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Women's experiences of the renewed National Cervical Screening Program in Australia 12 months following implementation: a qualitative study

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Abbreviations: HPV: human papillomavirus; NCSP: National Cervical Screening Program; GP: General Practitioner

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ABSTRACT

Objective: To explore women's experiences of the renewed National Cervical Screening Program in Australia from the perspective of women who have received different HPV test results.

Design: Qualitative interview study.

Setting: Australia

Participants: Women in Australia aged 25-74 who reported participating in cervical screening since December 2017, purposively sampled by test result.

Methods: 26 interviews with women aged 25-74 were conducted and analysed thematically.

Results: Three main themes emerged: knowledge and attitudes about the program changes, information dissemination, the meaning and responses to test results and the new test. Some women showed little awareness of the changes, but others understood that HPV is detected earlier than abnormal cells. Some expressed positive attitudes towards the test and were not anxious about less frequent screening. Most women envisaged the changes would have minimal impact on their screening behaviour. Women mainly wanted more information about the changes and the possible results from the new test. Overall women could recall their HPV results and understand the implications for future cervical screening. Anxiety about being at 'increased risk' was more apparent in women who were HPV positive without history of abnormal results.

Conclusions: Women show some understanding of HPV and the new test, but more written and public communication about the changes and possible results are warranted. Efforts are needed to ensure women who are HPV positive without history of abnormal results receive the information needed to alleviate anxiety.

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Keywords: attitudes, cancer screening, Cervical Intraepithelial Neoplasia, Human Papillomavirus

DNA Tests, Qualitative Research

ARTICLE SUMMARY

Strengths and limitations of this study

- The qualitative design enabled us to explore in depth experiences of women residing in Australia who reported cervical screening since implementation of the renewed NCSP and their understanding of the results from the new cervical screening test.
- A major strength is the inclusion of women with a range of test results and provide insight into how much information women perceived they received about the new program and how they understood their test results.
- Due to the qualitative nature of the study, we cannot express the findings as generalisable across the whole population and the sample was restricted to women who could speak English.

INTRODUCTION

As cervical cancer prevention strategies such as the human papillomavirus (HPV) vaccination and cervical screening are increasingly successful in reducing HPV infections[1] and cervical abnormalities,[2] countries worldwide are looking to switch from primary cytology-based cervical screening to primary HPV-based screening.[3–5] Australia was one of the first high-income countries to implement primary HPV-based screening in the Renewal of the Australian National Cervical Screening Program (NCSP) in December 2017, where women aged 25-74 are now screened every five years with primary HPV-based screening.[6]

Primary HPV-based screening changes the screening results women receive. In addition to being told their HPV test result (HPV positive/HPV negative), women will also receive information about their risk of a significant cervical abnormality, determined by the subtype of HPV they have (HPV 16/18 or HPV not 16/18 subtype). Women who are HPV negative (HPV-) will be told they are at low risk and are recommended to rescreen in five years' time (Figure 1). Women who are HPV positive (HPV+) will also have a cytology test. HPV+ women, non 16/18 subtype, who have normal cytology or low-grade abnormalities will be informed they are at intermediate risk and will be recommended to rescreen in 12 months' time. Women with any HPV+ result who have abnormal cytology will be informed that they are at higher risk and will be referred for a colposcopy.[7]

>Figure 1 here<

Previous research has demonstrated a number of negative psychosocial impacts for women testing HPV+ including anxiety and distress,[8,9] feelings of stigma, embarrassment and confusion, as well as concerns about their sexual relationships in terms of trust, fidelity and blame due to concern about the sexually transmitted nature of HPV.[10] Findings from our previous study which surveyed over 1000 women in Australia, also showed women who tested

HPV+ were more anxious and distressed than those who tested HPV-,[11] with anxiety scores 10 points higher than those found in a recent English study.[12]

As most research to date has been quantitative and conducted prior to implementing the NCSP changes, there is a need for in-depth qualitative exploration of women's views and experiences of the renewed NCSP in the year since its implementation. Qualitative findings can explore women's first-hand experience of the new program, and their response to the new test results along with their understanding of what these results mean for them, which may be useful for other countries implementing primary HPV-based screening. This study aimed to explore in-depth women's experiences of the renewed cervical screening program, from the perspective of women who have received different test results.

MATERIALS AND METHODS

Participants and recruitment

Participants were women residing in Australia who had received cervical screening since the renewal of the NCSP (December 2017). Participants were recruited through a market research company, Dynata during December 2018. Dynata have a database panel of 600,000 members in Australia to approach participants who meet the eligibility criteria. Participants listed on their database have already indicated a willingness to participate in online research. Women were directed to complete an online questionnaire eliciting demographic and cervical screening information as well as psychosocial measures. At the end of the survey, women were asked if they would like to participate in a follow up interview and if yes, asked to leave their contact details so the research team could contact them.

Participants received points from Dynata which can be redeemed for items such as gift vouchers, donations to charities or cash. Participants first received points that represented

modest compensation for the time spent completing the survey, with further points on completion of an interview.

Participants were purposively sampled from 449 women agreeing to be contacted for interview, to include women from a range of age groups, education and test results (HPV+ 16/18, HPV+ other, HPV-, HPV unknown; Table 1). Of these 449 women, 33 were HPV+, 374 HPV- and 42 didn't know or couldn't remember their result. Data collection ceased when no new themes were emerging from the data and therefore saturation was reached.[13]

>Table 1 here<

Procedure

Semi-structured interviews, using a purpose-designed interview guide informed by a review of previous literature on women's attitudes towards to changes to cervical screening programs, both in Australia[14–16] and overseas,[17,18] were conducted during December 2018.

The topic guide covered questions regarding attitudes, understanding and confidence, expected impact, understanding of results, any psychosocial impacts and helpful educational and other support resources, in relation to the NCSP changes (See supplementary information).

Interviews took place over the telephone and lasted between 10 and 27 minutes. Interviews were audio-recorded and professionally transcribed.

Patient and public involvement

Patients and the public were not directly involved in the design or planning of the study.

Analysis

Interviews were analysed using Framework Analysis, an approach well suited to this type of research due to the organisation of data into a thematic framework which then enables views and experiences to be grouped together and comparisons made across participants.

Both RD and OM familiarised themselves with the transcripts by reading over all the transcripts and making notes of recurring themes. RD developed the initial framework using the qualitative package NVivo 11.[19] The framework was amended through discussions between RD and OM and refined with input from KM. Using NVivo 11, data were summarised and organised into a matrix where each column represented a subtheme and each row a participant. Any disagreements in interpretation were resolved by discussion. The research team members work in the field of public health, with a special interest in reducing overdiagnosis and overtreatment.

RESULTS

We interviewed 26 women with sample characteristics shown in Table 2. Most women in the sample described being regular screeners (every two years). Some women in the sample had experienced abnormalities or a diagnosis of HPV previously and so had been monitored more closely than every two years under the old program.

>Table 2 here<

Three main themes emerged from the data: knowledge and attitudes about the changes, information dissemination, and focus on meaning of results and the new test.

1) Knowledge and attitudes about changes

Despite being screened under the renewed program, some women demonstrated a lack of awareness of the changes to the cervical screening program [Q1; Table 3]. Women who were knowledgeable about the changes tended to be high information seekers and had done their own research [Q2].

>Table 3 here<

Those who were aware regarded the main change to be the extended screening interval, from two year to five years, with a few women understanding that this was due to the change in screening technology [Q3]. Some women understood that what is being tested for has changed,

with the effectiveness of screening for HPV rather than abnormal cells, noting this was earlier detection [Q4]. Overall women noted that the testing procedure was identical to the Pap smear [Q5].

A concern expressed about the extended screening interval was that cancer might develop and be missed in between screens, particularly prominent in women with personal experience of abnormalities [Q6]. A few HPV- women described the need to take responsibility for their own health due to the increased screening interval, which included getting any symptoms which were 'unusual' checked out at the doctor. However, women also expressed positive attitudes including experiencing less anxiety, stress and discomfort due to screening less often. Those women with positive views tended to contextualise these in terms of the new testing technology being more sensitive and more accurate [Q7] and this woman explained how she thought the testing process was much easier if you test HPV+ than previously with the Pap smear due to the ability to test the same sample [Q8].

One woman alluded to the potential for overtreatment if screening with this new testing technology continued on a two-yearly basis, due to the high incidence of HPV and subsequent referrals for colposcopy [Q9].

Some women also related the program changes back to the HPV vaccination, recognising that uptake of the HPV vaccination should impact rates of HPV and therefore cervical cancer. This helped them make sense of the program changes and believed it could also help increase uptake of the HPV vaccination [Q10].

For most women, they envisaged that the NCSP changes would have minimal impact on their screening behaviour. The only tangible impact the NCSP changes would have on their screening behaviour would be having to screen less often.

2) Information dissemination

2.1 Changes to the program

The amount of information women described being given about the changes to the cervical screening program when they attended for screening varied, with women mostly being told about it being a new test and that the screening interval would now be every five years. Some women were made aware of the changes through discussions with their GP/other health professionals; usually these discussions took place in the consultation, when they attended for screening. Most women said that the explanation was brief, but were asked if they had any questions about the changes [Q11]. A few women who attended for their Pap smear prior to December 2017, had been advised by their GP to postpone their screen to December 2017, as then they would then enter into the new program [Q12].

While some women were happy with the amount of information they received and had good experiences [Q13], others described less positive experiences with health professionals when it came to cervical screening, with one woman explaining that she had to go back multiple times as the doctor did not believe she needed to be screened [Q14].

Very few women reported being provided with written information by their GP or other health professional. Women spoke about the need for advertisements on television and in the media to encourage them to go for screening. Radio and internet advertisements were viewed as more likely to reach younger women [Q15].

Women felt information resources such as a pamphlet containing information about HPV and how common it is, would be useful to refer to as well as communicating it as being 'normal'. Additionally, information on self-care in terms of what to do if something is wrong or what potential symptoms could be, was also perceived as important. Being signposted to a website with information about the changes to the screening program and the meaning of results, was also suggested.

2.2 New results

When asked if there was anything that would have helped to better understand screening under the revised program, most women suggested a “staggering of information” over time, where they would receive information about the changes/possible results prior to screening and then again when receiving the results. Women who tested HPV+ in particular wanted to know about the possible results/referral information prior to screening; women who tested HPV- were more indifferent about receiving information about possible results prior to screening. Information about what the results meant was the main focus of seeking information for these women.

Women acknowledged that too much information can be overwhelming and lead to increased anxiety. Women felt information could accompany the invitation letter or be displayed in waiting rooms, with the combination of a brochure and conversation with a health professional being optimal [Q16].

The key time points identified for information delivery were: i) prior to screening, when invited; ii) during screening; iii) when receiving screening results. Information formats suggested by women included information pamphlets in GP offices, web-links to reputable online sources; and posters in shopping centres/public toilets.

3) Meaning of test results and emotional responses to the new test

Women received their screening results in various ways including by letter, over the photo, face-to-face during a GP appointment, or not hearing anything and assuming everything was ok [Q17]. A few women described their anxiety in the time between the test and the results, with one woman expressing this was the first time she’d had the test and so didn’t know what to expect [Q18].

Overall women were able to recall their HPV results (positive or negative) and understand the implications these HPV results have for returning for screening in the future. Even among the

women who did not know their results, they knew when they were due to have screening again. However, these women did not demonstrate knowledge about the nature of HPV, its transmission, and the implications of testing positive (or negative) for HPV and the associated risk of progression to cervical cancer. Some women who were HPV+ did express knowledge that their HPV result did not mean that cancer is inevitable and that these abnormal cells can resolve by themselves without the need for treatment [Q19].

Higher risk women who had previously had an abnormal Pap smear result and/or already knew their HPV+ status (especially types 16/18) due to persistent infection, were less alarmed about receiving an HPV+ result. Similarly, women who had previously had a normal Pap smear result and received an HPV- result were also not alarmed by this new type of result. However, women who had previously had normal Pap smear results were somewhat anxious if they received HPV+ results [Q20]. One woman who tested HPV- but had a previous abnormality would have liked to be tested more frequently [Q21]. Those women who received an HPV+ result would have liked their GP/other health professional to have explained the possible results of this test prior to screening, as a means of preparing them [Q22].

One of the HPV+ women described how initially she was worried about waiting 12 months after being told she screened positive for HPV, but a better understanding reduced her worry [Q23]. Some women told to rescreen in five years were happy to follow the guidelines and recommendations, whereas others, particularly those with a history of abnormal results, were wanting further reassurance and said they would rescreen more frequently [Q24].

One older woman, who was not aware of the high prevalence of HPV, alluded to the stigma associated with an HPV+ result, however there were few instances of women expressing feelings of stigma about being HPV+ [Q25]. Women showed more limited understanding of accompanying cytology changes; especially amongst women with normal cytology and low-grade abnormalities. Women with high-grade abnormalities had better understanding, mainly

because they had a persistent form of HPV and had previously returned abnormal results and/or had also been referred to a gynaecologist for a subsequent colposcopy. Only a couple of women recalled their level of risk (e.g. intermediate risk) for cervical cancer.

Women who were HPV+ talked about their understanding and experiences of the new testing pathway, with one woman describing how the doctor explained it to her using the flowcharts [Q26].

There were some women who felt that healthcare professionals had not adequately explained their results to them. Some women felt the information was not made relevant to them or was too clinical, and that they wanted to be given more detail with their results. These women conducted their own research online to find out more about HPV and what their results meant [Q27].

DISCUSSION

The study findings contribute to our understanding of women's experiences of the deintensified cervical screening program in Australia and provide us with insight into how women have interpreted communication of their test results. Overall, women showed limited knowledge of the changes to the NCSP, but demonstrated understanding about what the results meant for them and their future screening. There was high variability in how the results were communicated to women by their GP/other health professional. Some women reported positive experiences of communication which provided reassurance and aided good understanding of the changes and implications of results, while others reported poor communication of results by their GP/other health professional and felt they had to independently search for further information. The impact of HPV+ results appeared greater in women who had previously had normal Pap smear results. Encouragingly, women envisaged that the changes to the NCSP would have minimal impact on their own screening behaviour. A few women were concerned about changes to the program

leading to missing cancers and getting lost in the system if they moved interstate. These findings mirror those from previous research.[14,20]

Women in this sample were mainly positive about the changes to the program, reflected in comments about the new cervical screening test and perceived the test to be more accurate and effective than the Pap smear. This perhaps reflects a trust in decision-makers, that despite some negative press surrounding the changes, women in this sample trusted that the changes had been made for the better and this was reinforced for some when they were advised by their GP to wait for the new program to be implemented.

It was evident that women still lacked knowledge about HPV and its transmission, particularly in women who were HPV-, and so there is still a great need for community education surrounding cervical screening and HPV. Linking the HPV vaccination to the changes made to the screening program, gave women a tangible way in which to understand reasons for the five-year interval being safe. This could be a good strategy to target both mothers and their daughters to educate them about the importance of cervical screening and how advances in technology has enabled us to now screen primarily for the HPV infection.

Although this sample of women mainly reported being told in their GP consultation about the changes in the test and the screening interval, most indicated that they would have liked to have received some written information and also seen some public advertisements about the program changes, supporting our previous findings.[21] Women also wanted written information about the test results and expressed importance that this is consistent across the program. In addition, how women receive their results should also be standardised, as women in this sample described multiple ways of receiving their results (e.g. phone, person, letter). Some women in this sample reported that they did not know or remember their test results. Our own survey data has shown anxiety and distress were higher in women who did not know their results compared to those who were HPV-.[11] The recommendations provided by the women in

this sample for information delivery to be staged across the screening journey, from prior to screening to receiving the results, are important to consider when implementing a new screening test to help women's understanding of both the reasons for the new test and what the results of the new test mean for them. Women have been shown to prefer active or shared decision making approaches regarding the follow-up of abnormal test results,[22] so it is important women understand what these results mean for them.

Encouragingly, women reported that their doctors communicated with them about the new test and what this now checks for, with women showing an understanding behind the reason for the change in test. This is important as our previous research showed that communicating to women about the change in test can then help provide reassurance and understanding to women about some of the other changes to the program.[21]

The psychosocial impact of screening and test results was evident across the sample, particularly with women screened HPV+. When worry and anxiety were expressed by these women, this was mostly related to testing, results and the extended screening interval. A focus needs to be given to information provision for those women who are HPV+ and who have not experienced abnormal results in the past. It is important that they receive the information they need to alleviate anxiety as these women demonstrated greater anxiety than women who were HPV+ with experience of previous abnormalities. Women with previous abnormalities were less alarmed by their results due to their previous experience and having a greater knowledge of the system, but those who screen HPV- who have a history of previous abnormalities may prefer to be screened more frequently.

Encouragingly, there was a good understanding among women who were HPV+ that cancer was not inevitable and that some cell changes might resolve without the need for treatment, demonstrating good communication from health professionals. This is particularly encouraging given around 8% of women (n=195,606) tested HPV+ in the first 6 months of the renewed

program.[23] Of important note is that this, combined with healthcare providers not adhering to the guidelines, has consequently resulted in the increase in number of colposcopy referrals being much greater than expected.[24] This holds implications for an increased number of women referred for colposcopy and experiencing long wait times, as awaiting to undergo colposcopy has been shown to increase anxiety levels.[25]

Conclusions

Despite women demonstrating an understanding about the new cervical screening test, more written information and public communication about the changes and possible results are warranted. In particular, efforts are needed to ensure women who are HPV+ with no history of abnormal results receive the information they need to alleviate anxiety. Tailored information could take into consideration women's previous cervical screening results and risk for a significant cervical abnormality.

Ethics approval and consent to participate: This study was approved by The University of Sydney Human Ethics Committee (2018/836).

Data availability: The datasets generated and/or analysed during the study are available from the corresponding author on reasonable request.

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Methodology, Funding acquisition, Formal analysis, Validation, writing – review and editing. All authors contributed to the interpretation of the analysis and critically revised the manuscript.

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Figure 1: Australian National Cervical Screening Program results pathway[26]

Table 1: Sampling frame

	Education		Age				HPV vaccine	
	No University	University or Diploma	<35	36-50	51-65	66+	Yes	No
Cervical Screening Test Result								
HPV positive (n=15)								
16/18	2	2	2	2	0	0	1	3
Other	0	6	1	3	1	1	2	4
Don't know/unsure	2	3	1	1	2	1	2	3
HPV negative (n=8)	2	6	3	1	3	1	2	6
Don't know/unsure (n=3)	2	1	2	0	1	0	2	1

NB: numbers total n under each test result across the columns of education, age and HPV vaccine.

Table 2: Sample characteristics

	n (%)
HPV status	
HPV+ high risk	4 (15.4)
HPV+ other risk	6 (23.1)
HPV+ don't know/unsure	5 (19.2)
HPV negative	8 (30.8)
Don't know/unsure result	3 (11.5)
Age	
<35	9 (34.6)
36-50	7 (26.9)
51-65	7 (26.9)
66+	3 (11.5)
Education	
No university	18 (69.2)
University	8 (30.8)
Employment	
Full-time	8 (30.8)
Part-time	7 (26.9)
Retired/studying/other	11 (42.3)
Born in Australia	
Yes	22 (84.6)
No	4 (15.4)
Marital status	
Single/dating	5 (19.2)
Married/living with partner	13 (50.0)
Partnered/not living with partner	1 (3.8)
Separated or divorced	6 (23.1)
Widowed	1 (3.8)
HPV vaccination	
Yes	9 (34.6)
No/don't know	17 (65.3)

Table 3: Quotes from interviews to support the themes

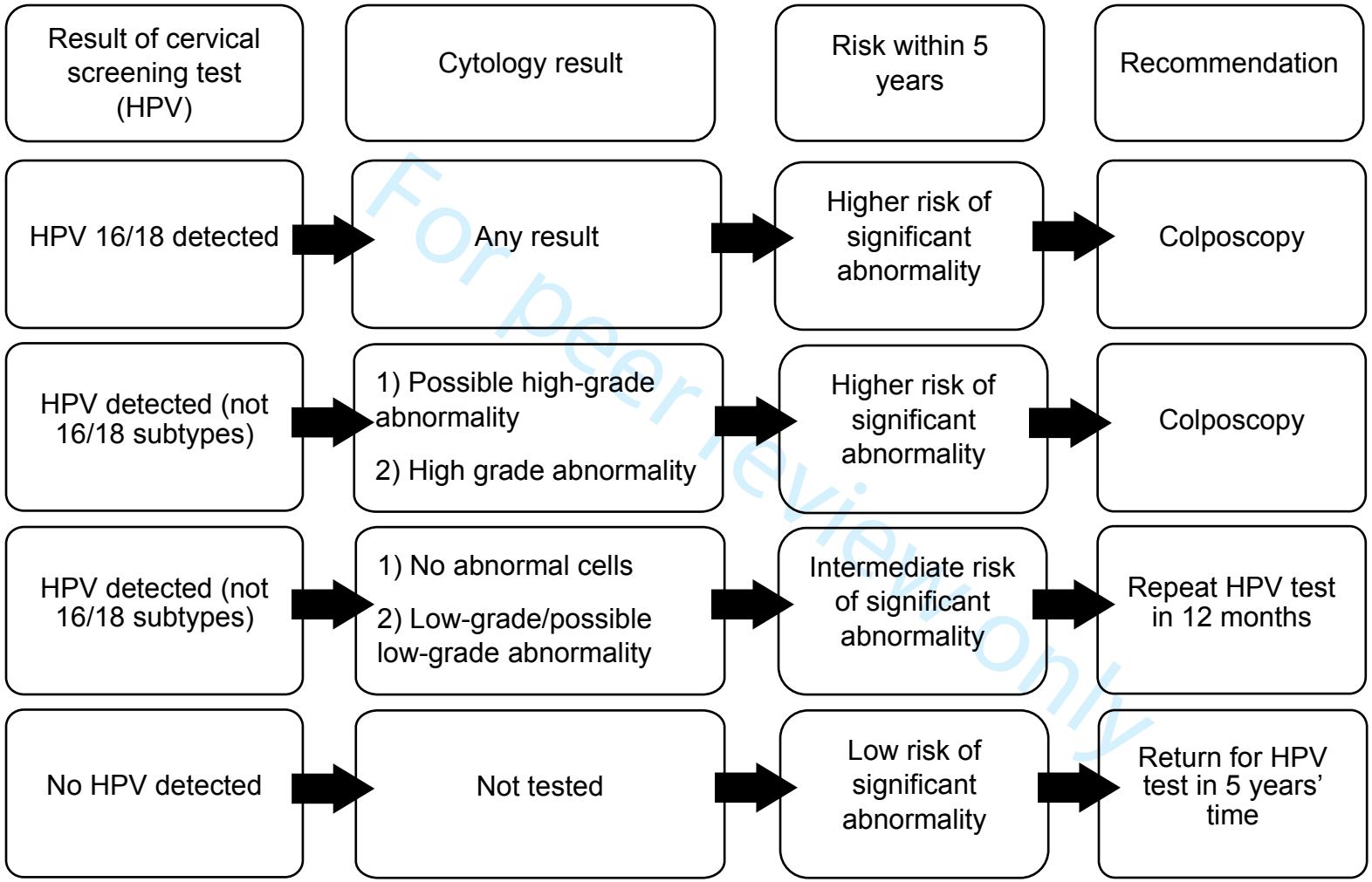
Code	Quote	Page
Knowledge and attitudes about changes		
Q1	*I did see I think a couple of little pop up things about it and I know that a couple of girls in my social circle have mentioned that the new test was available and it was a five year screening, but I haven't seen any other information about what difference it will make. (HPV-, 33 years old, unvaccinated, University degree)*	8
Q2	*I spent a couple of hours actually looking into everything I could find. Just even about HPV itself because I didn't understand any of it.* *It was really useful … but I had to actually go looking for it. It wasn't something that was put out there … If it had been out there it may have been discussed and I might have known a bit more … It would've been good to have been publicly informed in some ways. (HPV+ (not sure), 46 years old, unvaccinated, Diploma or certificate)*	8
Q3	*Well I know that the main change is you only have to go every five years and not every two years because they've developed a different way to look at the cells or something (HPV+ (not 16/18), 30 years old, vaccinated, Diploma or certificate)*	8
Q4	*From what I understand, the technology is drastically improved which means obviously its better technology and they trust the technology better. I think the fact they're tracking the virus that causes the cancer is really good. (HPV-, 47 years old, unvaccinated, Diploma or certificate)*	9
Q5	*I think in all honestly my experience is it's the same … I can't say I've noticed any change to be honest. (HPV+ 16/18 & CIN1, 37 years old, unvaccinated, Trade apprenticeship)*	9
Q6	*My instant reaction is horror because that's a long time without a Pap smear because you don't know what your body is doing. In there if you've got cancer somewhere in that area, it's got five years to spread. (HPV+ (not sure), 66 years old, unvaccinated, School certificate)*	9
Q7	*Well the fact that if it's done every five as opposed to two then obviously having to go for less testing, is less anxiety and less stress so on that basis that's good … If I have to only do it once every five years it's very positive in my view. I think it will encourage more people to do it because it's not something that you have to do that often. (HPV+ (not 16/18), 41 years old, unvaccinated, University degree)*	9
Q8	*What's easier now is I don't have to come back for another test and wait for a result then be told now you have to go to a specialist. The fact I knew immediately that's what the next step was really good. That was really positive. (HPV+ (not sure), 46 years old, unvaccinated, Diploma or certificate)*	9
Q9	*I do have concerns as to whether the HPV is over testing, are you finding things that are not meant to be there - is it over diagnosis as well which leads to unnecessary treatments, unnecessary follow ups and referrals. That did*	9

	cross my mind. (HPV+ (not 16/18), 41 years old, unvaccinated, University degree)	
Q10	*Because you're immunising your girls against the HPV they will be less likely to get cervical cancer, which is why they only have to be screened five yearly. (HPV-, 47 years old, unvaccinated, Diploma or certificate)*	9
Information Dissemination		
Q11	*Just about the difference now that they're testing for the virus that causes the cell changes rather than testing for cell changes, you can catch things earlier and prevent them. (HPV+ (16/18), 44 years old, unvaccinated, School certificate)*	10
Q12	*I was due to have one, I don't know what month it was, last year and she said wait till December because then they've got a new test. I didn't really worry about it - I mean I haven't had any negative [sic] results (i.e. abnormal) so she just said in December they're doing it a different way so do you want to wait till December. (HPV-, 61 years old, unvaccinated, School certificate)*	10
Q13	*She explained the process and how the test works and exactly what she does and how they get the samples and how it's tested. I was quite happy with the extent of the information that she provided. It coincided with my understanding of the test and what the results would show or not. (HPV-, 29 years old, vaccinated, Higher School Certificate)*	10
Q14	*I didn't end up getting it that day. Then … sent out a request to my old postal address, saying that I was on a high priority list to get it done. They called me up and apologised about it … The Doctor … she didn't really believe me again so she called up [Path lab] and asked them if I really needed to be there and they said yes, she's on the priority listing or urgent listing. (HPV+ 16/18, 26 years old, unvaccinated, Diploma or certificate)*	10
Q15	*I think there needs to be an ad done about it because it's prevalent it's there every day it's something women have to have done. It's an element that goes around and I think the public need to be more informed. TV ads, radio ads I think, internet ads because younger generation take much more notice of them. (HPV+ (not sure type), 46 years old, unvaccinated, Diploma or certificate)*	10
Q16	*Maybe it could be a brochure and a conversation from your GP or kind of the Doctor/gynaecologist whoever you're communicating with so that they can ask questions and then you have some information to go back and read if you want to. I don't know then I suppose on the brochure if there is a phone number for people to call if they have further questions. (HPV+ not 16/18 & negative cytology, 49 years old, unvaccinated, University degree)*	11
Meaning of test results and emotional responses to the new test		
Q17	*Results, no. They only really call you in for results if something is wrong and they need to discuss it otherwise you don't sort of hear from them. I would've liked just an acknowledgement to say that everything is fine instead of just assuming. Even if it was only a short email or something. (HPV unknown, 51 years old, unvaccinated, no school or other qualifications)*	11

Q18	*Oh, I was a little bit nervous. I didn't think that I was a high candidate to have issues. Still it's the first time I've done the test I could've had a dormant virus or something for a few years and not known about it. It was just generally, because I've never done it, I'm uncertain it might have been an underlying problem I had never known about but it wasn't so that was good. (HPV-, 29 years old, vaccinated, Higher School Certificate)*	11
Q19	*It didn't mean that I would get cancer but I would have a more increased risk and now I would have to have yearly Pap smears and they will be tested the old way to detect changes in my cells because we know I've already got the HPV virus. (HPV+ 16/18 & negative cytology, 44 years old, unvaccinated, School certificate)*	12
Q20	*I'm glad nothing is wrong but it's a little daunting knowing I'm in that increased risk group … Like I said to my husband it's more when I have my Pap smear every year now rather than not thinking about it because it's been normal for so long, now that I've got the virus I think I will be a little bit more anxious till I get the result now. (HPV+ 16/18 & negative cytology, 44 years old, unvaccinated, school certificate)*	12
Q21	*Well I would believe that it would mean I wouldn't need to go back for five years however given that I've had abnormal test results in the past I think I will probably still get one done two years after that test just to make sure and if that's clear then I would be reassured I could then go to five yearly screening … I think I will take myself to another test.*	12
Q22	*Probably explaining more about it, how you can get it. I think already having the pamphlet what it can turn into, cervical cancer and things like that. While you're having the Pap smear I think so too and also if you have to go to get a procedure like a biopsy or whatever just to explain it again. (HPV+ 16/18 & CIN1, 37 years old, unvaccinated, Trade apprenticeship)*	12
Q23	*Yeah, I will be making it [appointment] for when the 12 months is up for sure. Now I have a better understanding I'm okay with it and going back in 12 months it's fine. Hopefully it will be gone and if it's not go back in another 12 months or whatever the threshold is. My initial reaction was I have to wait 12 months, I'm going to have to worry about this for 12 months but now I'm okay about it. (HPV+ (not 16/18), 30 years old, vaccinated, Diploma or certificate)*	12
Q24	*Well I would believe that it would mean I wouldn't need to go back for five years however given that I've had abnormal test results in the past I think I will probably still get one done two years after that test just to make sure and if that's clear then I would be reassured I could then go to five yearly screening. (HPV-, 33 years old, unvaccinated, University degree)*	12
Q25	*I hadn't had sex for years … the diagnosis I got from the Pap smear [is] normally [for] people [who] are sexually active. I thought it was some kind of an STI and then when I thought about it I thought I hadn't been with anyone for years, how did I get this unless it's been in the body for years and shown up now. (HPV+ (not sure), 66 years old, unvaccinated, School certificate)*	12
Q26	*That's how it was explained and then when he was going through the flow charts and stuff about when you get this and then we have to do this next*	13

	treatment. (HPV+ (not 16/18) & negative cytology, 49 years old, University degree)	
Q27	*She just pretty much said how most people do have the virus; she wasn't particularly good at explaining it. It was just lucky that I've already been to so many Doctors who are better at explaining it so I've got a general understanding. (HPV+ 16/18, 26 years old, unvaccinated, Diploma or certificate)*	13

Figure 1: Australian National Cervical Screening Program results pathway



Supplementary Information: Interview topic guide

1. Knowledge of renewed cervical screening program
2. Last attendance for cervical screen (how came about attending, what happened, results, implications of results)
3. Exploring what/if told about results and how
4. Understanding of results and what they mean
5. Thoughts/feelings on results, any impact of results
6. Awareness of changes before December 2017 (what/how heard; thoughts on/expectations about the changes
7. Experience of cervical screening since renewed program
8. General thoughts/feelings on the changes to the cervical screening program
9. Whether doctor shared thoughts on the changes
10. Anything made it difficult to participate in screening since renewal (challenges/barriers)
11. Anything made it easier to participate in screening since renewal (enablers/facilitators) that may be different to you attending previously for cervical screening?
12. Changes (positive/negative) made or experienced seeing doctor for cervical screening/other health issues
13. Changes (positive/negative) towards seeing doctor for cervical screening/other health issues in the future
14. Explore information given from doctor about the changes
15. Explore educational materials or other resources helped better understand
16. Recommendations for educational materials or other resources for women eligible for screening (content/format/delivery)
17. Any other comments about renewed cervical screening program/anything else

Reporting checklist for qualitative study.

Based on the SRQR guidelines.

Instructions to authors

Complete this checklist by entering the page numbers from your manuscript where readers will find each of the items listed below.

Your article may not currently address all the items on the checklist. Please modify your text to include the missing information. If you are certain that an item does not apply, please write "n/a" and provide a short explanation.

Upload your completed checklist as an extra file when you submit to a journal.

In your methods section, say that you used the SRQRreporting guidelines, and cite them as:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. Acad Med. 2014;89(9):1245-1251.

	Reporting Item	Page Number
Title		
#1	Concise description of the nature and topic of the study identifying the study as qualitative or indicating the approach (e.g. ethnography, grounded theory) or data collection methods (e.g. interview, focus group) is recommended	1

Abstract			
	#2	Summary of the key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results and conclusions	2
Introduction			
Problem formulation	#3	Description and signifcance of the problem / phenomenon studied: review of relevant theory and empirical work; problem statement	5
Purpose or research question	#4	Purpose of the study and specific objectives or questions	6
Methods			
Qualitative approach and research paradigm	#5	Qualitative approach (e.g. ethnography, grounded theory, case study, phenomenolgy, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g. postpositivist, constructivist / interpretivist) is also recommended; rationale. The rationale should briefly discuss the justification for choosing that theory, approach, method or technique rather than other options available; the assumptions and limitations implicit in those choices and how those choices influence study conclusions and transferability.	7

		As appropriate the rationale for several items might be discussed together.	
Researcher characteristics and reflexivity	#6	Researchers' characteristics that may influence the research, including personal attributes, qualifications / experience, relationship with participants, assumptions and / or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results and / or transferability	8
Context	#7	Setting / site and salient contextual factors; rationale	6
Sampling strategy	#8	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g. sampling saturation); rationale	7
Ethical issues pertaining to human subjects	#9	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	16
Data collection methods	#10	Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources / methods, and modification of procedures in response to evolving study findings; rationale	7

Data collection instruments and technologies	#11	Description of instruments (e.g. interview guides, questionnaires) and devices (e.g. audio recorders) used for data collection; if / how the instruments(s) changed over the course of the study	7
Units of study	#12	Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	8
Data processing	#13	Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymisation / deidentification of excerpts	7
Data analysis	#14	Process by which inferences, themes, etc. were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale	7/8
Techniques to enhance trustworthiness	#15	Techniques to enhance trustworthiness and credibility of data analysis (e.g. member checking, audit trail, triangulation); rationale	7/8
Results/findings			
Syntheses and interpretation	#16	Main findings (e.g. interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	8

Links to empirical data	#17	Evidence (e.g. quotes, field notes, text excerpts, photographs) to substantiate analytic findings	Table 3
Discussion			
Intergration with prior work, implications, transferability and contribution(s) to the field	#18	Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application / generalizability; identification of unique contributions(s) to scholarship in a discipline or field	13
Limitations	#19	Trustworthiness and limitations of findings	4
Other			
Conflicts of interest	#20	Potential sources of influence of perceived influence on study conduct and conclusions; how these were managed	16
Funding	#21	Sources of funding and other support; role of funders in data collection, interpretation and reporting	16

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Women's experiences of the renewed National Cervical Screening Program in Australia 12 months following implementation: a qualitative study

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Main text word count: 3935

Abbreviations: HPV: human papillomavirus; NCSP: National Cervical Screening Program; GP: General Practitioner

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ABSTRACT

Objective: To explore women's experiences of the renewed National Cervical Screening Program in Australia from the perspective of women who have received different human papillomavirus (HPV) test results. Women aged 25 to 74 are now screened every five years with primary HPV screening.

Design: Qualitative interview study.

Setting: Australia

Participants: Women in Australia aged 25-74 who reported participating in cervical screening since December 2017, purposively sampled by test result (HPV positive, HPV negative, HPV status unknown).

Methods: 26 interviews with women aged 25-74 were conducted and analysed thematically.

Results: Three main themes emerged: knowledge and attitudes about the program changes, information dissemination, the meaning and responses to test results and the new cervical screening test (CST). Some women showed little awareness of the changes, but others understood that HPV is detected earlier than abnormal cells. Some expressed positive attitudes towards the CST and were not anxious about less frequent screening. Most women envisaged the changes would have minimal impact on their screening behaviour. Women mainly wanted more information about the changes and the possible results from the new CST. Overall women could recall their HPV results and understand the implications for future cervical screening. Anxiety about being at 'increased risk' was more apparent in women who were HPV positive without history of abnormal results.

Conclusions: Women show some understanding of HPV and the new CST, but more written and public communication about the changes and possible results are warranted. Efforts are needed

to ensure women who are HPV positive without history of abnormal results receive the information needed to alleviate anxiety.

Funding: This work was supported by a NHMRC Program Grant (APP1113532).

Keywords: attitudes, cancer screening, Cervical Intraepithelial Neoplasia, Human Papillomavirus DNA Tests, Qualitative Research

ARTICLE SUMMARY

Strengths and limitations of this study

- The qualitative design enabled us to explore in depth experiences of women residing in Australia who reported cervical screening since implementation of the renewed NCSP and their understanding of the results from the new cervical screening test.
- A major strength is the inclusion of women with a range of test results and provide insight into how much information women perceived they received about the new program and how they understood their test results.
- Due to the qualitative nature of the study, we cannot express the findings as generalisable across the whole population and the sample was restricted to women who could speak English.
- The method by which women were recruited into the study may reflect women who are more well-informed and therefore some caution is necessary when applying these findings to the whole population.

INTRODUCTION

As cervical cancer prevention strategies such as the human papillomavirus (HPV) vaccination and cervical screening are increasingly successful in reducing HPV infections[1] and cervical abnormalities,[2] countries worldwide are looking to switch from primary cytology-based cervical screening to primary HPV-based screening.[3–5] Australia was one of the first high-income countries to implement primary HPV-based screening in the Renewal of the Australian National Cervical Screening Program (NCSP) in December 2017, where women aged 25-74 are now screened every five years with primary HPV-based screening.[6] Although there was an initial announcement of the changes by the Australian government in April 2014, there was no mass awareness campaign to inform the public. Significant publicity of the changes rose in early 2017 following a petition started against the changes.[7]

Prior to the implementation of the Renewal, women were not invited for screening, but screened when due by their primary care provider. Once women had been screened, their details were recorded on their state or territory register and women overdue for screening would receive a reminder letter. Since the Renewal, details of women who have been screened will be recorded on the National Cancer Screening Register and they will receive an invitation letter for screening when they are due and reminder letters when they are overdue.

There is no standardised approach in Australia to informing women of their results, which varies by primary care provider. Primary HPV-based screening changes the screening results women receive. In addition to being told their HPV test result (HPV positive/HPV negative), women will also receive information about their risk of a significant cervical abnormality, determined by the subtype of HPV they have (HPV 16/18 or HPV not 16/18 subtype). Women who are HPV negative (HPV-) will be told they are at low risk and are recommended to rescreen in five years' time (Figure 1)[8]. Women who are HPV positive (HPV+) will also have a cytology test. HPV+ women, non 16/18 subtype, who have normal cytology or low-grade abnormalities will be

informed they are at intermediate risk and will be recommended to rescreen in 12 months' time. Women with any HPV+ result who have abnormal cytology will be informed that they are at higher risk and will be referred for a colposcopy.[9]

>Figure 1 here<

Previous research has demonstrated a number of negative psychosocial impacts for women testing HPV+ including anxiety and distress,[10,11] feelings of stigma, embarrassment and confusion, as well as concerns about their sexual relationships in terms of trust, fidelity and blame due to concern about the sexually transmitted nature of HPV.[12] Findings from our previous study which surveyed over 1000 women in Australia, also showed women who tested HPV+ were more anxious and distressed than those who tested HPV-,[13] with anxiety scores 10 points higher than those found in a recent English study.[14]

As most research to date has been quantitative and conducted prior to implementing the NCSP changes, there is a need for in-depth qualitative exploration of women's views and experiences of the renewed NCSP in the year since its implementation. Qualitative findings can explore women's first-hand experience of the new program, and their response to the new test results along with their understanding of what these results mean for them, which may be useful for other countries implementing primary HPV-based screening. This study aimed to explore in-depth women's experiences of the renewed cervical screening program, from the perspective of women who have received different test results.

MATERIALS AND METHODS

Participants and recruitment

Participants were women residing in Australia who had received cervical screening since the renewal of the NCSP (December 2017). Participants were recruited through a market research company, Dynata during December 2018. Dynata have a database panel of 600,000 members

in Australia to approach participants who meet the eligibility criteria. Participants listed on their database have already indicated a willingness to participate in online research. Women were directed to a web-link to read the participant invitation statement and provide their written consent to participate (via a tick-box) before completing an online questionnaire eliciting demographic and cervical screening information as well as psychosocial measures. At the end of the survey, women were asked if they would like to participate in a follow up interview and if yes, asked to leave their contact details so the research team could contact them.

Participants received points from Dynata which can be redeemed for items such as gift vouchers, donations to charities or cash. Participants first received points that represented modest compensation for the time spent completing the survey, with further points on completion of an interview.

Participants were purposively sampled from 449 women agreeing to be contacted for interview, to include women from a range of age groups, education and test results (HPV+ 16/18, HPV+ other, HPV-, HPV status unknown; Table 1). Of these 449 women, 33 were HPV+, 374 HPV- and 42 didn't know or couldn't remember their result (HPV status unknown). Data collection ceased when no new themes were emerging from the data and therefore saturation was reached.[15]

>Table 1 here<

Procedure

Semi-structured interviews, using a purpose-designed interview guide informed by a review of previous literature on women's attitudes towards to changes to cervical screening programs, both in Australia[7,16,17] and overseas,[18,19] were conducted during December 2018.

The topic guide covered questions regarding attitudes, understanding and confidence, expected impact, understanding of results, any psychosocial impacts and helpful educational and other support resources, in relation to the NCSP changes (See supplementary information).

Interviews took place over the telephone and lasted between 10 and 27 minutes. Interviews were audio-recorded and professionally transcribed.

Patient and public involvement

Patients and the public were not directly involved in the design or planning of the study.

Analysis

Interviews were analysed using Framework Analysis, an approach well suited to this type of research due to the organisation of data into a thematic framework which then enables views and experiences to be grouped together and comparisons made across participants.

Both RD and OM familiarised themselves with the transcripts by reading over all the transcripts and making notes of recurring themes. RD developed the initial framework using the qualitative package NVivo 11.[20] The framework was amended through discussions between RD and OM and refined with input from KM. Using NVivo 11, data were summarised and organised into a matrix where each column represented a subtheme and each row a participant. Themes were derived from the data in an inductive process and the topic guide was not used as a reference during the analysis and interpretation of the data. Any disagreements in interpretation were resolved by discussion. The research team members work in the field of public health, with a special interest in reducing overdiagnosis and overtreatment.

RESULTS

We interviewed 26 women with sample characteristics shown in Table 2. Most women in the sample described being regular screeners (every two years). Some women in the sample had

experienced abnormalities or a diagnosis of HPV previously and so had been monitored more closely than every two years under the old program.

>Table 2 here<

Three main themes emerged from the data: knowledge and attitudes about the changes, information dissemination, and focus on meaning of results and the new test.

1) Knowledge and attitudes about changes

Despite being screened under the renewed program, some women demonstrated a lack of awareness of the changes to the cervical screening program [Q1; Table 3]. Women who were knowledgeable about the changes tended to have sought further information and done their own research [Q2].

>Table 3 here<

Those who were aware regarded the main change to be the extended screening interval, from two year to five years, with a few women understanding that this was due to the change in screening technology [Q3]. Some women understood that what is being tested for has changed, with the effectiveness of screening for HPV rather than abnormal cells, noting this was earlier detection [Q4]. Overall women noted that the testing procedure was identical to the Pap smear [Q5].

A concern expressed about the extended screening interval was that cancer might develop and be missed in between screens, particularly prominent in women with personal experience of abnormalities [Q6]. A few HPV- women described the need to take responsibility for their own health due to the increased screening interval, which included getting any symptoms which were ‘unusual’ checked out at the doctor. However, women also expressed positive attitudes including experiencing less anxiety, stress and discomfort due to screening less often. Those women with positive views tended to contextualise these in terms of the new testing technology

being more sensitive and more accurate [Q7] and this woman explained how she thought the testing process was much easier if you test HPV+ than previously with the Pap smear due to the ability to test the same sample [Q8].

One woman alluded to the potential for overtreatment if screening with this new testing technology continued on a two-yearly basis, due to the high incidence of HPV and subsequent referrals for colposcopy [Q9].

Some women also related the program changes back to the HPV vaccination, recognising that uptake of the HPV vaccination should impact rates of HPV and therefore cervical cancer. This helped them make sense of the program changes and believed it could also help increase uptake of the HPV vaccination [Q10].

For most women, they envisaged that the NCSP changes would have minimal impact on their screening behaviour. The only tangible impact the NCSP changes would have on their screening behaviour would be having to screen less often.

2) Information dissemination

2.1 Changes to the program

The amount of information women described being given about the changes to the cervical screening program when they attended for screening varied, with women mostly being told about it being a new test and that the screening interval would now be every five years. Some women were made aware of the changes through discussions with their GP/other health professionals; usually these discussions took place in the consultation, when they attended for screening. Most women said that the explanation was brief, but were asked if they had any questions about the changes [Q11]. A few women who attended for their Pap smear prior to December 2017, had been advised by their GP to postpone their screen to December 2017, as then they would then enter into the new program [Q12].

While some women were happy with the amount of information they received and had good experiences [Q13], others described less positive experiences with health professionals when it came to cervical screening, with one woman explaining that she had to go back multiple times as the doctor did not believe she needed to be screened [Q14].

Very few women reported being provided with written information by their GP or other health professional. In terms of preferences for information about the changes to the cervical screening program, women talked about the need for advertisement on television and in the media to reach a lot of women to encourage them to go for screening, with radio and internet advertisements more likely to reach younger women [Q15].

Women felt information resources such as a pamphlet containing information about HPV and how common it is, would be useful to refer to as well as communicating it as being 'normal'. Additionally, information on self-care in terms of what to do if something is wrong or what potential symptoms could be, was also perceived as important. Being signposted to a website with information about the changes to the screening program and the meaning of results, was also suggested.

2.2 New results

When asked if there was anything that would have helped to better understand screening under the revised program, most women suggested a "staggering of information" over time, where they would receive information about the changes/possible results prior to screening and then again when receiving the results. Women who tested HPV+ in particular wanted to know about the possible results/referral information prior to screening; women who tested HPV- were more indifferent about receiving information about possible results prior to screening. Information about what the results meant was the main focus of seeking information for these women.

Women acknowledged that too much information can be overwhelming and lead to increased anxiety. Women felt information could accompany the invitation letter or be displayed in waiting rooms, with the combination of a brochure and conversation with a health professional being optimal [Q16].

The key time points identified for information delivery were: i) prior to screening, when invited; ii) during screening; iii) when receiving screening results. Information formats suggested by women included information pamphlets in GP offices, web-links to reputable online sources; and posters in shopping centres/public toilets.

3) Meaning of test results and emotional responses to the new test

Women received their screening results in various ways including by letter, over the phone, face-to-face during a GP appointment, or not hearing anything and assuming everything was ok [Q17]. A few women described their anxiety in the time between the test and the results, with one woman expressing this was the first time she'd had the test and so didn't know what to expect [Q18].

Overall women were able to recall their HPV results (positive or negative) and understand the implications these HPV results have for returning for screening in the future. Even among the women who did not know their results, they knew when they were due to have screening again. However, these women did not demonstrate knowledge about the nature of HPV, its transmission, and the implications of testing positive (or negative) for HPV and the associated risk of progression to cervical cancer. Some women who were HPV+ did express knowledge that their HPV result did not mean that cancer is inevitable and that these abnormal cells can resolve by themselves without the need for treatment [Q19].

Higher risk women who had previously had an abnormal Pap smear result and/or already knew their HPV+ status (especially types 16/18) due to persistent infection, were less alarmed about

receiving an HPV+ result. Similarly, women who had previously had a normal Pap smear result and received an HPV- result were also not alarmed by this new type of result. However, women who had previously had normal Pap smear results were somewhat anxious if they received HPV+ results [Q20]. One woman who tested HPV- but had a previous abnormality would have liked to be tested more frequently [Q21]. Those women who received an HPV+ result would have liked their GP/other health professional to have explained the possible results of this test prior to screening, as a means of preparing them [Q22].

One of the HPV+ women described how initially she was worried about waiting 12 months after being told she screened positive for HPV, but a better understanding reduced her worry [Q23]. Some women told to rescreen in five years were happy to follow the guidelines and recommendations, whereas others, particularly those with a history of abnormal results, were wanting further reassurance and said they would rescreen more frequently [Q24].

One older woman, who was not aware of the high prevalence of HPV, alluded to the stigma associated with an HPV+ result, however there were few instances of women expressing feelings of stigma about being HPV+ [Q25]. Women showed more limited understanding of accompanying cytology changes; especially amongst women with normal cytology and low-grade abnormalities. Women with high-grade abnormalities had better understanding, mainly because they had a persistent form of HPV and had previously returned abnormal results and/or had also been referred to a gynaecologist for a subsequent colposcopy. Only a couple of women recalled their level of risk (e.g. intermediate risk) for cervical cancer.

Women who were HPV+ talked about their understanding and experiences of the new testing pathway, with one woman describing how the doctor explained it to her using the flowcharts [Q26].

There were some women who felt that healthcare professionals had not adequately explained their results to them. Some women felt the information was not made relevant to them or was

too clinical, and that they wanted to be given more detail with their results. These women conducted their own research online to find out more about HPV and what their results meant [Q27].

DISCUSSION

The study findings contribute to our understanding of women's experiences of the deintensified cervical screening program in Australia and provide us with insight into how women have interpreted communication of their test results. Overall, women showed limited knowledge of the changes to the NCSP, but demonstrated understanding about what the results meant for them and their future screening. There was high variability in how the results were communicated to women by their GP/other health professional. Some women reported positive experiences of communication which provided reassurance and aided good understanding of the changes and implications of results, while others reported poor communication of results by their GP/other health professional and felt they had to independently search for further information. The impact of HPV+ results appeared greater in women who had previously had normal Pap smear results. Encouragingly, women envisaged that the changes to the NCSP would have minimal impact on their own screening behaviour. A few women were concerned about changes to the program leading to missing cancers and getting lost in the system if they moved interstate. These findings mirror those from previous research.[7,21]

Women in this sample were mainly positive about the changes to the program, reflected in comments about the new cervical screening test and perceived the test to be more accurate and effective than the Pap smear. This perhaps reflects a trust in decision-makers, that despite some negative press surrounding the changes, women in this sample trusted that the changes had been made for the better and this was reinforced for some when they were advised by their GP to wait for the new program to be implemented.

It was evident that women still lacked knowledge about HPV and its transmission, particularly in women who were HPV-, and so there is still a great need for community education surrounding cervical screening and HPV. Linking the HPV vaccination to the changes made to the screening program, gave women a tangible way in which to understand reasons for the five-year interval being safe. This could be a good strategy to target both mothers and their daughters to educate them about the importance of cervical screening and how advances in technology has enabled us to now screen primarily for the HPV infection.

Although this sample of women mainly reported being told in their GP consultation when they attended for screening about the changes in the test and the screening interval, most indicated that they would have liked to have received some written information and also seen some public advertisements about the program changes, supporting our previous findings.[22] Women also wanted written information about the test results and expressed importance that this is consistent across the program. In addition, how women receive their results should also be standardised, as women in this sample described multiple ways of receiving their results (e.g. phone, person, letter). Some women in this sample reported that they did not know or remember their test results. Our own survey data has shown anxiety and distress were higher in women who did not know their results compared to those who were HPV-.[13] The recommendations provided by the women in this sample for information delivery to be staged across the screening journey, from prior to screening to receiving the results, are important to consider when implementing a new screening test to help women's understanding of both the reasons for the new test and what the results of the new test mean for them. Women have been shown to prefer active or shared decision making approaches regarding the follow-up of abnormal test results,[23] so it is important women understand what these results mean for them.

Encouragingly, women reported that their doctors communicated with them about the new test and what this now checks for, with women showing an understanding behind the reason for the

change in test. This is important as our previous research showed that communicating to women about the change in test can then help provide reassurance and understanding to women about some of the other changes to the program.[22]

The psychosocial impact of screening and test results was evident across the sample, particularly with women screened HPV+. When worry and anxiety were expressed by these women, this was mostly related to testing, results and the extended screening interval. A focus needs to be given to information provision for those women who are HPV+ and who have not experienced abnormal results in the past. It is important that they receive the information they need to alleviate anxiety as these women demonstrated greater anxiety than women who were HPV+ with experience of previous abnormalities. Women with previous abnormalities were less alarmed by their results due to their previous experience and having a greater knowledge of the system, but those who screen HPV- who have a history of previous abnormalities may prefer to be screened more frequently.

Encouragingly, there was a good understanding among women who were HPV+ that cancer was not inevitable and that some cell changes might resolve without the need for treatment, demonstrating good communication from health professionals. This is particularly encouraging given around 8% of women (n=195,606) tested HPV+ in the first 6 months of the renewed program.[24] Of important note is that this, combined with healthcare providers not adhering to the guidelines, has consequently resulted in the increase in number of colposcopy referrals being much greater than expected.[25] This holds implications for an increased number of women referred for colposcopy and experiencing long wait times, as awaiting to undergo colposcopy has been shown to increase anxiety levels.[26]

Clear messages to women about the reasons for a change in test, as well as information which normalises HPV and explains what their test results mean for them, are important to communicate and provide reassurance. These messages could be in the form of written or

verbal communication, with the need for women testing HPV+ for the first time to receive individualised messages which acknowledge their previous normal test results.

To the best of our knowledge, this is the first study exploring the experiences of women receiving different results after receiving primary HPV screening as part of the National Cervical Screening Program. The qualitative design enabled us to explore in depth experiences of women residing in Australia who reported cervical screening since implementation of the renewed NCSP, and their understanding of the results from the new cervical screening test. These findings provide insight into how much information women perceived they received about the new program and how they understood their test results. Due to the qualitative nature of the study, this aim was not to produce findings which are generalisable across the whole population, but to provide some insight across a purposively collected sample of women who received a range of test results from the renewed cervical screening program. Most women in the sample were regular screeners and so may not reflect the experiences of women who were previous non-attenders or irregular screeners in the old NCSP and have now had screening under the renewed NCSP. The sample was restricted to women who could speak English.

Conclusions

Despite women demonstrating an understanding about the new cervical screening test, more written information and public communication about the changes and possible results are warranted. In particular, efforts are needed to ensure women who are HPV+ with no history of abnormal results receive the information they need to alleviate anxiety. Tailored information could take into consideration women's previous cervical screening results and risk for a significant cervical abnormality.

Ethics approval and consent to participate: This study was approved by The University of Sydney Human Ethics Committee (2018/836).

Data availability: The datasets generated and/or analysed during the study are available from the corresponding author on reasonable request.

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Disclosure of interests: None declared

Author Statement: Rachael Dodd: Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Project administration, Writing – Original draft preparation **Olivia Mac:** Formal analysis, Writing – Reviewing and Editing; **Kirsten McCaffery:** Conceptualization, Methodology, Funding acquisition, Formal analysis, Validation, writing – review and editing. All authors contributed to the interpretation of the analysis and critically revised the manuscript.

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Figure 1: Australian National Cervical Screening Program results pathway

Table 1: Sampling frame

	Education		Age				HPV vaccine	
	No University	University or Diploma	<35	36-50	51-65	66+	Yes	No
Cervical Screening Test Result								
HPV positive (n=15)								
16/18 (HPV+ 16/18)	2	2	2	2	0	0	1	3
Other (HPV+ other risk)	0	6	1	3	1	1	2	4
Type unknown (HPV+ type unknown)	2	3	1	1	2	1	2	3
HPV negative (n=8)	2	6	3	1	3	1	2	6
HPV status unknown: Don't know/unsure (n=3)	2	1	2	0	1	0	2	1

NB: numbers total n under each test result across the columns of education, age and HPV vaccine.

Table 2: Sample characteristics

	n (%)
HPV status	
HPV+ 16/18	4 (15.4)
HPV+ other risk	6 (23.1)
HPV+ type unknown	5 (19.2)
HPV negative	8 (30.8)
HPV status unknown: Don't know/unsure result	3 (11.5)
Age	
<35	9 (34.6)
36-50	7 (26.9)
51-65	7 (26.9)
66+	3 (11.5)
Education	
No university	18 (69.2)
University	8 (30.8)
Employment	
Full-time	8 (30.8)
Part-time	7 (26.9)
Retired/studying/other	11 (42.3)
Born in Australia	
Yes	22 (84.6)
No	4 (15.4)
Marital status	
Single/dating	5 (19.2)
Married/living with partner	13 (50.0)
Partnered/not living with partner	1 (3.8)
Separated or divorced	6 (23.1)
Widowed	1 (3.8)
HPV vaccination	
Yes	9 (34.6)
No/don't know	17 (65.3)

Table 3: Quotes from interviews to support the themes

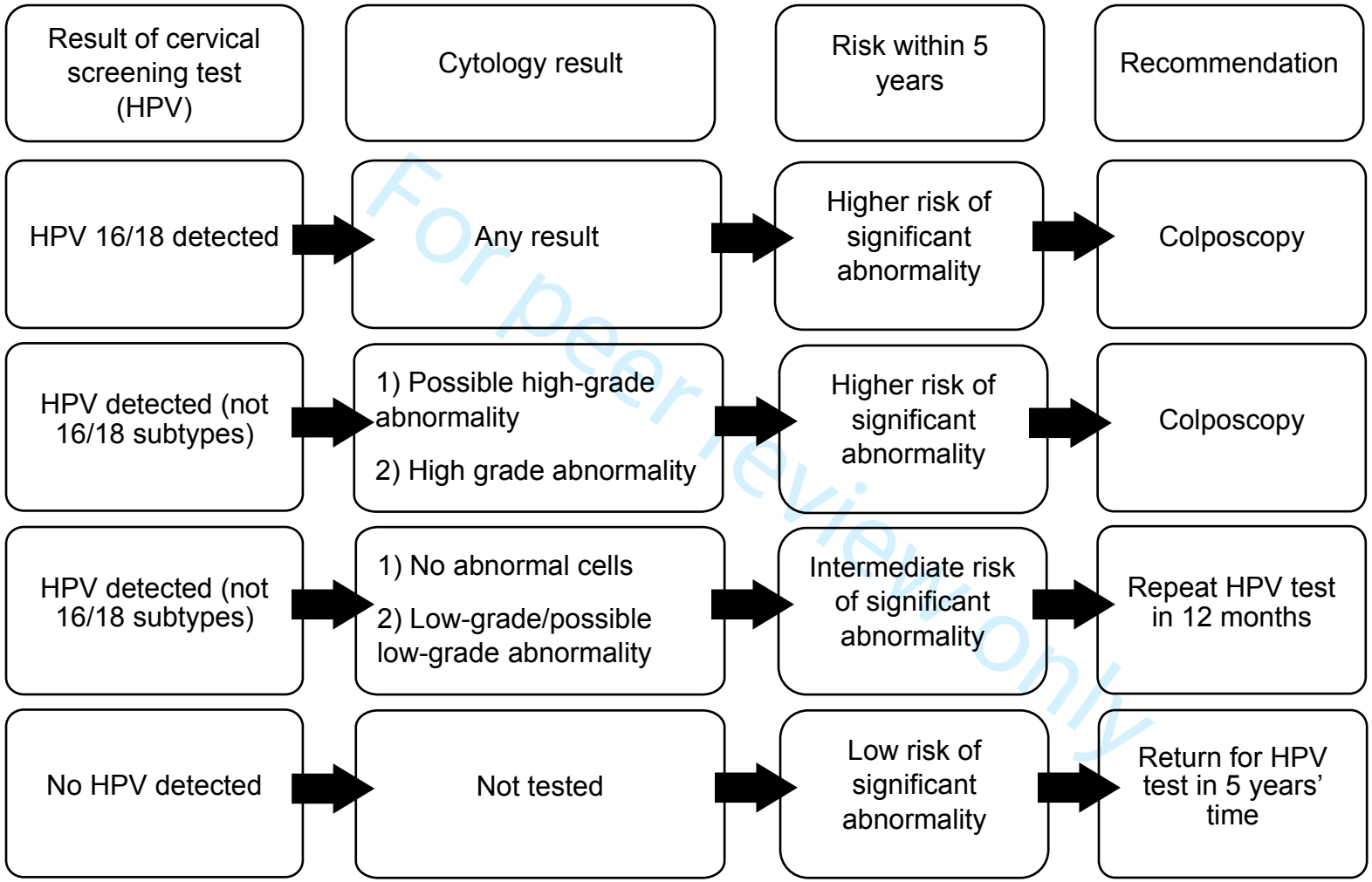
Code	Quote	Page
Knowledge and attitudes about changes		
Q1	*I did see I think a couple of little pop up things about it and I know that a couple of girls in my social circle have mentioned that the new test was available and it was a five year screening, but I haven't seen any other information about what difference it will make. (HPV-, <35 years old, unvaccinated, University degree)*	9
Q2	*I spent a couple of hours actually looking into everything I could find. Just even about HPV itself because I didn't understand any of it.* *It was really useful … but I had to actually go looking for it. It wasn't something that was put out there … If it had been out there it may have been discussed and I might have known a bit more … It would've been good to have been publicly informed in some ways. (HPV+ (type unknown), 36-50 years old, unvaccinated, Diploma or certificate)*	9
Q3	*Well I know that the main change is you only have to go every five years and not every two years because they've developed a different way to look at the cells or something (HPV+ (not 16/18), <35 years old, vaccinated, Diploma or certificate)*	9
Q4	*From what I understand, the technology is drastically improved which means obviously its better technology and they trust the technology better. I think the fact they're tracking the virus that causes the cancer is really good. (HPV-, 36-50 years old, unvaccinated, Diploma or certificate)*	9
Q5	*I think in all honestly my experience is it's the same … I can't say I've noticed any change to be honest. (HPV+ 16/18 & CIN1, 36-50 years old, unvaccinated, Trade apprenticeship)*	9
Q6	*My instant reaction is horror because that's a long time without a Pap smear because you don't know what your body is doing. In there if you've got cancer somewhere in that area, it's got five years to spread. (HPV+ (type unknown), 66+ years old, unvaccinated, School certificate)*	9
Q7	*Well the fact that if it's done every five as opposed to two then obviously having to go for less testing, is less anxiety and less stress so on that basis that's good … If I have to only do it once every five years it's very positive in my view. I think it will encourage more people to do it because it's not something that you have to do that often. (HPV+ (not 16/18), 36-50 years old, unvaccinated, University degree)*	10
Q8	*What's easier now is I don't have to come back for another test and wait for a result then be told now you have to go to a specialist. The fact I knew immediately that's what the next step was really good. That was really positive. (HPV+ (type unknown), 36-50 years old, unvaccinated, Diploma or certificate)*	10
Q9	*I do have concerns as to whether the HPV is over testing, are you finding things that are not meant to be there - is it over diagnosis as well which leads to unnecessary treatments, unnecessary follow ups and referrals. That did*	10

	cross my mind. (HPV+ (not 16/18), 36-50 years old, unvaccinated, University degree)	
Q10	*Because you're immunising your girls against the HPV they will be less likely to get cervical cancer, which is why they only have to be screened five yearly. (HPV-, 36-50 years old, unvaccinated, Diploma or certificate)*	10
Information Dissemination		
Q11	*Just about the difference now that they're testing for the virus that causes the cell changes rather than testing for cell changes, you can catch things earlier and prevent them. (HPV+ (16/18), 36-50 years old, unvaccinated, School certificate)*	10
Q12	*I was due to have one, I don't know what month it was, last year and she said wait till December because then they've got a new test. I didn't really worry about it - I mean I haven't had any negative [sic] results (i.e. abnormal) so she just said in December they're doing it a different way so do you want to wait till December. (HPV-, 51-65 years old, unvaccinated, School certificate)*	10
Q13	*She explained the process and how the test works and exactly what she does and how they get the samples and how it's tested. I was quite happy with the extent of the information that she provided. It coincided with my understanding of the test and what the results would show or not. (HPV-, <35 years old, vaccinated, Higher School Certificate)*	11
Q14	*I didn't end up getting it that day. Then … sent out a request to my old postal address, saying that I was on a high priority list to get it done. They called me up and apologised about it … The Doctor … she didn't really believe me again so she called up [Path lab] and asked them if I really needed to be there and they said yes, she's on the priority listing or urgent listing. (HPV+ 16/18, <35 years old, unvaccinated, Diploma or certificate)*	11
Q15	*I think there needs to be an ad done about it because it's prevalent it's there every day it's something women have to have done. It's an element that goes around and I think the public need to be more informed. TV ads, radio ads I think, internet ads because younger generation take much more notice of them. (HPV+ (type unknown), 36-50 years old, unvaccinated, Diploma or certificate)*	11
Q16	*Maybe it could be a brochure and a conversation from your GP or kind of the Doctor/gynaecologist whoever you're communicating with so that they can ask questions and then you have some information to go back and read if you want to. I don't know then I suppose on the brochure if there is a phone number for people to call if they have further questions. (HPV+ not 16/18 & negative cytology, 36-50 years old, unvaccinated, University degree)*	12
Meaning of test results and emotional responses to the new test		
Q17	*Results, no. They only really call you in for results if something is wrong and they need to discuss it otherwise you don't sort of hear from them. I would've liked just an acknowledgement to say that everything is fine instead of just assuming. Even if it was only a short email or something. (HPV status unknown, 51-65 years old, unvaccinated, no school or other qualifications)*	12

Q18	*Oh, I was a little bit nervous. I didn't think that I was a high candidate to have issues. Still it's the first time I've done the test I could've had a dormant virus or something for a few years and not known about it. It was just generally, because I've never done it, I'm uncertain it might have been an underlying problem I had never known about but it wasn't so that was good. (HPV-, <35 years old, vaccinated, Higher School Certificate)*	12
Q19	*It didn't mean that I would get cancer but I would have a more increased risk and now I would have to have yearly Pap smears and they will be tested the old way to detect changes in my cells because we know I've already got the HPV virus. (HPV+ 16/18 & negative cytology, 36-50 years old, unvaccinated, School certificate)*	12
Q20	*I'm glad nothing is wrong but it's a little daunting knowing I'm in that increased risk group … Like I said to my husband it's more when I have my Pap smear every year now rather than not thinking about it because it's been normal for so long, now that I've got the virus I think I will be a little bit more anxious till I get the result now. (HPV+ 16/18 & negative cytology, 36-50 years old, unvaccinated, school certificate)*	13
Q21	*Well I would believe that it would mean I wouldn't need to go back for five years however given that I've had abnormal test results in the past I think I will probably still get one done two years after that test just to make sure and if that's clear then I would be reassured I could then go to five yearly screening … I think I will take myself to another test. (HPV-, <35 years old, unvaccinated, University degree)*	13
Q22	*Probably explaining more about it, how you can get it. I think already having the pamphlet what it can turn into, cervical cancer and things like that. While you're having the Pap smear I think so too and also if you have to go to get a procedure like a biopsy or whatever just to explain it again. (HPV+ 16/18 & CIN1, 36-50 years old, unvaccinated, Trade apprenticeship)*	13
Q23	*Yeah, I will be making it [appointment] for when the 12 months is up for sure. Now I have a better understanding I'm okay with it and going back in 12 months it's fine. Hopefully it will be gone and if it's not go back in another 12 months or whatever the threshold is. My initial reaction was I have to wait 12 months, I'm going to have to worry about this for 12 months but now I'm okay about it. (HPV+ (not 16/18), <35 years old, vaccinated, Diploma or certificate)*	13
Q24	*Well I would believe that it would mean I wouldn't need to go back for five years however given that I've had abnormal test results in the past I think I will probably still get one done two years after that test just to make sure and if that's clear then I would be reassured I could then go to five yearly screening. (HPV-, <35 years old, unvaccinated, University degree)*	13
Q25	*I hadn't had sex for years … the diagnosis I got from the Pap smear [is] normally [for] people [who] are sexually active. I thought it was some kind of an STI and then when I thought about it I thought I hadn't been with anyone for years, how did I get this unless it's been in the body for years and shown up now. (HPV+ (type unknown), 66+ years old, unvaccinated, School certificate)*	13

Q26	*That's how it was explained and then when he was going through the flow charts and stuff about when you get this and then we have to do this next treatment. (HPV+ (not 16/18) & negative cytology, 36-50 years old, University degree)*	13
Q27	*She just pretty much said how most people do have the virus; she wasn't particularly good at explaining it. It was just lucky that I've already been to so many Doctors who are better at explaining it so I've got a general understanding. (HPV+ 16/18, <35 years old, unvaccinated, Diploma or certificate)*	14

Figure 1: Australian National Cervical Screening Program results pathway



Supplementary Information: Interview topic guide

1. Knowledge of renewed cervical screening program
2. Last attendance for cervical screen (how came about attending, what happened, results, implications of results)
3. Exploring what/if told about results and how
4. Understanding of results and what they mean
5. Thoughts/feelings on results, any impact of results
6. Awareness of changes before December 2017 (what/how heard; thoughts on/expectations about the changes
7. Experience of cervical screening since renewed program
8. General thoughts/feelings on the changes to the cervical screening program
9. Whether doctor shared thoughts on the changes
10. Anything made it difficult to participate in screening since renewal (challenges/barriers)
11. Anything made it easier to participate in screening since renewal (enablers/facilitators) that may be different to you attending previously for cervical screening?
12. Changes (positive/negative) made or experienced seeing doctor for cervical screening/other health issues
13. Changes (positive/negative) towards seeing doctor for cervical screening/other health issues in the future
14. Explore information given from doctor about the changes
15. Explore educational materials or other resources helped better understand
16. Recommendations for educational materials or other resources for women eligible for screening (content/format/delivery)
17. Any other comments about renewed cervical screening program/anything else

Reporting checklist for qualitative study.

Based on the SRQR guidelines.

Instructions to authors

Complete this checklist by entering the page numbers from your manuscript where readers will find each of the items listed below.

Your article may not currently address all the items on the checklist. Please modify your text to include the missing information. If you are certain that an item does not apply, please write "n/a" and provide a short explanation.

Upload your completed checklist as an extra file when you submit to a journal.

In your methods section, say that you used the SRQRreporting guidelines, and cite them as:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. Acad Med. 2014;89(9):1245-1251.

	Reporting Item	Page Number
Title		
#1	Concise description of the nature and topic of the study identifying the study as qualitative or indicating the approach (e.g. ethnography, grounded theory) or data collection methods (e.g. interview, focus group) is recommended	1

Abstract			
	#2	Summary of the key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results and conclusions	2
Introduction			
Problem formulation	#3	Description and signifcance of the problem / phenomenon studied: review of relevant theory and empirical work; problem statement	5
Purpose or research question	#4	Purpose of the study and specific objectives or questions	6
Methods			
Qualitative approach and research paradigm	#5	Qualitative approach (e.g. ethnography, grounded theory, case study, phenomenolgy, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g. postpositivist, constructivist / interpretivist) is also recommended; rationale. The rationale should briefly discuss the justification for choosing that theory, approach, method or technique rather than other options available; the assumptions and limitations implicit in those choices and how those choices influence study conclusions and transferability.	7

		As appropriate the rationale for several items might be discussed together.	
Researcher characteristics and reflexivity	#6	Researchers' characteristics that may influence the research, including personal attributes, qualifications / experience, relationship with participants, assumptions and / or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results and / or transferability	8
Context	#7	Setting / site and salient contextual factors; rationale	6
Sampling strategy	#8	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g. sampling saturation); rationale	7
Ethical issues pertaining to human subjects	#9	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	16
Data collection methods	#10	Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources / methods, and modification of procedures in response to evolving study findings; rationale	7

Data collection instruments and technologies	#11	Description of instruments (e.g. interview guides, questionnaires) and devices (e.g. audio recorders) used for data collection; if / how the instruments(s) changed over the course of the study	7
Units of study	#12	Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	8
Data processing	#13	Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymisation / deidentification of excerpts	7
Data analysis	#14	Process by which inferences, themes, etc. were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale	7/8
Techniques to enhance trustworthiness	#15	Techniques to enhance trustworthiness and credibility of data analysis (e.g. member checking, audit trail, triangulation); rationale	7/8
Results/findings			
Syntheses and interpretation	#16	Main findings (e.g. interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	8

Links to empirical data	#17	Evidence (e.g. quotes, field notes, text excerpts, photographs) to substantiate analytic findings	Table 3
Discussion			
Intergration with prior work, implications, transferability and contribution(s) to the field	#18	Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application / generalizability; identification of unique contributions(s) to scholarship in a discipline or field	13
Limitations	#19	Trustworthiness and limitations of findings	4
Other			
Conflicts of interest	#20	Potential sources of influence of perceived influence on study conduct and conclusions; how these were managed	16
Funding	#21	Sources of funding and other support; role of funders in data collection, interpretation and reporting	16