

Knowledge and attitudes of Australian women towards cervical cancer screening

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DECLARATION

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LITERATURE REVIEW

A review of the literature on cervical cancer and the current climate of cervical cancer screening in Australia is presented in this chapter. The epidemiology is outlined, followed by a discussion of risk factors for cervical cancer. Next, cancer prevention is presented with a particular focus on the newly implemented changes to the National Cervical Screening Program (NCSP). Finally, current attitudes towards these changes and preliminary data indicating the current performance of the renewed program are discussed.

Epidemiology

Cervical cancer is a global public health priority and is considered “one of the world’s greatest public health failures” (World Health Organisation [WHO], 2019, p. 6). With an estimate of almost 50% more deaths by 2040 without immediate action, WHO (2018) has highlighted the need for coordinated international action. Thus, a global health strategy (WHO, 2019) has been drafted, proposing that countries meet several interim targets by 2030 to ensure that cervical cancer does not remain a public health problem by 2100.

Among women, cervical cancer is the fourth most common cancer (International Agency for Research on Cancer [IARC], 2019) and the fourth leading cause of cancer mortality worldwide (Arbyn, 2020). However, Australia is amongst one of the countries with the lowest incidence and mortality rates (Bray et al., 2018; Hall et al., 2019), with a stable yearly increase of nine to ten new cases and two deaths per 100,000 women since 2002 (Australian Institute of Health and Welfare [AIHW], 2019b). The 5-year relative survival rate for 2011-2015 was 73.5% (AIHW, 2019b). The median age at diagnosis is 46.9 years and at death is 61.0 years (AIHW, 2019b, 2019c). Findings from *The Burden of Vaccine Preventable Diseases (VPD) in Australia* study revealed that, in 2015, the rate of VPD burden was highest in adults aged 25-29 mainly due to the likelihood of developing cervical cancer after being infected by human papillomavirus (HPV; AIHW, 2019a).

Cervical cancer incidence and mortality increase with increasing remoteness and socioeconomic disadvantage (AIHW, 2019e). Additionally, disparities in cervical cancer rates have also been observed in population sub-groups. Aboriginal and Torres Strait Islander women, hereafter respectfully referred to as Indigenous women, are more likely to be diagnosed and to die from cervical cancer than non-Indigenous women (AIHW, 2019e). Although there has been a reduction in incidence and mortality rates amongst migrant women

(Aminisani et al., 2012), the Asian community has been observed instead to have higher rates of hospitalisation and mortality (Strong et al., 1998).

Cervical cancer

Cervical cancer is a cancer of the cervix. Abnormal cells developing in the cervical lining may lead to precancerous abnormalities (i.e. cervical intraepithelial neoplasia [CIN] or cervical dysplasia), which eventually develop into cervical cancer and ultimately spread into surrounding tissues (AIHW, 2019a). Subtypes of cervical cancer (see Figure 1) are classified by the origin of the abnormal cell, namely

- a) carcinoma (from the epithelium),
 - a. squamous cell carcinoma (from squamous cells covering the outer surface of the cervix)
 - b. adenocarcinoma (from glandular cells in the endocervical canal)
 - c. adenosquamous carcinoma (containing squamous cells and glandular cells)
 - d. other specified and unspecified carcinoma
- b) sarcoma (from connective tissue), and
- c) other specified and unspecified malignant neoplasms (AIHW, 2018b).

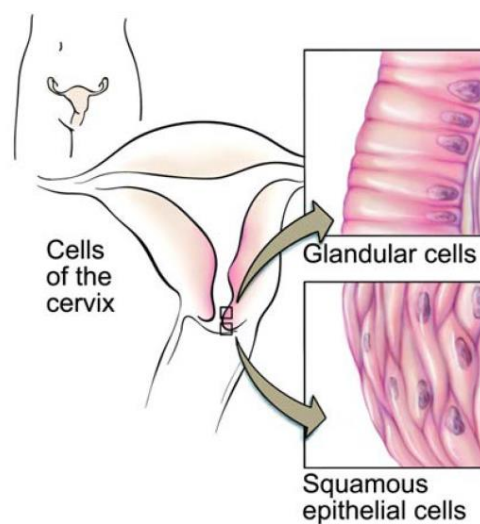


Figure 1. Anatomy of the cells of the cervix and nearby organs. Reprinted from National Cancer Institute Visuals Online 2014.

Of the 757 new cases diagnosed in Australian women aged 25-74 years in 2015, 97.7% were carcinomas, 0.3% were sarcomas, with the remaining classified as other specified and unspecified malignant neoplasms (AIHW, 2019e). The most common subtype for carcinomas was squamous cell carcinomas (69.6%), followed by adenocarcinomas (24.3%; AIHW, 2019e).

Human papillomavirus

The landmark study by Walboomers and colleagues (1999) established the causal role of HPV in the development of cervical cancer. HPV is a very common virus, with more than 100 types (WHO, 2019). An acute HPV infection may lead to low-grade CIN that the immune system eliminates (AIHW, 2018b). However, persistent infection and high-grade CIN may result from an infection by oncogenic HPV types. If left undetected, and/or untreated, over an extended period of one to two decades, high-grade CIN develops into cervical cancer (AIHW, 2018b). Currently, the IARC (2018) recognises 12 different HPV types as causal factors for cervical cancer, with HPV 16 and 18 linked to nearly 70% of diagnoses (IARC, 2012a; WHO, 2019).

Research indicates that HPV infection is the leading cause of almost all squamous cervical cancers and up to 90% of adenocarcinomas (Brotherton et al., 2020). In Australia, HPV is detected in 92.9% of diagnosed cervical cancers (Brotherton et al., 2017). There is, however, a subgroup of cervical cancers that may have become HPV-negative over time due to degeneration of tissue sample (Brotherton et al., 2019) or have developed without HPV, such as rarer forms of adenocarcinoma (Hodgson & Park, 2019; McCluggage, 2016) and a small percentage of neuroendocrine carcinoma and squamous cell carcinoma (Casey et al., 2015; Castle et al., 2018).

Behavioural determinants

Alongside HPV, some behavioural determinants are considered as possible factors in the development of cervical cancer. In Australia, tobacco use and unsafe sexual practices have been recognised as such factors (AIHW, 2019b). The former is an independent risk factor for cervical cancer (Collins et al., 2010; Kapeu et al., 2009), with an increase in risk being proportionate to the duration (Roura et al., 2014) and intensity (Collins et al., 2010; Roura et al., 2014) of smoking. There is a beneficial effect of quitting smoking because the risk of cervical cancer decreases with increasing time since cessation (Roura et al., 2014). Moreover, women who have not smoked in 20 years or more have a similar risk to those who have never smoked (Roura et al., 2014).

Although non-sexual modes of transmission for HPV exist (Sabeena et al., 2017), it is routinely transmitted via sexual contact (Burchell et al., 2006; Burd, 2003), and is recognised as a common sexually transmitted infection (Sabeena et al., 2017). Hence, the risk of contracting HPV increases when one engages in unsafe sexual practices, such as having multiple sexual partners or engaging in irregular or non-condom usage (Burchell et al., 2006; Burd, 2003; Hernandez et al., 2008), leading to an elevated risk of cervical cancer.

Regular cervical screening is identified as a protective factor by Cancer Australia (2017) due to detection of high-grade CIN through screening, allowing CIN to be treated before it develops into cervical cancer. The reduction in incidence and mortality rates in Australia has been attributed to the introduction of the National Cancer Screening Program (NCSP) in 1991 (AIHW, 2019e; Blomfield & Saville, 2008; Canfell et al., 2006; Luke et al., 2007). Higher risk was observed in women who did not screen regularly; 18.7% of women screening at regular intervals, 29.8% of women who engaged in irregular screening (i.e. under-screeners), and 51.5% of women who had never screened (i.e. never-screeners) were diagnosed with cervical cancer between 1 January 2002 and 31 December 2012 (AIHW,

2018a). In addition, women who received a diagnosis through screening were 87% less likely to die than never-screeners (AIHW, 2018a).

Long-term contraceptive usage of more than five years is another possible risk factor (Cancer Australia, 2017; WHO, 2014). However, due to contradictory findings concerning the relationship between cervical cancer and contraceptive usage (Peng et al., 2017), WHO (2014) has considered this risk factor to have the weakest evidence. Collectively, the evidence suggests that the long-term usage of oral contraceptives doubles the risk of cervical cancer (International Collaboration of Epidemiological Studies of Cervical Cancer, 2007) in women infected with oncogenic HPV types (IARC, 2012). This risk decreases within five years of discontinuing usage of oral contraceptives with no evidence of increased risk in women who discontinued (IARC, 2012; Iversen et al., 2017).

Cancer prevention

Cervical cancer is highly preventable (AIHW, 2018b). Hall and colleagues (2019) anticipated the elimination of cervical cancer in Australia by 2035 due to the successful implementation of the National HPV Vaccination Program (NHVP) and the NCSP.

HPV vaccination is considered the most effective long-term intervention against cervical cancer (WHO, 2019), and was first introduced to Australian females in 2007 and extended to males in 2013 through the NHVP. It is Australia's primary method to prevent infection with oncogenic HPV types using the vaccine, Gardasil, which protects against HPV Types 6, 11, 16 and 18 (AIHW, 2019e). Significant declines in HPV 16/18 infection rates were documented for women aged 18-35 years in 2015 (Machalek et al., 2018), which is indicative of the effectiveness of Gardasil because women vaccinated during school years were moving into the age groups at which screening is recommended (AIHW, 2018b). In 2018, a new vaccine, Gardasil9, that protects against five additional HPV types (i.e. 31, 33, 45, 52, 58) was introduced (AIHW, 2019e). Gardasil9, hence, protects against nine strains of

HPV, which are associated with most cervical cancers diagnosed in Australia (Brotherton et al., 2017). Furthermore, HPV vaccination has led to herd immunity, thereby increasing the protective effect for the community (WHO, 2019). However, neither vaccines provide full protection against cervical cancer.

Secondary prevention is achieved through identification and treatment of precancerous lesions (WHO, 2019). Through cervical screening, women who are more likely to have abnormal cells are identified and undergo further diagnostic testing (AIHW, 2018a). Most high-grade CIN can persist for many years before progressing to malignant tumours, so it is possible to detect and treat them at the precancerous stage, especially since screening is conducted with asymptomatic women, allowing for better prognosis (AIHW, 2018a, 2018b). Moreover, regular screening increases accuracy and allows for better detection of CIN (AIHW, 2018b). However, approximately 1% of cervical cancers cannot be detected by cervical screening due to the lack of a precancerous stage (AIHW, 2018b) so cervical cancer screening is unable to prevent all cervical cancers. Nevertheless, it is crucial to attend regular screening even when vaccinated because the vaccines do not cover all oncogenic HPV types. Furthermore, cervical screening is a crucial prevention strategy for unvaccinated women (AIHW, 2019e), especially older women who are not eligible for vaccination.

National Cervical Screening Program

The NCSP, implemented in 1991, is a nationwide screening program (AIHW, 2018b) for identification and treatment of high-grade CIN in asymptomatic women before they develop into cervical cancer, and has successfully halved the number of new cases and deaths since implementation (AIHW, 2019e; Blomfield & Saville, 2008; Canfell et al., 2006; Luke et al., 2007). Research has consistently shown regular screeners having a lower risk of cervical cancer and mortality if diagnosed than under- and never-screeners (AIHW, 2018a; Victorian Cytology Service, 2017). Between 2002 and 2012, there were 3.5 times more

diagnoses in never-screeners compared to those who were regular or irregular screeners (AIHW, 2018a). Women whose cervical cancers were identified through screening had an 87% lower risk of mortality compared to never-screeners (AIHW, 2018a).

Discrepancies in screening

Although the NCSP has been considered a success within Australia, low participation within certain socio-demographic groups and the failure to engage in regular screening have been factors that limit its effectiveness (Mullins et al., 2014). As mentioned previously, women from lower socio-economic backgrounds, rural areas, migrant backgrounds and Indigenous heritage are less likely to screen (Aminisani et al., 2012; Anaman et al., 2017; AIHW, 2019; Strong et al, 1998). In turn, this has been reflected in the incidence and mortality rates (Aminisani et al., 2012; AIHW, 2019; Strong et al, 1998).

Barriers in screening

Other than socio-demographic factors, several individual barriers impact cervical cancer screening participation. These barriers appear to be universal (Hope et al., 2017; Mullins et al., 2014; Waller et al., 2009). A recent survey commissioned by the Australian Cervical Cancer Foundation (ACCF, 2019) revealed that of the 1005 women surveyed, 32.3% found cervical screening awkward, and 27.6% felt embarrassed. One in ten also had concerns regarding their vagina's smell, appearance, or whether it was irregular (ACCF, 2019). 37.1% of the women delayed their screening due to the perception of it being uncomfortable (ACCF, 2019). Other reasons include screening being painful (18.5%); needing to expose oneself (17.7%); feeling fearful (15.8%); feeling violated (8.6%); and having a male general practitioner (8.4%; ACCF, 2019). Some Australian women have also identified logistical barriers, in which they delay screening due to the difficulty finding the time or a suitable doctor (Mullins et al., 2014)

In other countries, identified barriers include distrust of the screening test (Waller et al., 2009); distrust of the medical profession (Hope et al., 2017; Jia et al., 2013); finding it unnecessary to screen due to not being sexually active (Waller et al., 2009) or in the absence of symptoms or discomfort (Hope et al., 2017; Jia et al., 2013; Waller et al., 2009); lack of invitation/reminder from medical professionals to attend screening (Enerly et al., 2016; Marlow et al., 2019); previous sexual abuse (Cadman et al., 2012); and adverse childhood experiences (Alcala et al., 2017). There are also cultural barriers in certain demographic groups; for example, in China, the disapproval of the husband decreases the likelihood of the wife engaging with screening services (Jia et al., 2013).

Similar to other countries (Marlow et al., 2019), the ACCF survey also found a general lack of knowledge regarding cervical cancer and its screening, with 57% of Australian women surveyed not knowing or being unsure of what HPV is (ACCF, 2019). Nearly half of women did not realise that the Papanicolaou smear (i.e. Pap Test) has been replaced by the Cervical Screening Test (CST), and only 34% correctly identified CST as a screening tool for HPV DNA. Additionally, the majority were unsure about the five-yearly interval for screening. The lack of understanding about cervical cancer and its screening poses as an obstacle in engagement with screening services. Studies in the Netherlands (Hansen et al., 2011) and China (Jia et al., 2013) have shown that women who are more knowledgeable about cervical cancer and its screening are more likely to screen. In Australia, women who have received the HPV vaccine are also more likely to screen than unvaccinated women, possibly because they have a better understanding of the reasoning behind screening and/or will potentially engage in healthy behaviours (AIHW, 2018a). Hence, this highlights the importance of well-designed public health campaigns in raising awareness and public knowledge about cervical cancer and the benefits of screening.

Implemented changes to the Australian National screening program

The reduction in incidence and mortality have not been uniform across all cervical cancer subtypes despite the implementation of NCSP (Blomfield & Saville, 2008). The number of new cases per 100,000 women for squamous cell carcinoma dropped from 12.4 in 1991 to 6.8 in 2014 whereas for adenocarcinoma, the rate went from 2.8 new cases per 100,000 women in 1991 to 2.4 in 2014 (AIHW, 2018b). Cytology has since been recognised as being more sensitive in detecting squamous abnormalities and less sensitive when identifying glandular abnormalities (Bansal et al., 2016; Blomfield & Saville, 2008; Cullimore & Waddell, 2010). Moreover, the introduction of an HPV vaccine, improved knowledge of the development of cervical cancer, and advancements in screening/diagnostic technology led to concerns around the effectiveness and cost-effectiveness of the pre-existing NCSP (AIHW, 2019e). The program was reviewed, to ensure that the NCSP reflects best practice, and on 1 December 2017, a “renewed” NCSP was fully rolled-out (see Table 1; AIHW, 2019e).

Table 1. Implemented changes to the National Cervical Screening Program.

	Cervical Screening Test	Pap Test
Testing	Primary HPV DNA testing (and liquid-based cytology if HPV test is positive)	Conventional cytology
Detection	HPV infections (and abnormal cells if there is an HPV infection)	Abnormal cells
Screening interval	Every five years	Every two years
Age range	25-74 years	18-69 years
Reminder/invitation	Invitation, recall, reminder letters	Overdue reminder
Register	National Cancer Screening Register	State and territory cervical cytology registers
Sell-collection	For women aged 30 years or older who are under-screened or never-screened	No

Adapted from Family Planning NSW (2017).

Testing technology

Within the old program, the presence of abnormal cervical cells was tested for using conventional image-read cytology from samples obtained through the Pap Test (AIHW, 2018b). The Pap Test has since been replaced by the CST (AIHW, 2018b). Although the method for sample collection remains unchanged (i.e. a vaginal spectrum examination with a cervical sample obtained; AIHW, 2018b), the testing technology has been revised. CST consists of two components: 1) testing for the presence of oncogenic HPV DNA, and 2) reflex liquid-based cytology if the HPV test is positive (Canfell, Saville, & Cancer Council Australia Cervical Cancer Screening Guidelines Working Party, 2018; Family Planning NSW, 2017). Results from the test allocated women to three different risk levels with varying clinical recommendations (AIHW, 2019e).

The recommended transition from cytology to HPV testing as a primary screening tool is highly recommended by the WHO (2019). HPV testing is reported to be more sensitive (Canfell, Saville, & Cancer Council Australia Cervical Cancer Screening Guidelines Working Party, 2018; Koliopoulos et al., 2017; Ogilvie et al., 2018) and can detect high-grade abnormalities, including adenocarcinoma and its precursors, earlier than cytology (Ogilvie et al., 2018). However, HPV testing is less specific than cytology, leading to concerns amongst researchers regarding unnecessary colposcopies and biopsies that may cause more harm and increased costs (Koliopoulos et al., 2017; Ogilvie et al., 2018). An Australian randomised control trial, Compass, has been initiated to compare the performance between conventional (i.e. image-read) cytology and primary HPV testing and is in the 5-year follow-up phase with an estimated completion date of December 2023 (Canfell & Saville, 2014; Canfell, Saville, Caruana, et al., 2018).

Screening interval and age

The interval between screening has been changed to every five years (AIHW, 2018b) as recommended by WHO (2019) due to the high specificity and strong negative predictive value of the HPV test.

As recommended by the IARC (2004), women are invited to screen at age 25 years and have an “exit” test performed between 70-74 years (AIHW, 2018b). The incidence of cervical cancer in women below 25 years of age is relatively low with reduced risks stemming from HPV vaccination (Canfell, Saville, & Cancer Council Australia Cervical Cancer Screening Guidelines Working Party, 2018; IARC, 2004). Moreover, CIN occurs regularly and resolve without treatment in these women (Family Planning NSW, 2017; Moscicki et al., 2018). Hence, under the old guidelines, low-grade CIN caused by acute HPV infection are more likely to be detected in women under 25 years, leading to over-diagnosis and overtreatment in this age group (Bekos et al., 2018; Moscicki et al., 2018). Research has since indicated that the harm (i.e. unnecessary treatment with increased risk of adverse pregnancy outcomes, anxiety, financial costs) outweighs the benefits (i.e. cancer prevention and down-staging) in a group of women who have not commenced or completed childbearing (Bekos et al., 2018; IARC, 2004; Kyrgiou et al., 2016; Landy et al., 2014). Furthermore, screening those under the age of 25 years has little or no impact on the incidence rate for cervical cancer (Sasieni et al., 2009), and usually, diagnoses in Australian women aged 25 years and below are made due to the presence of abnormal symptoms instead of a positive Pap Test (Morgan et al., 2017).

Self-collection

As identified previously, various barriers affect engagement with cervical screening services. Hence, as part of the new NCSP, self-collection is now offered to under- or never-screeners through a healthcare provider (AIHW, 2018b). Eligible women can obtain their

vaginal samples by using a device that is subsequently tested for the presence of oncogenic HPV DNA. If the sample tests positive, they will be recommended to see a medical professional for a clinician-collected sample or referred for colposcopy (AIHW, 2019e). Self-collection is widely recognised as a method to increase cervical screening participation (Gupta et al., 2018; Madzima et al., 2017; Pedersen et al., 2018; Racey et al., 2013). Many countries have either included self-collection as part of their screening program (e.g., the Netherlands; Aitken et al., 2019) or begun trials (e.g. Malaysia; Hendrie, 2019) or investigations into the effectiveness of self-collection (e.g. America; Reisner et al., 2018; Waits, 2019). A recent study revealed that both self- and clinical-based sampling achieved similar accuracy (Polman et al., 2019). However, within Australia, consistent with the meta-analytic findings of Arbyn et al. (2014), self-collection is considered as less sensitive and specific than a clinician-collected sample (Family Planning NSW, 2017) but more sensitive than a Pap Test.

In terms of acceptability of self-collection, a meta-analysis of 37 studies revealed that on average, 97% of women ($n=1470$) considered self-collection to be generally acceptable and 87% of those sampled ($n=2660$) were willing to engage in self-collection again (Nelson et al., 2017). Within a random sample of 3000 Australian women aged 18-69 years, 34.0% preferred to self-collect their samples, and under-screeners and never-screeners were more likely to have a preference for self-collection (Mullins et al., 2014). Findings from another Australian study ($n=746$) investigating home self-sampling revealed that majority of participants found the instructions clear (98%) and the swab easy to use (95%), with 88% of them willing to self-collect again (Sultana et al., 2015). In addition, 75.8% of those who tested positive for oncogenic HPV DNA ($n=140$) followed clinical recommendations for further colposcopy or cytology within six months (Sultana et al., 2016). These findings are consistent with those from studies conducted in Norway (Enerly et al., 2016), Italy (Giorgi

Rossi et al., 2015) and the Netherlands (Gok et al., 2012). However, the above-mentioned studies used a home-sampling model, so their findings are only suggestive due to being incomparable with the NCSP recommendations. Despite that, preliminary results from the renewed NCSP program are positive. 65.2% of Australian women who tested positive through self-collection in 2018 complied with having a clinician-collected sample within six months (AIHW, 2019e), suggesting compliance with clinical recommendations.

Although there are similar fears around self-collection as to clinician-based collection (e.g. discomfort, anxiety, pain), self-collection can potentially overcome many of the practical and perceived barriers that exist for clinician-collected samples (Gupta et al., 2018). For example, those who preferred self-collection reported it to be easier, more convenient and comfortable, less embarrassing and as providing more privacy (Howard et al., 2009; Mullins et al., 2014; Nelson et al., 2017; Sultana et al., 2015). With an expected lifetime risk of cervical cancer to be reduced by 41% if women engage in a single round of self-sampling at age 30 or 40 years (Smith et al., 2016), barriers, including the lack of confidence in collecting the sample correctly and concerns about test accuracy, need to be addressed to further increase the acceptability and usage of self-collection among under- and never-screeners.

National-based cancer registry

The delivery of the renewed NCSP is now supported by the National Cancer Screening Register (NCSR) whereas previously, each state and territory were in charge of their cervical cytology registers (AIHW, 2019e). The NCSR is an “opt off” service, which stores screening participation and results, and allows various stakeholders to access relevant information to inform recommendation for follow-up or action (Family Planning NSW, 2017). It also issues letters of invitation or reminders to eligible participants (Family Planning NSW, 2017).

Australian attitudes towards cervical cancer and a renewed NCSP

The success of the renewed NCSP is dependent on both the medical profession and the general community accepting and being willing to make changes alongside the new program (Yap et al., 2016). Within both cohorts, gaps in knowledge of cervical cancer and understanding of the new changes have led to unnecessary concerns. Current health promotion campaigns need to address these gaps to increase understanding and alleviate fears to ensure the continued effectiveness and success of the NCSP.

Health professionals

Royal Australian College of Obstetricians and Gynaecologists (RANZCOG) affiliates ($n=956$; Yap et al., 2016), and non-RANZCOG affiliated general practitioners and nurse practitioners ($n=161$; Denham et al., 2016) were surveyed to investigate their attitudes towards the new NCSP. The majority were willing to follow the new guidelines, but less than 40% of RANZCOG affiliates found the changes acceptable, and 74.3% of non-RANZCOG health professionals felt uncomfortable with delayed screening. They were concerned about the potential impact of the delay in screening age, especially in high-risk groups (i.e., women who were immunosuppressed, unvaccinated or had a history of sexual abuse), and identified a possible consequence as women not participating in other health checks (Denham et al., 2016; Yap et al., 2016). Some were also worried that cervical cancers would be missed due to the increased time between screenings (Denham et al., 2016; Yap et al., 2016). However, they reported being more willing to follow the new guidelines when they knew what the potential changes were and if they considered national guidelines as important (Yap et al., 2016).

Other than ensuring that healthcare professionals understand the new changes, they must have an improved understanding of cervical cancer and its screening. Reported common misconceptions held by health professionals include women in a same sex relationship having a lower risk; cervical cancer in women under 25 years not considered to be very rare

irrespective of HPV vaccination; and cervical cancer in young women being more aggressive and having a poorer prognosis (Denham et al., 2016; Yap et al., 2016). Moreover, contrary to well-established evidence and WHO recommendations (Kyrgiou et al., 2006), many thought screening would not expose young women to unnecessary obstetric risks (Denham et al., 2016; Yap et al., 2016).

However, the survey conducted by Yap and colleagues (2016) is affected by response bias due to the low participation rate of 22.5% so it might not reflect the true attitudes of health professionals towards the changes. Participants in both surveys were also surveyed before implementation of the new NCSP, and their attitudes may have changed since.

General population

Research examining the attitudes of Australian women was mostly conducted by a Sydney-based research team (Dodd et al., 2019; Obermair et al., 2018; Obermair et al., 2019) who analysed 19,633 comments received by a web-based petition (Rossi, 2017) opposing the NCSP changes. 34.6% of comments were related to concerns that were also shared by health professionals (Dodd et al., 2019), that is, screening intervals being too long and screening starting too late meaning mortality rates will increase (Dodd et al., 2019; Obermair et al., 2018). Similarly, a survey conducted with 149 women aged 16-28 years found that 64.9% expressed concerns about the delayed screening age and 68.7% were worried about cancers being missed (Jayasinghe et al., 2016). Although 78.5% of those surveyed were willing to switch to the CST, only 34.1% were willing to screen at five-yearly intervals from 25 years of age whereas 66.2% preferred to screen yearly (Jayasinghe et al., 2016), consistent with findings from Dodd and colleagues (2019) of women preferring more frequent screening.

Such concerns were more likely to be observed in those under 25 years and/or those who previously had and/or knew someone who had been diagnosed with cervical abnormalities (Dodd et al., 2019; Obermair et al., 2019). These women also expressed

support for the Pap Test, which they identified as preventing their (or their family member/friend's) death (Obermair et al., 2019). A similar theme was identified within online comments whereby commenters believed that the CST was less advanced than the Pap Test, and the latter could detect all abnormalities (Dodd et al., 2019). Participants also perceived the changes made were more of a cost-cutting measure (Dodd et al., 2019; Jayasinghe et al., 2016; Obermair et al., 2018). Additionally, unvaccinated women have expressed an unwillingness to adhere to these new changes (Jayasinghe et al., 2016).

Similar to the survey conducted by ACCF (2019), some of the online petition comments and findings from the survey with younger women reflected a lack of understanding around cervical cancer and its screening. For example, some commenters did not realise that screening at a younger age would lead to overdiagnosis and overtreatment; instead, equating more screening to early detection and successful treatment (Dodd et al., 2019). Others believed that cervical cancer is a fast-progressing cancer (Dodd et al., 2019) or found it reassuring to be in a same-sex relationship since they presumed they had a reduced risk of developing cervical cancer (Jayasinghe et al., 2016). However, research has indicated that women's willingness to screen is related to their perception of the importance of the national guidelines rather than their understanding of these guidelines (Jayasinghe et al., 2016) and is likely to improve if health promotion campaigns also provide adequate information for women to understand the importance of adhering to the national guidelines. Information drawn from the petition, in particular, should be considered, but its findings should not be generalised to represent the general population. These findings likely represent a minority who feel passionately against the changes.

Current performance of the renewed NCSP

Performance indicators have been developed by the AIHW (2019e) to monitor key aspects of the renewed NCSP. With the program only having commenced two years ago,

there is insufficient data to calculate many of these performance indicators (AIHW, 2019e). Therefore, this section presents the preliminary data that have since been released by the Australian government and independent researchers. In 2018, 53.7% of women aged 25-74 years screened under the renewed program; women living in more remote and/or lower socioeconomic areas were less likely to screen (AIHW, 2019e). Over three years, 2016-2018, 67.6% of women aged 25-69 years screened for cervical cancer under either the previous or renewed program (AIHW, 2019e). Within the same period, service engagement was lowest in women aged 25-29 years (59.5%) and highest in women aged 40-59 years (above 70%; AIHW, 2019e). In 2018, 19.8% of the eligible population screened within six months of receiving an invitation for screening (AIHW, 2019e).

Hence, NCSP is limited in its reach despite the effectiveness of the program in the reduction of incidence and mortality rates. A substantial proportion of the eligible population in Australia is screening less frequently than recommended unlike other high-income countries who reported participation rates of 70% or above (WHO, 2019). Targeted health promotion campaigns are needed to encourage women to screen more regularly to avoid adverse outcomes.

Conclusion

In this literature review, important aspects of cervical cancer and screening were reviewed. The epidemiology and aetiology of cervical cancer were briefly discussed. The primary and secondary methods of cervical cancer prevention were then presented, followed by an in-depth discussion of the NCSP with a particular focus on the changes that have been implemented as of 1 December 2017. Attitudes towards these changes and the current performance of the renewed program were presented to conclude the review. As proposed in this review, it is important to consider the many barriers to screening, and health promotion campaigns need to target these systematic and individual barriers to increase screening

participation so that the incidence and mortality rates can be further decreased. Future research exploring current knowledge and understanding of cervical cancer and the renewed program will assist with the development of such campaigns.

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JOURNAL ARTICLE

Title Page

Knowledge and attitudes of Australian women towards cervical cancer screening

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Highlights:

1. Poor understanding of changes to the National Cervical Screening Program (NCSP)
2. Health anxiety related to dissatisfaction towards the renewed NCSP including delayed screening age and larger intervals between screening.
3. Well-designed campaigns needed to raise public knowledge about cervical cancer and benefits of screening.

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Abstract

Objective: To examine the knowledge and views of Australian women concerning recent changes implemented to the National Cervical Screening Program.

Methods: 284 female Australians recruited through social media and online forums anonymously completed the online questionnaire, which included questions about demographics, cervical cancer, screening practices, attitudes towards changing practices, and health anxiety. Knowledge of cervical cancer and screening practices was assessed using the Cervical-Cancer-Knowledge-Prevention-64 questionnaire. Health anxiety was assessed using the short version of the Health Anxiety Inventory. Data were analysed using descriptive statistics and correlation analyses.

Results: Gaps in knowledge of cervical cancer and its screening, and a poor understanding of the new changes were observed. Higher levels of health anxiety were significantly related to having a better understanding of cervical cancer ($r=.17, p<0.01$), and greater dissatisfaction towards the renewed program ($r=.13, p=.01$), in particular, a delayed commencement screening age of 25 years ($r=.17, p<0.01$) and the increased interval between screening ($r=.10, p=.05$).

Conclusion: It is essential to address the dissatisfaction within the general community towards the new changes to encourage regular cervical screening.

Practice Implications: Health promotion campaigns should address gaps in knowledge to alleviate fears around screening.

1. Introduction

Cervical cancer is regarded by the World Health Organisation (WHO) as “one of the world’s greatest public health failures” [1] and is anticipated to cause an estimated 50% more deaths by 2040 if immediate action is not taken [2]. In Australia, however, cervical cancer is expected to be eliminated by 2035 due to the successful implementation of two nationwide preventative measures, namely the National human papillomavirus (HPV) Vaccination Program (NHVP) and the National Cervical Screening Program (NCSP) [3], allowing Australia to have one of the lowest incidence and mortality rates [3,4]. Vaccination against HPV is Australia’s primary method [5] of protecting women against oncogenic HPV types associated with the majority of cervical cancers diagnosed within the country [6]. It is considered the most effective long-term intervention by the WHO [1] and has been successful in reducing the number of HPV infections [7]. However, researchers have found HPV-negative cervical cancers, indicating that vaccines do not provide full protection [8,9]. Also, there remains a substantial group of older women who have not received the vaccine and are, hence, not protected from HPV-positive cervical cancers. Therefore, for unvaccinated women, cervical screening remains a vital measure [5].

1.1 National Cervical Screening Program

Introduced as a population-based secondary preventative method in 1991, the NCSP aims to identify and treat precancerous lesions in asymptomatic women before cervical cancer develops [10]. Regular participants of the program are less likely to be diagnosed, and if diagnosed, less likely to die than women who have never participated in cervical screening [11]. Furthermore, the incidence and mortality rates of cervical cancer have halved since the implementation of the NCSP [12,13].

With the success of the NHVP, an increased understanding of cervical cancer, and advancements in screening/diagnostic technologies, concerns around the effectiveness and

cost-effectiveness of the pre-existing NCSP were raised [5]. For example, conventional image-read cytology used to detect the presence of abnormal cervical cells has higher sensitivity in the detection of specific cervical cancer subtypes [14–16], so uniform reductions of incidence and mortality through cervical screening across all subtypes have not been observed [15]. Moreover, women under 25 years of age are more likely to be over-diagnosed and receive unnecessary treatment from the detection of low-grade precancerous lesions, which can otherwise be resolved by the immune system if left untreated [10,17,18]. Thus, screening younger women may cause unmerited outcomes, such as an increased risk of adverse pregnancy outcomes [19]. Therefore, a “renewed” program commenced in December 2017 [5]. The main changes include

- a) replacing the Papanicolaou Smear or “Pap Test” with the Cervical Screening Test (CST);
- b) testing for oncogenic HPV DNA instead of only looking for cervical abnormalities;
- c) changing the screening interval from every two years to every five years;
- d) screening women aged 25-74 years instead of those aged 18-69 years; and
- e) allowing for women aged 30 years or older who do not participate in regular screening or have never screened to undertake self-collection.

1.2 Barriers to screening

Despite its success, low participation rates amongst women from lower socioeconomic backgrounds, rural areas, migrant backgrounds, and Aboriginal and Torres Strait Islander heritage, have limited the NCSP’s effectiveness [5,20,21]. Unlike other high-income countries who reported participation rates of 70% or above [1], only 53% of Australian women eligible for screening participated in 2017-2018, and 68% between 2016 and 2018 [5]. Australian women have identified logistical barriers around finding the time or a suitable doctor as a reason for delaying screening [22]. Individual barriers have also limited participation in cervical screening. A recent Australian Cervical Cancer Foundation (ACCF)

[23] survey of 1005 women revealed that 37.1% of women had delayed screening because of perceived discomfort around the screening procedure. Feelings of awkwardness (32.3%), embarrassment (27.6%) and fear (15.8%) were also reported, and one in ten women had expressed concerns around the smell and appearance of their vagina [23]. Similar negative experiences of screening have also been reported amongst Aboriginal and Torres Strait Islander [24]. Additionally, recent research suggests that concerns held by the medical profession and general community around the renewed program are due to a lack of understanding of cervical cancer, its screening, and the new changes, which has affected their acceptance and willingness to follow the latest guidelines [25–30].

1.3 Attitudes towards cervical cancer and the renewed program

Engagement with the renewed NCSP will remain unclear until sufficient time has passed for collection and longitudinal analysis of participation data. Preliminary results from the renewed program are indicative of compliance with clinical recommendations. The Australian Institute of Health and Welfare found that in 2018, 53.7% of women aged 25-74 years participated in screening, but barriers arising from remoteness and socio-economic status remained [5]. For women who engaged in self-collection, the majority who tested positive for oncogenic HPV DNA returned to obtain a clinician-collected sample within six months [5].

Although healthcare professionals express willingness to follow the new guidelines, many are concerned about possible consequences of delayed screening, such as women forgoing other health checks, and cervical cancers remaining undetected for a longer time [25,26]. Such views are consistent with those held by the general community [29,30]. The public also prefers to screen more frequently than recommended [30,31]. Women diagnosed, or who know of someone diagnosed with cervical abnormalities, are more likely to be supportive of the Pap Test [27] and question the sensitivity of CST, believing it to be inferior

to the former [30]. Moreover, these women support the notion that the changes were part of a government strategy to reduce expenditure [29–31]. The ACCF [23] survey also revealed that a substantial proportion of the Australian population was unaware of the changes made to the program.

A good understanding of cervical cancer is necessary to alleviate further fears among health professionals and women. Despite well-established evidence and WHO recommendations, common misconceptions are prevalent among both groups. The majority are unaware of the obstetric risks that cervical screening has for younger women [25,26,30]. They also believe that women in a same-sex relationship have a lower risk of developing cervical cancer, and that cervical cancers in younger women are more likely to be more aggressive with a poorer prognosis [25,26,30,31]. Some consider cervical cancer to be fast-progressing [30], which may impact their desire to screen more regularly. Therefore, to ensure the continued effectiveness and success of the NCSP, adequate information needs to be provided to women and healthcare professionals to address gaps in knowledge and alleviate their fears. However, most research in this area was conducted before the full roll-out of the renewed program; attitudes and knowledge may have changed since and should be examined.

1.4 The Information-Motivation-Behavioral model

Many researchers have utilised the Information-Motivation-Behavioral (IMB) skills model [32] to develop interventions to increase participation in screening [33–35]. In the context of cervical screening, the IMB model (see Figure 1) proposes three conditions needed for women to participate in screening: (a) an adequate understanding of cervical cancer and its screening; (b) motivation to act based on their personal and cultural beliefs, and social norms; and (c) possession of the behavioural skills needed to take action. When the general population has access to and can interpret accurate information meaningfully, personal or

cultural misconceptions about cervical cancer or screening will likely dissipate, increasing motivation to screen. With sound knowledge and motivation, women will be more likely to make an appointment with their general practitioner (GP) to obtain a clinician-collected sample. Furthermore, self-collection will likely further increase the participation rate, especially since it addresses many of the practical and perceived barriers that exist for clinician-collected samples [36].

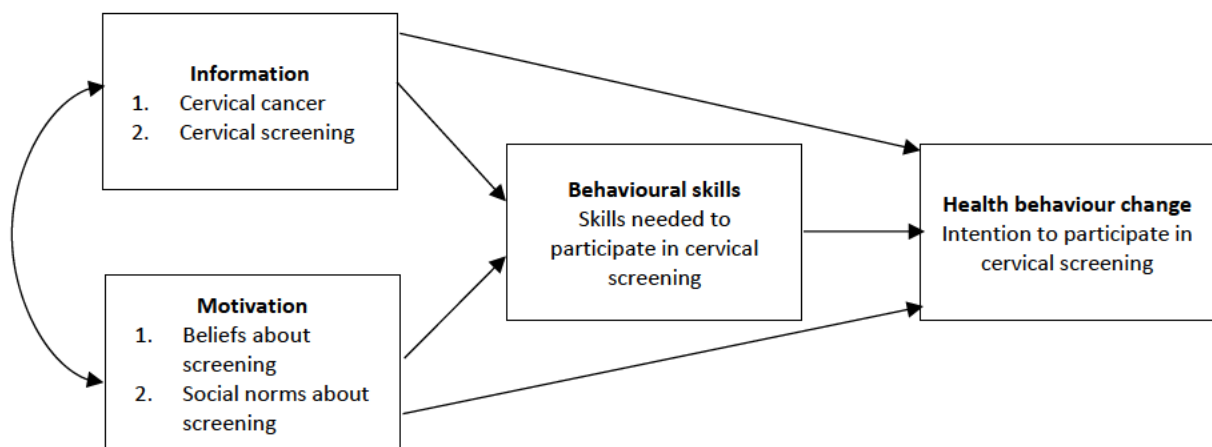


Figure 1. The Information-Motivation-Behavioural (IBM) Skills Model of health behaviour. Adapted from Fisher and Fisher [32] for the context of cervical cancer screening.

1.5 Study rationale

Women vaccinated against HPV have been reported to be more likely to participate in screening than unvaccinated women, possibly due to having a better understanding of the reasoning behind screening and/or will potentially engage in healthy behaviours [11].

Research also indicates that women who are knowledgeable about cervical cancer and its screening are more likely to screen [37,38]. Hence, a lack of understanding of cervical cancer,

and subsequently, not realising the importance to screen may dissuade women from participating in screening.

People who experience health anxiety have been reported to misinterpret health information [39] and their levels of health anxiety increase even after receiving accurate information from a trustworthy source [40]. The literature on whether health anxiety acts as a facilitator or barrier to screening is conflictual. Non-participation has been linked to anxiety in breast cancer screening [41] and skin monitoring [42]. Reviews have shown that the fear of being diagnosed may stop some people from participating in cancer screening, but others tend to use screening to alleviate their fear and are more likely to screen [43,44]. In the latter case, research suggests that health anxiety may not only be related to early cancer detection but also lead to cancer overdiagnosis and over-treatment [45].

Hence, this study aims to extend on existing research by examining the knowledge and current views of Australian women concerning cervical cancer and the renewed screening program, and their receptivity to screening since the revision of NCSP. The relationship between health anxiety and understanding of cervical cancer and its screening will be explored. Past research has indicated that the general attitude towards the renewed NCSP is one of dissatisfaction, so this study aims to explore the relationship between dissatisfaction with the NCSP and higher levels of health anxiety. The findings from this study may inform suitable public health promotion campaigns that will help to address women's concerns and encourage screening.

2. Methods

2.1 Participants

379 potential participants commenced the survey. There were 300 partial completions with 284 women aged between 18 and 80 years ($M = 29.1$, $SD = 13.1$) having knowledge of cervical cancer and completing the entire survey (a completion rate of 74.9%). Most

participants were likely to be in a relationship, have at least Year 12 or equivalent education, and to identify as an Australian for their ethnic group. Demographic information for included participants is reported in Table 1. No significant differences were found between completers and non-completers on demographic measures.

Table 1

Summary of Participant Characteristics (n=284)

Characteristic	<i>n</i> (%)
Age, Mean in years (<i>SD</i>)	29.1 (13.1)
Marital status	
Single / Never married	126 (44.4)
In a relationship	147 (51.8)
Separated / Divorced	11 (3.9)
Education	
Year 12 or equivalent	146 (51.4)
Bachelor Degree	64 (22.5)
Graduate Diploma or Graduate Certificate	12 (4.2)
Certificate / Trade Certificate	40 (14.1)
Postgraduate degree	7 (2.5)
Ethnicity	
African	4 (1.4)
Aboriginal or Torres Strait Islander	2 (0.7)
American	3 (1.1)
Asian	45 (15.8)
Australian	155 (54.6)
European	51 (18.0)
Maori Islander	2 (0.7)
Middle Eastern	7 (2.5)
New Zealander	2 (0.7)
Other	13 (4.6)
Previously diagnosed with cancer	
Yes	5 (1.8)
No	279 (98.2)
Family or friends diagnosed with cancer	
Yes	54 (19.0)
No	206 (72.5)
I do not know	24 (8.5)

2.2 Measures

The survey hosted online via SurveyMonkey consisted of four sections: demographics (i.e., age, education, relationship status, ethnicity, history of cancer for self and family or friends), knowledge about cervical cancer, health anxiety and attitudes towards the newly implemented changes to the NCSP.

Questions about knowledge of cervical cancer, its primary and secondary prevention (including the Pap Test and CST), and sources of information were adapted from the Cervical-Cancer-Knowledge-Prevention-64 questionnaire (CCKP-64) [46]. This measure includes three response formats, dichotomous, Likert scale, and multiple-choice questions. Adaptive questioning was used to reduce the number of questions if participants indicated that they had not heard of the Pap Test and/or CST. Different questions were also displayed based on participants' responses to screening history.

Participants also completed the short version of the Health Anxiety Inventory (SHAI) [47], an 18-item measure, where participants select the statement that best describes their feelings over the past six months. Total scores can range from 0 to 54, with a higher score indicating a higher level of health anxiety. The SHAI has a Cronbach alpha coefficient of 0.89 [38], and 0.88 for the current sample.

2.3 Procedure

The School of Psychology Human Research Ethics Subcommittee at the University of Adelaide study approved this study (Protocol #19/88). Females aged 18 years and above, residing in Australia, and fluent in English were recruited between late September 2019 and May 2020. Recruitment occurred through (a) flyers displayed in public locations (e.g., university campuses); and (b) advertisements on social media (e.g., Facebook, Twitter, LinkedIn), online forums (e.g., Reddit, Whirlpool), and cancer-related organisations. Finally,

the study was also advertised on the SONA platform where first-year Psychology students could complete the research for course credit. No other participants received incentives.

2.4 Data analysis

SPSS Statistics 25 was used for all statistical analyses. Demographic characteristics were summarised using descriptive statistics. Analysis of knowledge and attitudes towards cervical cancer and its screening was only conducted for participants who reported knowing about cervical cancer ($n=284$) to ensure the findings are generalizable to women who have heard of cervical cancer. The relationships between (a) knowledge of cervical cancer and its screening, (b) health anxiety, and (c) attitudes towards the renewed NCSP, were examined using correlations.

3. Results

3.1 Knowledge of cervical cancer

86.6% of participants considered cervical cancer to be a terminal illness, but only 50.0% agreed that it is associated with an infection. 67.3% reported knowing of an effective method to reduce its risk significantly. The top three risk factors reported were HPV infection (98.9%), genetic factors (98.6%), and having a history of sexually transmitted diseases (97.2%). 74.5% of participants selected all four risk factors recognised by Cancer Australia. The top three protective factors reported were regular physical exercise (58.1%), avoidance of highly processed food (53.5%), and refraining from casual sex (47.9%). The top three symptoms reported were intensive periods or bleeding between periods (72.9%), bleeding after intercourse (66.9%), and irregular or lack of menstruation (65.8%). The symptoms recognised by Cancer Australia were accurately identified by 23.9% of the women, but 9.2% of women were not able to accurately identify any of these symptoms.

Table 2

Knowledge of Cervical Cancer (n=284)

	Yes <i>n</i> (%)	No <i>n</i> (%)	I do not know <i>n</i> (%)
Terminal illness	246 (86.6)	2 (0.7)	36 (12.7)
Association with an infection	142 (50.0)	14 (4.9)	128 (45.1)
Effective method to reduce risk	191 (67.3)	5 (1.8)	88 (31.0)
Possible risk factors			
Young age	257 (90.5)	27 (9.5)	-
Genetic factors	280 (98.6)	4 (1.4)	-
Human papillomavirus infection ^a	281 (98.9)	3 (1.1)	-
Human immunodeficiency virus infection	272 (95.8)	12 (4.2)	-
Multiple sexual partners	269 (94.7)	15 (5.3)	-
Early sexual initiation	263 (92.6)	21 (7.4)	-
History of sexually transmitted diseases	276 (97.2)	8 (2.8)	-
Alcohol abuse	247 (87.0)	37 (13.0)	-
Smoking ^a	258 (90.8)	26 (9.2)	-
Miscarriages and abortions	239 (84.2)	45 (15.8)	-
A large number of pregnancies and childbirths ^a	238 (83.8)	46 (16.2)	-
Early menarche	238 (83.8)	46 (16.2)	-
Use of condoms	181 (63.7)	103 (36.3)	-
Hormonal contraception ^a	246 (86.6)	38 (13.4)	-
Breastfeeding	172 (61.6)	112 (39.4)	-
Use of drugs or psychoactive substances	224 (78.9)	60 (21.1)	-
Using public swimming pools	155 (54.6)	129 (45.4)	-
Possible protective factors			
A diet rich in “so-called” antioxidants	73 (25.7)	97 (34.2)	114 (40.1)
Regular physical exercise	165 (58.1)	63 (22.2)	56 (19.7)
Use of vitamin supplements	64 (22.5)	145 (51.1)	75 (26.4)
Proper, long and relaxing sleep	122 (43.0)	90 (31.7)	72 (25.4)
Avoiding highly processed food	152 (53.5)	65 (22.9)	67 (23.6)
Avoiding genetically modified food	99 (34.9)	112 (39.4)	73 (25.7)
Weight loss	91 (32.0)	102 (35.9)	91 (32.0)
Refraining from casual sex	136 (47.9)	83 (29.2)	65 (22.9)
Possible symptoms			
Lack of symptoms from genital areas	109 (38.4)	175 (61.6)	-
Painful menstruation	173 (60.9)	111 (39.1)	-
Intensive periods or bleeding between periods ^b	207 (72.9)	77 (27.1)	-
Irregular or lack of menstruation	187 (65.8)	97 (34.2)	-
Smelly vaginal discharge ^b	135 (47.5)	149 (52.5)	-
Blood stained mucus ^b	169 (59.5)	115 (40.5)	-
Itching in the genital area	73 (25.7)	211 (74.3)	-
Bleeding after intercourse ^b	190 (66.9)	94 (33.1)	-
High fever	66 (23.2)	218 (76.8)	-

^a Risk factors recognised by Cancer Australia; ^b Cervical cancer symptoms recognised by Cancer Australia.

62.3% of participants had heard of the HPV vaccine, of which 53.1% had been vaccinated. The majority of participants reported knowing that the HPV vaccine is available in Australia (92.1%), that it does not provide 100% protection against cervical cancer (83.1%), and where to go to obtain the vaccine (78.0%). 58.8% thought the vaccine is offered free of charge. Nearly half of the participants felt that the best age group to get vaccinated is 14-18-year-olds, whereas 29.4% felt 12-13-year-olds should receive the vaccine.

Table 3

Attitudes Towards the Renewed NCSP (n=284)

	Yes <i>n</i> (%)	No <i>n</i> (%)
Reasons for changes		
Saving costs	125 (44.0)	159 (56.0)
Availability of a more effective detection method	191 (67.3)	93 (32.7)
Advances in treatment	119 (41.9)	165 (58.1)
Uncommon in younger women	156 (54.9)	128 (45.1)
Vaccine effectiveness	143 (50.4)	141 (49.6)
Concerns		
CST being less effective	80 (28.2)	204 (71.8)
CST being less sensitive	103 (36.3)	181 (63.7)
Increased screening interval leading to more serious forms of cervical cancer	190 (66.9)	94 (33.1)
Delayed starting age leading to more serious forms of cervical cancer	169 (59.5)	115(40.5)
Not everyone received vaccination	167 (58.8)	117 (41.2)

3.2 Knowledge of cervical screening

Most participants reported that cervical screening does not offer a 100% chance of early diagnosis (69.0%) and that there is no cost for screening (73.2%). A small group of women believed that screening once eliminated the risk of cervical cancer (5.3%), and screening can lead to complications (5.6%) or increases susceptibility to cervical cancer (9.2%).

Regarding their knowledge and attitudes towards the changes within the renewed NCSP, 43.7% reported knowing of at least one change within the renewed program, with 9.9% being aware of the major changes. 16.2% of participants recognised CST and self-collection as the currently available screening methods within the renewed NCSP, and 61.6% reported knowing either (76.8% for CST; 17.3% for self-collection), while the remaining 22.2% did not realise screening methods had changed. Only 34.5% of participants knew the currently recommended screening interval was five years. The most commonly reported ages for commencing screening were 18 years old (27.8%) and 25 years old (26.4%). 81.7% of participants felt that screening should start by 25 years of age, and 6.0% felt that it should begin once an individual becomes sexually active. When asked about ceasing screening, 19.0% of participants did not know the age or the age bracket and 10.9% thought screening should never stop. The most commonly reported ages for ceasing screening were 60 years old (13.4%), 70 years old (13.0%), 50 years old (8.1%) and 65 years old (8.1%). A small group of women thought screening should stop before 50 years of age (4.9%) or after menopause (2.8%).

3.3 Attitudes towards cervical screening

92.3% of the women felt that they should attend screening. More women knew about the Pap Test ($n=255$) than CST ($n=163$); 83.1% were agreeable to screen using the Pap Test, and 87.1% would undergo CST. However, only 40.5% reported previous participation in cervical screening with the majority of these women (75.7%) having screened within the last three years. In line with the present and past NCSP guidelines, most participants preferred to screen either every two years (37.3%) or every five years (29.6%). 89.8% of participants also felt that screening should begin within three years after sexual initiation.

Of those who had participated in screening, 56.5% reported having the Pap Test, and 18.3% had screened using the CST. Notably, 7.8% confused the CST for the Pap Test or did

not know its name and 19.1% were unsure about which procedure they had. These women reported feeling discomfort or pain during the screening process (53.0%), awkward (42.6%) and embarrassed (30.4%). Other concerns included having a male GP (33.0%), lack of time (20.9%), and smell or appearance concerns about their vagina (20.0%).

Among the non-screener, 75.7% reported that they had not received advice to screen. Other reasons for not screening included not having symptoms (49.7%), concerns around discomfort or pain during screening (27.8%), and feelings of awkwardness (23.7%). Notably, 18.3% did not think cervical screening was necessary because they had been vaccinated, and 10.7% was unsure about the importance of cervical screening.

Of the changes to the NCSP, participants were least satisfied with the delay in the age at which screening commences, with 59.6% having concerns that this delay may lead to the development of more severe forms of cervical cancer (see Table 3). Other primary concerns included the fear of more severe forms of cervical cancer developing due to an increase in screening interval (66.9%) and the possible consequences for unvaccinated women (58.3%). 67.3% of participants believed that changes were made to the NCSP due to the availability of a more effective detection method, while 54.9% thought it was due to cervical cancer being uncommon in younger women with no reductions of incidence or mortality rates despite screening those under 25 years of age. One participant noted that the information she received was “[so] poorly explained...[that she] really have no solid idea” about the changes despite her activeness in seeking information. Overall, 47.5% of participants expressed satisfaction with the current NCSP with 8.8% being dissatisfied, and 43.7% expressing neutrality towards the program.

3.4 Relationship to health anxiety

The range of scores for health anxiety was between 2 and 40 ($M=15.8$; $SD=6.9$). There was no significant difference between screeners ($M=15.7$; $SD=7.1$) and non-screener

($M=15.8$; $SD=6.8$) on health anxiety, $t(282)=-.20$, $p=.85$, $d=0.02$. There was no significant relationship between health anxiety and screening ($r=.05$, $p=0.44$), or changes to the renewed NCSP ($r=.00$, $p=0.95$). However, higher levels of health anxiety were significantly related to a better understanding of cervical cancer ($r=.17$, $p<0.01$). Higher levels of health anxiety were also significantly related to greater dissatisfaction towards the renewed NCSP ($r=.13$; $p=.01$) and to two of the newly implemented changes: a delayed screening commencement age of 25 years ($r=.17$; $p<0.01$) and the increased interval between screening ($r=.10$; $p=.05$). However, there was no significant relationship between health anxiety and the change from Pap Test to CST ($r=.06$; $p=.14$) or screening ending at ages 70-74 ($r=-.04$; $p=.27$).

4. Discussion and Conclusion

4.1 Discussion

This study expanded on previous research by examining the current knowledge and attitudes of Australian women concerning cervical cancer and the renewed screening program, including their receptivity to screening since the revision of NCSP. Women who participated in this study had a better understanding of cervical cancer risk factors than its symptoms or the changes implemented to the renewed NCSP, with a small number having misconceptions around the vaccine and/or cervical screening. The majority were agreeable to screening, but less than half reported ever participating in screening. Concerns around the screening process and implemented changes were explored, revealing misconceptions about cervical cancer, its screening and changes to the NCSP. Almost half of participants expressed satisfaction towards the current program with the least satisfaction around the delayed screening age due to fears more severe forms of cervical cancer may develop due to waiting an additional three years for the next screen. Although dissatisfaction towards the changes was significantly related to higher levels of health anxiety, the women's understanding of screening and the implemented changes were not related to health anxiety levels.

Gaps in knowledge about cervical cancer and its screening observed in the current study are congruent with previous research [25,26,30,31]. Although most participants accurately reported the risk factors, only one quarter knew the symptoms. Moreover, non-screeners thought they did not need to screen due to a lack of symptoms. A small group of women did not know where to obtain the HPV vaccine or believed that the vaccine and/or attending a single screening provided full protection against cervical cancer. This finding is consistent with an Australian study [48], who found that adolescent girls believed cervical screening would be unnecessary after having the HPV vaccine.

The current study identified a poor understanding of the changes within the renewed NCSP. Similar to ACCF's [23] findings, most women did not know about the available screening methods, the recommended screening interval or the age range for screening. Self-collection was the least recognised screening method despite being widely acknowledged as a means to increase screening [36] and preliminary studies indicating good acceptance rates, especially among non- or irregular-screeners [22]. Although many participants were aware that changes were made to the NCSP due to the availability of a more effective detection method, more than half viewed it as a cost-saving measure, did not believe the changes were due to technological advances, and expressed concerns that delaying screening to 25 years of age and screening every five years may lead to the development of more severe forms of cervical cancer. Such concerns have previously been reported among both health professionals [25,26] and the general community [29–31]

Concerns around screening are also consistent with recent Australian findings [23,24]. Similarly, the women in this study who had participated in screening reported feeling discomfort or pain during the screening process, awkwardness, and embarrassment. Many non-screeners reported that they had not received advice about the need to screen. This lack of advice may be due to many participants in the current study being women in their early

20s who are not currently eligible for screening, so future research should target women who are within the current screening range.

Health anxiety was related to knowledge about cervical cancer. Health information about cervical cancer has likely been misinterpreted [39], which may lead to health anxiety. Future studies should explore whether misconceptions around cervical cancer is the main cause for health anxiety or whether there are other significant contributing factors. However, health anxiety was not associated with knowledge about cervical screening or the newly implemented changes. Participants in this study are, on average, relatively young, and may have limited knowledge due to not falling within the screening age range, and, hence, have not developed anxiety around screening.

A significant relationship between higher levels of health anxiety and dissatisfaction towards the current NCSP was found. In particular, higher levels of health anxiety were related to dissatisfaction around the delayed commencement age for screening and the increased interval between screening. This finding may reflect beliefs about the changes being a cost-cutting measure and that delayed screening will lead to more severe forms of cervical cancer. These women are more likely to attend screening earlier and in more regular intervals than recommended, and within the younger population, early detection may lead to over-diagnosis and over-treatment [45]. Both scenarios may impact and overwhelm the health system.

The findings of this study need to be considered in light of its limitations. An online self-report method can lead to biases in sampling. Given that this study examined current knowledge and attitudes about a topical matter, people responding may be those who feel passionately for or against the changes. Moreover, findings from the current study can only be generalised to a specific population: women in their twenties, literate in English. Most participants were in their twenties despite the wide age range and identified as Australian.

Future studies should not only explore the knowledge and attitudes of women who are aged 30 years and above, but also those who identify as belonging to a culturally and linguistically diverse population. This study provides only a snapshot of the current attitudes towards the NCSP. For example, although a significant relationship was found between higher levels of health anxiety and dissatisfaction with the NCSP, correlation analyses do not imply causation. It will be useful to examine trends and whether higher levels of health anxiety lead to dissatisfaction or vice versa using longitudinal studies.

Despite its limitations, this study has provided a greater understanding on the current knowledge and attitudes of Australian women concerning cervical cancer and the renewed program, and highlighted the need for more public education to improve women's understanding in this area. It has also shown that dissatisfaction towards the renewed NCSP was related to higher levels of health anxiety, which may potentially adversely impact the health system. Only with an improved understanding of cervical cancer and the renewed program, along with more positive views of the changes, will women be more motivated to participate in screening [32].

4.2 Conclusion

Almost 75% of Australian women in the current sample reported participating in cervical screening within the last three years, which is higher than the reported rate by the AIHW [5]. This number may increase with increasing satisfaction towards the renewed program. Therefore, it is essential to address the dissatisfaction within the general community and clearly outline the reasons behind the changes, alongside providing education regarding cervical cancer and its screening. Under the IMB model, when women have access to and can interpret accurate information meaningfully, they are less likely to hold misconceptions around cervical cancer and screening, which may, in turn, increase their motivation to attend screening.

4.3 Practice implications

Current health promotion campaigns need to address the gaps in knowledge of cervical cancer, cervical screening, and the newly implemented changes to maximise the effectiveness of the NCSP. The findings from this study, in particular, the significant relationship between health anxiety and satisfaction level towards the current NCSP, may inform potential changes to current campaigns by suggesting the importance of addressing women's concerns and alleviating fears around screening.

"I confirm all personal identifiers have been removed or disguised so the person(s) described are not identifiable and cannot be identified through the details of the story."

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Instructions to Authors (Patient Education and Counseling)

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PEC Manuscript Categories

During online submission, the author can select a category from the following list: Research Paper, Review Article, Short Communication, Reflective Practice, Discussion or Correspondence. The type of manuscript should be indicated in the cover letter.

Research Papers Preference is given to empirical research which examines such topics as provider-patient communication, patient education, patient participation in health care, adherence to therapeutic regimens, social support, decision-making, health literacy, physiological changes, health/functional status etc. Maximum 4000 words. Please note that manuscript word counts EXCLUDE the following: Abstract, acknowledgements, references, tables, figures, conflict of interest statements. Both descriptive and intervention studies are acceptable. Each Research Paper will also require a heading selected from the following to identify the section of the journal to which it best applies: Communication Studies, Patient Education, Healthcare Education, Healthcare and Health Promotion, Patient and User Perspectives and Characteristics, Assessment and Methodology.

Review Articles In-depth reviews of the empirical research in an area relevant to the journal, including analytical discussion of contemporary issues and controversies (maximum 5000 words not including references and tables)

Short Communications Brief articles in any of the above categories will also be considered (maximum 1500 words not including references and tables).

Reflective practice We welcome personal narratives on caring, patient-clinician relationships, humanism in healthcare, professionalism and its challenges, patients' perspectives, and collaboration in patient care and counseling. Most narratives will describe personal or professional experiences that provide a lesson applicable to caring, humanism, or relationships in health care. No abstract is needed. No (section) headings, no numbering. Maximum 1500 words. Submissions are peer-reviewed. For further information, see the editorial published in PEC: Hatem D, Rider EA. Sharing stories: narrative medicine in an evidence-based world. *Patient Education and Counseling* 2004;54:251-253.

Discussion Forum - Papers in the Discussion Forum will include two categories: Discussion Papers up to 3000 words with discussion and commentary on relevant topics within the Aims and Scope of the journal. A Discussion paper should elucidate a theory, concept or problem in an area relevant to the journal.

Correspondence Papers (up to 1500 words) with brief comments on articles in previous issues of the journal.

Guidelines

We encourage authors to consult appropriate guidance, depending on the design of their study. For randomized trials, consult CONSORT (Consolidated Standards Of Reporting Trials) <http://www.consort-statement.org/>

For systematic reviews and meta-analyses consult PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) <http://www.prisma-statement.org/>

For statistical analysis and reporting, consult SAMPL (Basic Statistical Reporting for Articles Published in Biomedical Journals: The "Statistical Analyses and Methods in the Published Literature") <http://www.equator-network.org/reporting-guidelines/sampl/>

For qualitative studies, see specific editorials published in PEC: Finset A. Qualitative methods in communication and patient education research. *Patient Educ Couns*, Volume 73, Issue 1, October 2008, Pages 1-2. DOI: 10.1016/j.pec.2008.08.004

Salmon P. Assessing the quality of qualitative research. *Patient Educ Couns* Volume 90, Issue 1, January 2013, Pages 1-3. DOI: 10.1016/j.pec.2012.11.018

Salmon P, and Young B. Qualitative methods can test and challenge what we think we know about clinical communication - if they are not too constrained by methodological 'brands'.

Patient Educ Couns Volume 101, Issue 9, September 2018, Pages 1515-1517. DOI: 10.1016/j.pec.2018.07.005

PCI Author Instructions**PATIENT-CENTERED INNOVATION****International. Interdisciplinary. Practical.**Author Instructions

In general, submissions to *Patient-Centered Innovation* should clearly reflect the Aims + Scope, with a focus on bringing patient perspectives into the design, implementation, and evaluation of interventions intended to improve health and transform health care delivery. The editors are particularly interested in submissions that highlight user-centered design and innovation with practical value that can advance the pace and sustainability of meaningful change in areas such as care coordination, communication, health care encounters, medical and health professional education, patient activation, patient experience, patient and family engagement, patient involvement, patient-reported outcomes, relationship-centered care, remote monitoring, resilience, self-care, shared decision making, telehealth, and virtual access.

As *Patient-Centered Innovation* is a special feature of *Patient Education and Counseling* (PEC), authors will use the PEC site for online submission. The first line of the cover letter must: (1) clearly state that the manuscript is being submitted for *Patient-Centered Innovation*; (2) clearly indicate the type of submission by choosing a category from the following list:

- Research Articles - 2,500 words
- Review Articles - 3,500 words
- Invited Articles + Primers - 2,500 words
- Commentaries + Letters - 500 words

Authors must follow the category-specific instructions before submitting a manuscript. Research Articles, Review Articles, Invited Articles + Primers will go through a rigorous peer-review process to assess scientific quality as well as relevance and utility to patients and health professionals in real-world settings. All accepted and published submissions will be open to a constructive exchange of ideas with a diverse group of stakeholders.

Research Articles (2,500 words). Preference is given to empirical research that either sets the stage for patient-centered innovation (e.g., well designed feasibility studies) or measures the impact of interventions intended to improve health and transform health care delivery. Thoughtful articles on patient-centered research design and/or negative findings are welcome, as they can be instructive for others in the field. Robust use of established measures is encouraged unless there is clear need for a new measurement approach. All Research Articles should have a structured abstract of up to 300 words, using the following subheadings:

- Background
defining the problem to be solved
- Objective
testing the innovation intended to solve the problem

- Patient Involvement
outlining if/how patients were involved in problem definition, solution design or selection, and impact measurement
- Methods
making the process understandable and replicable
- Results
presenting major findings with appropriate, compelling visualizations
- Discussion
integrating results and implications, with attention to limitations, sustainability and spread
- Practical Value
clearly stating why the results of this study matter at a very practical level (i.e., answer the 'so what?' question)
- Funding
sources and role, if any, of the funding organization in the study and/or submission

While the SQUIRE Guidelines were constructed for quality improvement work, authors may find them helpful when constructing their submissions to Patient Centered-Innovation.

Review Articles (3,500 words). Given the variety and volume of work on innovation in health care, well-constructed reviews can be an extremely valuable contribution to the literature. Review articles should catalyze progress by highlighting overlap of, or conflict between, ideas and approaches. All Review Articles should have a structured abstract of up to 300 words, using the following subheadings:

- Background
defining the problem to be solved
- Objective
specifying the scope of the review and the question it aims to answer
- Patient Involvement
outlining if/how patients were involved in the review process
- Methods
making the process understandable and replicable
- Results
presenting major findings with appropriate, compelling visualizations
- Discussion
integrating results and implications, with attention to limitations
- Practical Value
clearly stating why the results of this study matter at a very practical level (i.e., answer the 'so what?' question)
- Funding
sources and role, if any, of the funding organization in the study and/or submission

All systematic reviews and meta-analyses should follow the [PRISMA Guidelines](#).

Invited Articles + Primers (2,500 words). In an effort to build a coherent literature base and common vocabulary, innovators may be invited to share lessons learned and/or essential background that can advance work in Patient-Centered Innovation. These may include articles on innovation design and development, innovation capacity and sustainability, health care delivery science, or useful definitions and approaches to work in the field.

Commentaries + Letters (500 words). The editors are very open to submissions - in the form of commentary on published articles, ideas for invited articles, and other correspondence to advance the field - from the full spectrum of stakeholders, including patients, caregivers, other laypersons, innovation leaders, health professionals, and social scientists.

Submission checklist

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- Ensure all figure and table citations in the text match the files provided
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For work described in your article involving human experimental investigations of any kind, must have been carried out in accordance with The Code of Ethics of the Declaration of Helsinki; <http://www.wma.net/e/policy/b3.htm>

Declaration of interest

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Authorship

All authors should have made substantial contributions to all of the following: (1) the conception and design of the study, or acquisition of data, or analysis and interpretation of data, (2) drafting the article or revising it critically for important intellectual content, (3) final approval of the version to be submitted.

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OR

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Title page, Abstract, 1. Introduction, 2. Methods, 3. Results, 4. Discussion and Conclusion, References, Legends.

Discussion and Conclusion should be headed as one section and divided into three parts.

Example: 4. Discussion and Conclusion, 4.1. Discussion, 4.2. Conclusion. 4.3 Practice Implications

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Discussion and Conclusion should be headed as one section and divided into three parts. Example: 4. Discussion and Conclusion, 4.1. Discussion, 4.2. Conclusion. 4.3 Practice Implications

Practice Implications

Articles should include a paragraph or paragraphs entitled 'Practice Implications' as part of the discussion and conclusion, which outlines the implications for practice suggested by the study. Authors should take care that these implications follow closely from the data presented, rather than from other literature. In the event that an article presents very preliminary data or conclusions, these paragraphs may be omitted

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[1] J. van der Geer, J.A.J. Hanraads, R.A. Lupton, The art of writing a scientific article, J. Sci. Commun. 163 (2010) 51–59. <https://doi.org/10.1016/j.Sc.2010.00372>.

Reference to a journal publication with an article number:

[2] J. van der Geer, J.A.J. Hanraads, R.A. Lupton, 2018. The art of writing a scientific article. Heliyon. 19, e00205. <https://doi.org/10.1016/j.heliyon.2018.e00205>.

Reference to a book:

[3] W. Strunk Jr., E.B. White, The Elements of Style, fourth ed., Longman, New York, 2000.

Reference to a chapter in an edited book:

[4] G.R. Mettam, L.B. Adams, How to prepare an electronic version of your article, in: B.S. Jones, R.Z. Smith (Eds.), *Introduction to the Electronic Age*, E-Publishing Inc., New York, 2009, pp. 281–304.

Reference to a website:

[5] Cancer Research UK, *Cancer statistics reports for the UK*.

<http://www.cancerresearchuk.org/aboutcancer/statistics/cancerstatsreport/>, 2003 (accessed 13 March 2003).

Reference to a dataset:

[dataset] [6] M. Oguro, S. Imahiro, S. Saito, T. Nakashizuka, Mortality data for Japanese oak wilt disease and surrounding forest compositions, *Mendeley Data*, v1, 2015.

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