.
Healthcare provider resources

Clinical Audit Tool – describes process for using PENCAT to identify under-screened and never-screened women.

Letter/email to under-screened patients – introduces the changes to the NCSP and invites under-screened women to make an appointment.

A range of resources have been developed to support you to communicate the changes to the National Cervical Screening Program to practice staff and patients.
Section 4: Guidelines and screening pathways
These guidelines are important references for the management of screen-detected abnormalities.

The summaries include screening pathways and advice on the management of different HPV test results.

The Clinical Guidelines provide detailed information and recommendations on all aspects of the NCSP.

**Healthcare provider resources**

- NCSP Clinical Guidelines - guidelines for the management of screen-detected abnormalities, screening in specific populations and investigation of abnormal vaginal bleeding, 2016 (291 pages). Sections that may be of interest to healthcare providers working with under-screened and never-screened women include:
  - Chapter 6 – Management of oncogenic HPV test results
  - Chapter 12 - Screening in Aboriginal and Torres Strait Islander women
  - Chapter 15 - Screening in women who have experienced early sexual activity or have been victims of sexual abuse.
Section 5:
Consumer resources
Consumer resources about the National Cervical Screening Program are available on the [Cervical screening resources](#) page.

These resources are available in various languages and for different population groups. Some may be downloaded for printing while others can be ordered in hard copy for your health service.

This diagram of the female reproductive system may be useful for explaining HPV, cervical cancer and the Cervical Screening Test:
Community education sessions

Community education sessions about cervical screening can help to engage under-screened and never-screened women.

Health educators might conduct sessions with existing women’s groups or gather women together for special events, such as Women’s Health Days. Groups may include women’s groups, carers groups, Aboriginal Elders groups, consumer groups, church groups etc.

Tips:

- Where possible, deliver the information in the group’s first language. If group members are from CALD backgrounds, bilingual health educators may be available locally to deliver education sessions about cervical screening. If they are not, engage the assistance of an interpreter.
- For groups of Aboriginal or Torres Strait Islander women, consider engaging, or working in partnership with, local Aboriginal health workers or educators to deliver education sessions about cervical screening.
- Ensure the health educator has a good understanding of their audience and is able to deliver information in a culturally sensitive manner.
- Use visual aids, such as diagrams of the female reproductive system and cervical screening equipment (speculums etc) to explain concepts.
- Allow plenty of time for questions.
- If planning a larger event, include a range of interesting topics and engaging guest speakers to increase the appeal of the event and hopefully, attract more women.
- Providing transport and/or child care may encourage more women to attend.
- Choose a time that works well for the women you are trying to attract. You might find that evenings work better in your community.
Section 6: References and further information
This section provides information on further reading, as well as references for the information included throughout the Toolkit. References include the published evidence behind the barriers to cervical screening and suggested engagement strategies.

**Further information**

- [National Cancer Screening Register](https://ncri.org.au).
- [Cancer Council Australia](https://www.cancer.org.au) – links to the healthcare providers’ section of the Cancer Council website. Section includes clinical guidelines and primary care resources for all cancers.

**Journal articles**

The following journal articles have been included because they include information relevant to engaging under-screened or never-screened women in cervical screening. Although some are several years old and refer to Pap tests as the screening modality, they may still be of interest to healthcare providers.

- **A care team model for cervical screening** - provides an example of a team-approach to increasing cervical screening in general practice and reports on the effectiveness of invitation letters for women with no cervical screening record. *Australian Family Physician*, RACGP, 2015 (4 pages).
- **The role of general practitioners in the continued success of the National Cervical Screening Program** – presents strategies for engaging all women, particularly high-risk and vulnerable women, in cervical screening. *Australian Family Physician*, RACGP, 2014 (3 pages).

**References – General**


References – Aboriginal and Torres Strait Islander women


References – Women from CALD backgrounds


• Victorian Cervical Cytology Registry. Improving Cancer Screening Participation in Under-Screened, Never-Screened and Hard-to-Reach Populations: Environmental Survey Results for Participants. Victoria, Australia: 2010.

**References – Women who have experienced female genital cutting**


• Homed I. *Female genital mutilation/cutting: a mandatory reporting tool to support health professionals*. Melbourne: Women’s Health West; 2014.


References – Women with disabilities


• Walker J, Allan H. Cervical screening and the aftermath of childhood sexual abuse: are clinical staff trained to recognise and manage the effect this has on their patients? *Journal of Clinical Nursing*. 2014;23(13-14):1857-65.


**References – LGBTI women**


• Fish J. *Cervical screening in lesbian and bisexual women: a review of the worldwide literature using systematic methods*. Leicester: NHS Cervical Screening Programme; 2009.


• Smith E, Dyson S. Victorian lesbian, gay, bisexual, gender diverse and intersex people’s participation in cervical cancer screening. Melbourne: Australian Research Centre in Sex, Health and Society, La Trobe University; 2016.


References – Women who have experienced sexual assault


• Carlson K. Barriers to cervical screening experienced by victims/survivors of sexual assault – a pilot study. Melbourne: Centre Against Sexual Assault; 2002.


• Walker J, Allan H. Cervical screening and the aftermath of childhood sexual abuse: are clinical staff trained to recognise and manage the effect this has on their patients? Journal of Clinical Nursing. 2014;23(13-14):1857-65.

References – Women from remote areas


References – Older women


References – Women who experience socio-economic disadvantage


References – Women who have had the HPV vaccine
