

Ability Relationships Sexuality

Accessible Cervical Screening Test Resource Jordina Quain & Felicity Pheasant

Quarterly Forum September 2022





SEXUALITY

EDUCATION

COUNSELLING

CONSULTANCY

AGENCY

SECCA is a non-profit organisation designed to support people with disabilities, in their efforts to learn about human relationships, sexuality and sexual health.



SECCA is a non-profit organisation which supports people with disabilities to learn about relationships, sexuality and sexual health. For support in using this resource or accessing disability appropriate health services, please call us, or visit secca.org.au

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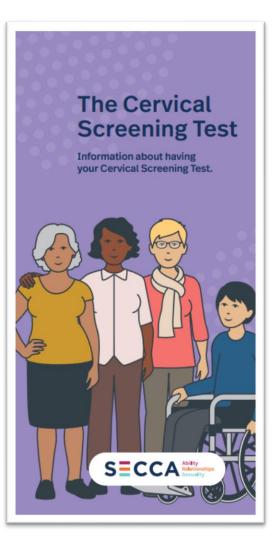
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Your Guide to Cervical Screening

A book about the Cervical Screening Test.





This project was developed in partnership with the WA **Cervical Cancer Prevention Program (WACCPP)**

Thank you to:

- Aboriginal Health Council of • Western Australia
- Centre for Women's Safety ٠ and Wellbeing
- Ishar Multicultural Women's **Health Services**
- Kin Disability Advocacy Inc
- Living Proud •
- People with Disabilities WA
- Self Advocacy WA •
- Sexual Health Quarters



Who?



Who are these resources for?

- Made for people with disabilities who have a cervix and their supports; (25-74 years**)
 - Family/carers
 - Support workers
- Further used by:
 - Health professionals such as general practitioners and nurses
 - Health services who offer Cervical Screening Tests
 - School based teachers (ESC and non-ESC)
 - Teaching Culturally and Linguistically Diverse (CaLD) people









Why?



Why do PWD need to know about cervical screening?

To combat the under-screening of PWD, it is important for organisations to create accessible information to promote the need for cervical screening.

- 70% of Australian women who develop cervical cancer are under-screened or have never been screened (National Cervical Screening Program 2021). They are also under screened for sexual health related testing (Eastgate, 2011).
- In Australia, **1** in **4** (25%) women with disability have experienced sexual violence after the age of 15 (AIHW, 2022). **46%** of women with disability experienced some form of violence since age 15, in comparison with **32.5%** of women without disability (AIHW, 2022).
- The United Nations Convention on the Rights of Persons with Disabilities states PWD have the right to receive sexuality education and have access to information related to sexuality in a format that they can understand (UN, 2016).
- However, PWD are less likely to receive comprehensive sexuality and relationships education. Policies, health professionals, and supports of PWD can sometimes be barriers to accessing adequate sexuality education or information (Frawley and Wilson, 2016).



How?

Development

- Partnership with the WA Cervical Cancer Prevention Program
- Connected with women with disabilities and key stakeholder organisations (listed inside of book)
- Gave feedback on;

What	Explanation	
Layout	Design of the information, how it is presented on the page. Order,	
	organisation of the page, images (e.g., illustrations vs photos)	
Format	How the resource should actually be presented i.e., Brochure, book,	
	flipchart, video, one resource or many etc.	
Language	Specific terminology or general approach of the booklet	
Topics	What information should be included, what should be talked about?	
	What should not be talked about? Order of topics.	
Other resources	Looked at several other existing cervical screening resources – what	
	works, what doesn't work, what would you change/adapt?	



Feedback from women with disabilities

- It does hurt it is not just 'uncomfortable' for everyone
- "Let people know all the things that might happen and why no surprises then."
- Explain words when they are first mentioned
- Booking a longer appointment
- To be able to choose doctor and choose if they are male or female
- Mention that you'll be asked to get undressed
- Having the right to say no or stop etc
- Have had doctors who are rough, so need to be able to ask to be gentle and careful
- Where to go for the test if you are a woman with a physical disability who needs an adjustable bed etc?

Feedback from stakeholders



- How you might be offered an STI check at the same time
- That you can take a support person with you
- Lubricant options and modesty sheet you should be offered them and if you aren't you can ask
- Your rights to say stop, ask questions, you don't have to go to the same doctor again, you can choose a female doc/your choice
- Don't use gendered language "With a cervix" trans inclusive language
- More info about results i.e. who will contact them about results, how long they take, negative results etc.
- Don't say it is a 'quick and easy procedure'
- There is no one size fits all have a range of resources
- Like picture sequencing, photos = bad



Included Chapters & Topics

Human Papillomavirus	Cervical Screening Test	Getting Your Test	Results
What is HPV?HPV vaccine	 What is the Test? Who Should Have the Test? 	 Booking Your Test The Day of the Test 	 What Do Your Results Mean If the Test Dees Net
Cervical Cancer	 Where Do you Get 	 Having the Doctor Do the Test 	 If the Test Does Not Find HPV
The cervixWhat is cervical	the Test?	 Doing the Test Yourself** 	 If the Test Finds HPV
cancer?		After the Test	Glossary
		**Self- collection	Words explained



Challenges

Abstract nature of inside body parts

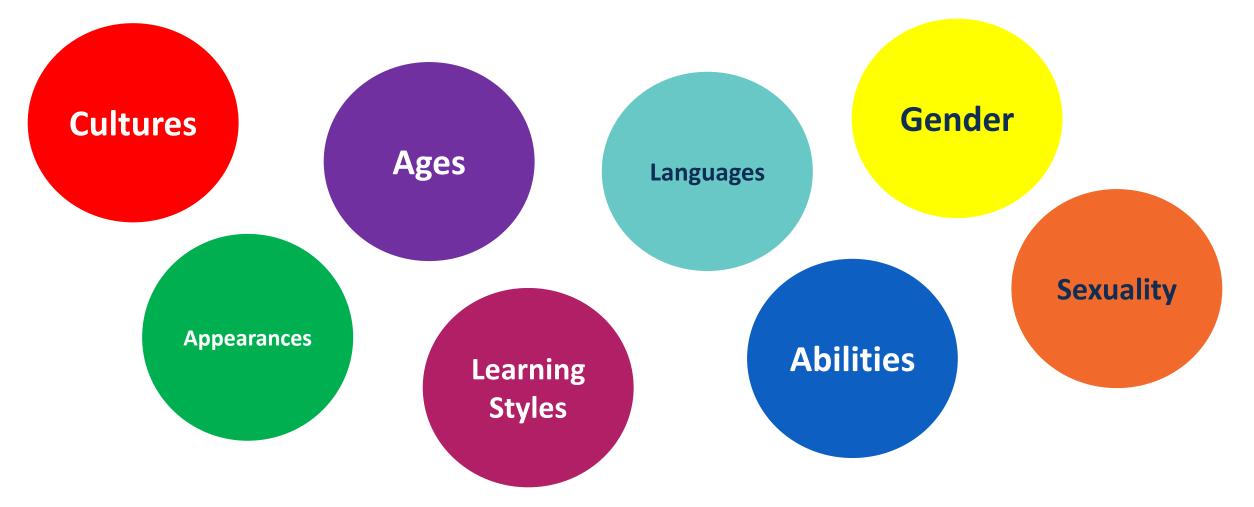
- Explaining cells and cancer
- Describing the cervix and where it is in the body
- Messaging around the test being painful and uncomfortable for many
 - Being trauma-informed
 - Incorporation of self-care before, during and after the Test i.e. breathing exercises, bringing a support person
- Using language that is inclusive of all genders and relationships while maintaining ease of understanding.
 - 'People with a cervix'
- Policy changes around self-collection
 - Extended the project deadline to fall in line with self-collection availability July 2022



What?



Core considerations– **diversity and inclusion!** Evident in images, content discussion and language.





An Inclusive Approach to Different Abilities

People with ...

- Autism Spectrum Disorder –
- Intellectual Disabilities
- Learning Difficulties

Accommodations we can make ...

- Visual information
 - Low reliance of text
 - Tell-it-how-it-is information



SECCA takes a harm minimisation, sex positive, and inclusive approach to resource development.

This was done through 6 main steps...

Your Guide to Cervical Screening

1. Easy English conventions where possible

- Scaffolded information
- Not assuming knowledge
- Not fear based/clarity needed

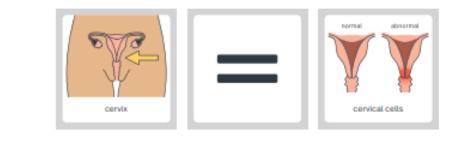
What is Cervical Cancer?

There are lots of **cells** that make up your body. New cells grow every day.

Sometimes they can grow differently. These different cells may turn into a **cancer**. When this happens to the cells of the **cervix**, it is called **cervical cancer**.

Cervical cancer can take a long time to develop.

It can take 10 to 15 years for cervical cancer to develop. It does not happen quickly.





2. Non-shaming and gender-neutral language

- Rare consideration
- Practical
- Importance of diverse team



If your gender on Medicare is listed as male and you have a **cervix**, you will not get a letter inviting you to get a Cervical Screening Test.

You will need to book and have your first test. You will then be added to the Register and will receive reminder letters when you are due for your next test.

Your Guide to Cervical Screening

3. Language that represents diverse people and relationships

- Not making assumptions
- Assume diversity
- Number of partners

Who Should Have the Test?

People between 25 and 74 years of age who have a **cervix** and have ever had **sexual activity** with another person or people should have a Cervical Screening Test.

This includes people who:

- → are healthy
- → are pregnant
- → no longer menstruate
- → have had the HPV vaccine
- → are no longer having sexual activity
- → have not had sexual activity in a long time
- → have only had one sexual partner
- → only have sex with women and other people with vulvas
- → have an intellectual or physical disability
- have a cervix and are transgender, gender diverse, or non-binary.



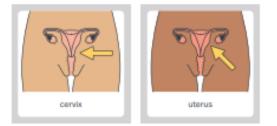
4. Anatomically and functionally correct illustrations

- 'May'
- Skin tone
- 'Inside'

Where and what is the cervix?

If you have a **vagina**, you may have a **cervix**. The cervix connects the **uterus** to the vagina. The cervix is inside your body. You cannot see it from the outside.







5. Images that show representation of diverse people and relationships

- Age
- Ability
- Expression





6. Sharing fact-based rather than values-based information.

- Should



- If your test results show HPV, it is good to remember that:
- → HPV is very common.
- → Most people get HPV at some point in their life.
- → The body can clear most HPV infections within 1 to 2 years.



It can take 10 to 15 years for **cervical cancer** to develop. HPV may not develop into **cancer**.



What now?



General Accessibility Considerations

Practical Content Considerations*

→ Is it a relevant sexuality topic? Yes, if people without a disability have access to the information.

→ Is it age-appropriate?

If under 18 years of age, follow usual government guidelines. Over 18 years of age, PWD have the same right to information as any adult.

→ Do you need to ask for parent or guardian permission?

No, unless the person is under 18 years of age or has a legally appointed guardian.

→ Are you preventing harm?

Key approaches to consider are harm minimisation paired with duty of care vs. dignity of risk.

→ Are you being sex positive?

Don't shame people for their questions, practices, or interests. *These points are expanded on in the support flyer.

Note! These accessibility elements also serve to assist young people, people who speak English as a second language or people with low literacy to understand and comprehend complex health and rights-based information.

Practical Visual Considerations

- → Use high contrast text on light background. Carefully consider font colour with regards to juxtaposition and readability.
- → Use minimum 12pt for text.
- → Use easy-to-read sans-serif fonts such as Arial or Calibri.
- → Leave space throughout text. This can provide "thinking space" or a visual rest.
- → Are PWD represented in the images? Hearing aids, canes, wheelchairs etc.
- → Use symbolic pictures as often as possible to support text.
- ➔ Image sequencing or sorting layout are best.
- → Consider Easy English best practice where possible – one image on the left of the page with matching one sentence on the right.
- → The best and most effective way to convey an image is through a photo, then anatomically-correct illustrations, followed by sketches or outlines.

Practical Written Considerations

- ✓ Be clear and straightforward.
- Include information relevant to how, where or when a support person may be able to assist.
- Provide specific details where possible.
 For example provide phone numbers and referral names rather than "google it" or "go to your local health clinic".
- ✓ Define all acronyms.
- Include image descriptions or "alt-text" on social media posts, in addition to captions.
- Repetition of messaging is encouraged if space allows.
- X Avoid contractions. For example, instead of "don't", use "do not".
- Avoid commas where practicable.
 Create two shorter sentences instead.
- X Avoid complex or long words simple English is best. Alternatively, add a glossary or describe the word in the following sentence.
- X Avoid slang and colloquialisms.

Main takeaways

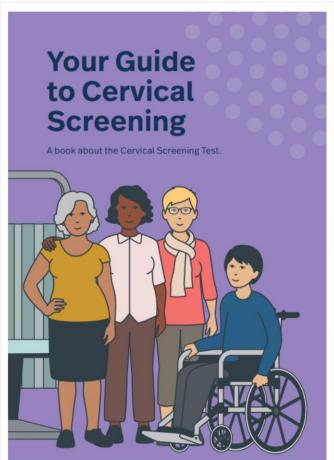
- Don't make assumptions about experiences or knowledge
- Low reliance on text be clear and straightforward
- Use Easy English conventions where possible
- Share fact-based rather than values-based information
- Diverse representation of people and relationships is important
- Use non-shaming and gender-neutral language
- Use anatomically and functionally correct illustrations



Cervical Screening Resources Now

- 100 Hard Copy A5 books and 1100 brochures printed (Launched start of August)
- Free downloadable PDFs of both brochure and book





How can you get copies?

- PDF download on website (brochure & book)
- Come in to the SECCA office
- Contact SECCA or WACCPP to arrange bulk orders of book

ightarrow National Cancer Screening Register (NCSR)	Recement	All SECCA brochur
Change your personal information or find out when you are due for your Cervical Screening Test.	Access the S	Hard copies are al email contact us h
ightarrow WA Cervical Cancer Prevention Program	Access the s	
Information and answers to common questions about cervical screening, including where you can have the test.	Learn	If you need extra s
→ National Cervical Screening Program		→ Your doctor
Information and resources in different languages		Your doctor is the
WACCPP have compiled an access and inclusion guide about Western Australian health providers specialising in sexual health. You can find information about services which have access to facilities such as a bed hoist, ramps, or if there is access to an interpreter.		
Download a PDF here.		
-		

Home → Resources → Your Guide to Cervical Screening Your Guide to Cervical Screening Information about the Cervical Screening Test	
In partnership with the WA Cervical Cancer Prevention Program, SECCA has created a booklet and brochure about the Cervical Screening Test. They are to make sure you feel comfortable before, during and after the test. They will also tell you why it is important to have the test and where you can go to get your test. All SECCA brochures are available to download as a PDF. Hard copies are also available. To place your order for a free copy of any of our brochures, please email contact us here, or call us on 08 9420-7226.	Download 'The Cervical Screening Test' Brochure
If you need extra support with your Cervical Screening Test, there are places you can go for help. → Your doctor Your doctor is the best person to speak with about cervical screening.	Screening Book
Your doctor is the best person to speak with about cervical screening.	$\frac{\text{Download PDF}}{\text{Download PDF}}$

WACCPP's access and inclusion guide**

SECCA

**Which is currently being updated!

Thank you to

The organisations who helped make this book:

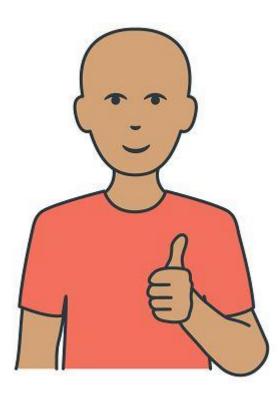
- Aboriginal Health Council of Western Australia
- Centre for Women's Safety and Wellbeing
- Ishar Multicultural Women's Health Services
- Kin Disability Advocacy Inc
- Living Proud
- People with Disabilities WA
- Self Advocacy WA
- Sexual Health Quarters

Special thanks to:

Georgie & Ingrid from Self Advocacy WA

Sharing their lived experiences helped to shape these resources and we are incredibly thankful!

Thank you



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