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For peer review only

“I could be that one percent”: A qualitative study of North Queensland women’s knowledge and perspectives on the new National Cervical Screening Program

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Abstract

Objectives

To investigate women's understanding and attitudes towards the National Cervical Screening Program (NCSP) and to explore methods to improve screening participation.

Design

Semi-structured face to face interviews were conducted through convenience and snowball sampling. Thematic analysis occurred using the interpretivist framework.

Setting

A private general practice in North Queensland.

Participants

Fourteen women between 18-74 years who attended the general practice.

Results

Participants were concerned that the new NCSP would miss cancer due to longer screening intervals and reliance on primary HPV testing. They believed that young women are at increased risk of cervical cancer, due to perceived HPV vaccine ineffectiveness and parent objection to vaccination. Most participants were not agreeable to self-sampling and preferred their doctor to perform screening. Personal and practitioner beliefs influenced a woman's screening participation. Personal factors include being healthy for themselves and their family, previous abnormal smears and family history of cancer. Emphasis was placed on feeling 'comfortable' with their practitioner which included patient rapport and gender preference. Proposed methods to improve cervical screening included education programs, advertising campaigns, general practitioner interventions and improving accessibility.

Conclusions

Women are hesitant about the new NCSP however when provided with additional information they were more amenable to the changes. This highlights the need to improve awareness of cervical screening and the new NCSP.

Article Summary

Strengths and limitations of this study

- Interviews explored participants' attitudes towards the new NCSP, where there is currently little research.
- Individual interviews were conducted until theoretical data saturation and the interview template was piloted.
- Convenience and snowball sampling through a private general practice may have led to inaccurate sample representation.
- Most participants were well-screened for cervical cancer, which may not be inclusive of high risk groups.
- The study was completed in an outer regional centre and may not apply to the general Australian population.

Background

While the National Cervical Screening program (NCSP) has more than halved cervical cancer mortality, only 54-56% of eligible Australian women[1] participated in screening between January 2016-June 2017. This is especially concerning as over 90% of women diagnosed with cervical cancer were under-screened or never-screened. Women from lower socioeconomic status, rural areas or those that identify as Aboriginal and Torres Strait Islander have lower screening participation rates and higher cervical cancer mortality.[1] Recently the NCSP has moved away from traditional pap smears screening for abnormal cells, towards a 5 yearly cervical screening test (CST) for the Human Papilloma Virus (HPV) and reflex cytology. Australian women begin cervical screening at 25 years old and have an exit CST from 70-74 years old. Women over 30 years who are considered never or under-screened are also eligible for self-sampling, consisting of a high vaginal swab for HPV.[2,3]

Due to the recent nature of changes to cervical screening, there is limited qualitative literature assessing Australian women's attitudes towards the new NCSP. Thematic analysis of an online petition against the new NCSP revealed that the greatest concerns were missing cancer due to prolonged screening intervals and the delay in screening age.[4] Previous international studies stated that some women may experience a negative emotional response towards primary HPV testing as it is a sexually transmitted infection.[5,6]

The researchers' primary aim was to explore North Queensland women's awareness and perceptions of the new NCSP. Knowledge of cervical cancer, factors that affect screening participation and methods to improve screening awareness were also investigated.

Methods

Authors followed the Consolidated Criteria for Reporting Qualitative Health Research (COREQ).

Patient selection and setting

Women between 18-74 years old who attended a specific North Queensland general practice were eligible for this study with convenience and snowball sampling. This project was conducted with a concurrent quantitative survey. Receptionists provided waiting room surveys and an expression of interest form for a follow-up interview. Quantitative results will be published separately. The interviews were advertised on the practice's Facebook page and participants were encouraged to promote the study to their family and friends. Women who expressed interest were contacted by phone or email.

Data collection

A semi-structured, face-to-face individual interview was conducted at the participant's convenience at their home or a hospital meeting room between March and April 2019. The average length of the interview was 20 minutes. All interviews were conducted by the primary author, a female medical student (AN) with training in qualitative research. The interviewer (AN) may have some personal bias as she is eligible for cervical screening. No participants were known to AN and participants were aware that this interview was part of an Honours project.

The piloted interview guide included questions about knowledge of cervical cancer and screening, opinions regarding the NCSP, barriers to screening and thoughts to improve screening participation. During the interview, participants were asked their opinions of the new NCSP, both with their baseline knowledge and after the interviewer provided basic information on the program. The interview guide was developed after analysis of the existing literature[7,8] and discussion amongst the investigators, including a general practitioner and a research officer, both experienced in qualitative research. Prior to the interview, participants signed a consent form for the interview to be audio recorded. The interviews were transcribed verbatim, including notes on non-verbal cues and were uploaded to nVivo. Transcribed interviews were not returned to participants for comments and no repeat interviews were conducted. Data collection continued until theoretical data saturation was achieved.

Patient and public involvement

No participants were involved with the development of this study protocol or data analysis.

Data analysis

Transcribed interviews were analysed using NVivo 12 Plus[9] using thematic analysis and the interpretivist paradigm. Data was analysed under relevant headings, for example 'Attitudes towards NCSP' and 'Factors affecting screening participation' but no themes were predetermined. AN completed line-by-line coding to identify the preliminary themes and codes in the data, which was reviewed by another author (JB). Data was further analysed to cluster themes under the appropriate research questions to create a thematic schema.

Ethical Considerations

Ethical approval was provided by the James Cook University Human Research Ethics Committee (H7465). Participants completed a consent form that stated that they agreed to a recorded interview.

Results

Participant Characteristics

Twenty-eight women expressed interest to be interviewed and were contacted by phone or email. Fourteen women consented to be interviewed. Table 1 displays individual participant characteristics. The age of participants ranged between 20 and 58 years old. Most women participated in screening and only two were considered under-screened as per the previous NCSP.

Themes

Thematic analysis revealed three major themes on participant's attitudes towards the NCSP: 'Fear of missing cancer',' younger women are at greater risk' and 'change is good'. Screening beliefs were subdivided into personal and practitioner factors. Based on participants' suggestions, four potential intervention strategies emerged. Table 2 displays illustrative quotes for these themes. A thematic schema depicting conceptual links throughout the themes is displayed in Figure 1.

Knowledge of Cervical Cancer and NCSP

Participants identified genetics and infection as the main causes of cervical cancer. Most participants did not specify HPV as the main cause of cervical cancer but when asked, participants were frequently aware of the link between HPV and cervical cancer. Hormones, contraceptive pill, smoking and toxins were listed by participants as causes of cervical cancer. Women considered family history and sexual activity the main risk factors for cervical cancer. Other risk factors included not participating in regular screening, previous abnormal smears and being unvaccinated. Participants believed abnormal bleeding and pain were symptoms of cervical screening though, many women were unsure of the symptoms. Bloating, abnormal discharge and pain during sex (dyspareunia) were also reported by some participants as symptoms of cervical cancer.

Participants understood that cervical screening occurs using pap smears and often could describe that pap smears look for abnormal cells. Some participants were aware of the change to screening and could correctly identify that screening was now 5-yearly. Women stated that cervical screening should occur in their early twenties and some said that it began with the onset of sexual activity.

Attitudes towards the new NCSP

FEAR OF MISSING CANCER

Participants were anxious that 5 years was ‘a long time for cancer to grow’ (P12) and may lead to more women diagnosed with cancer. More regular screening was identified as having 'a better chance of picking something up’ (P14) as ‘things in our body change very quickly’ (P1). There were fears that increased screening intervals may miss cancer, as clinicians may not always get a ‘clear swab’ (P8) and hence more regular screening was preferable. Additionally, participants were apprehensive that primary HPV testing would miss cancer caused by ‘things other than HPV’ (P9). They were uncomfortable with the CST not testing for abnormal cells as ‘I could be that one percent’ (P12) with cervical cancer not caused by HPV. Subsequently, some participants preferred co-testing for both HPV and abnormal cells to receive the benefits of both screening methods.

Women believed that ‘every 2 years is easy enough to recall but not 5 years’ (P12) and may not remember to participate in screening, due to increased screening intervals. Participants were concerned that increased screening intervals will make women more ‘complacent’ (P12) in their screening behaviour and will delay screening even longer. They proposed that increased intervals required a register to provide appropriate reminders to women. A participant stated that increased intervals may also affect the feasibility of contacting patients, as after five years ‘not everyone lives at the same address’ (P7).

Those with a history of previous abnormal smears thought 5 yearly screening was ‘a little bit concerning’ (P8). Participants who had family or friends with cervical cancer were concerned by the increased screening interval as ‘they didn’t pick up hers until it was too late’ (P4). One participant negatively viewed delaying screening until a woman is 25 years, as her friend was diagnosed with cervical cancer earlier than this, and ‘if they didn’t catch it early, she’d be dead’ (P2). These personal experiences with abnormal smears or cervical cancer made women more ‘paranoid’ (P4) about cervical cancer.

YOUNG WOMEN ARE AT GREATER RISK

Participants perceived that commencing screening from 25 years old, placed women at increased risk for cancer due to earlier sexual activity of young women. Participants stated that children are ‘having sex a lot younger nowadays’ (P13). They highlighted that as young women are sexually active from their early teens, it may be ‘over 10 years that kids are sexually active before they have screening’ (P3). Participants also believed that delaying cervical screening would prevent opportunistic testing for sexually transmitted infections in young women.

While some women identified that the introduction of the Gardasil vaccination was beneficial in reducing cervical cancer incidence, there was also a perception that ‘a lot of parents won’t let their kids have that’ (P5). This raised concerns as to whether unvaccinated women would be protected under the new NCSP in the future. Additionally, participants feared that ‘even though you are vaccinated you can still get diseases’ (P7) and believed that delaying screening will lead to cervical cancer being missed in women under 25 years. Some participants thought that patients diagnosed with cancer are becoming ‘younger and younger’ (P2). Younger women were described to be at ‘higher risk’ (P2) of cervical cancer and participants felt that earlier detection of cervical cancer in women would improve their survival rates.

CHANGE IS GOOD

Several participants expressed their ‘faith in the doctors’ (P11) and believed that screening would not have changed without underlying improvements in science. They perceived that ‘testing is that good’ (P7) if screening intervals have increased from every 2 years to 5 years. Participants highlighted that HPV testing is a positive change as it would ‘catch it (HPV)’ (P11) before abnormal cells became detectable by a traditional pap smear. They accepted that if HPV was ‘linked so strongly’ (P9) with cervical cancer, primary HPV testing was a beneficial change to cervical screening. After participants were provided information on the new NCSP and cervical cancer’s slow progression, they were more receptive towards the new guidelines. An additional benefit of the new

NCSP was that reduced screening would ‘make life easier’ (P6) for women, as cervical screening was described as ‘uncomfortable’ (P14) by participants.

SELF-SAMPLING

Participants were generally hesitant to accept self-sampling as they did not ‘feel confident enough in myself’ (P14) to administer the test. This stemmed from the fear of incorrectly completing the test as they may not ‘swab far enough’ (P5) or that ‘it might be contaminated’ (P4). Doctors were thought to be better equipped to perform cervical screening as they had appropriate training to ensure it was ‘done properly’ (P8). It was perceived that doctors had better visualisation of the cervix as they used a speculum and would take a sample from ‘the right places’ (P3).

Nonetheless, participants acknowledged that self-sampling would provide women ‘more privacy’ (P10) and could improve screening participation. The test was deemed to be ‘less invasive’ (P5) than traditional cervical screening, especially for those who have had previous negative experiences with cervical screening. Participants often had the misconception that self-sampling required a cervical swab. When informed it was in fact, a high-vaginal swab more participants reported they would consider self-sampling. Some participants indicated that they would complete self-sampling if they were provided instructions or shown by a practitioner. Women highlighted that technological improvements allowed for ‘smaller traces’ (P2) of HPV to be detected and this made self-sampling more acceptable.

Factors affecting screening participation

PERSONAL

Participants explained that cervical screening was a part of their normal health ‘routine’ (P11). Screening allowed them to have ‘peace of mind’ that they were healthy, and it allowed them to receive ‘further help’ (P1) if required. Many women emphasised that their family was the key reason they had cervical screening. They described their sense of responsibility to their family who required them to ‘make the right choices’ (P3) by undergoing screening. Participants disclosed that cancer could destroy their families and thus they chose to screen. A woman’s personal experiences with cancer shaped her willingness to participate in cervical screening. A history of abnormal smears motivated women to ‘keep on top’ (P13) of their screening to prevent re-occurrence. Women with a family history of cancer had firsthand experience as to how it devastated their families, which motivated them to undergo regular cervical screening.

PRACTITIONER

Several participants described feeling ‘comfortable’ (P10) with their general practitioner as a facilitator to screening participation. This feeling of being ‘comfortable’ was influenced by the doctor’s bedside manner, professional behaviour and hygienic technique throughout the procedure. Some women expressed that they trusted their regular doctor due to their pre-existing relationship, as they have known them for a ‘long time’ (P4). Participants frequently mentioned their practitioner’s gender when discussing screening participation. Most participants indicated that they are more ‘comfortable’ with a female doctor as she ‘has the same bits’ (P2). However, some women had no gender preference as cervical screening is ‘just something that happens’ (P7) and one participant thought that ‘once you have a few kids, you’re over it’ (P4).

Improving CST Awareness and Participation

Cost and Accessibility

A lack of bulk-billed services in regional areas was identified by women as a key barrier to cervical screening participation. The cost of cervical screening was a ‘deterrent’ (P5) for attending the general practitioner for screening, especially in low socioeconomic women as ‘their priority is probably not money for them, it’s going to be feeding their children’ (P5). Participants also emphasised that cervical screening is not bulk-billed, unlike breast and bowel cancer. Women expressed the need for increased accessibility of cervical screening, especially in regional communities. It was suggested that cervical screening should have ‘pop-up’ (P9) clinics, as seen with blood donation and breast screening.

Media Campaigns

The role of a media campaign to potentially increase cervical screening awareness was discussed by participants. Participants proposed that television advertisements should be aired to encourage discussion about screening. Social media was deemed to be a valuable platform to educate about cervical screening due to its ‘really big role in young women’s lives’ (P9) and the interaction remained ‘private’ (P2). Women also suggested that an ambassador should lead the discussion on cervical cancer, such as in England when a celebrity ‘found out on Big Brother that she had cervical cancer’ (P3). Participants expressed that it is important to hear personal stories from survivors as it provides a ‘scare factor’ (P8) and would encourage screening.

Education Programs

Participants explained the importance of education to improve screening participation, especially in schools through sex education to ensure young women have the ‘right information’ (P5) about HPV and cervical cancer. Education programs should inform women about the purpose of the Gardasil vaccine, the NCSP and symptoms of cervical cancer. Participants believed that education will reduce any fears related to screening and solidify ‘how important it is’ (P12). It was also suggested that education sessions should also occur at universities, playgroups and the workplace.

General Practitioner

Participants emphasised the importance of their general practitioner as a trusted source of information about cervical screening as ‘you listen to them’ (P6). It was indicated that general practitioners should facilitate opportunistic discussions about screening, especially when a woman turned 25 years old. Practices should display information in the waiting rooms and provide written information such as pamphlets or fact sheets, with this information being ‘very direct, black and white’ (P1) to increase the likelihood that a woman will read it. It was also proposed that general practices should provide information by phone or email.

Discussion

It became apparent that women were hesitant about the new NCSP, as they were apprehensive that screening will miss cancers due to primary HPV testing and increased screening intervals. A qualitative Irish study highlighted that even when women understood HPV causes cancer, they were anxious about screening changes due to their attachment to traditional pap smears.[10] Participants were afraid that the new program would endanger young women as they were perceived to be at increased risk of cervical cancer. Young women are becoming sexually active earlier and participants were also concerned about the effectiveness of vaccination. In reality however, women over 50 years are at higher risk for cervical cancer and this misconception of age related risk may indicate the need for more patient education.[11] Moreover, the new screening program is predicted to have a greater impact in cervical cancer mortality in unvaccinated cohorts (36%) over vaccinated cohorts (29%).[12] It appears that participants are wary of the change to screening, though some women became more accepting of the new program when provided information and this reiterates the need for improved health literacy on cervical cancer.

Participants suggested a variety of methods to improve screening, including education programs concentrating on young women. Minimal education about cervical cancer and HPV occurs in schools and parents perceived it is not their responsibility to educate their children on this topic. Although, school-based education programs were an acceptable solution to this.[13] Media and social media campaigns were proposed to increase awareness, with previous research suggesting an emphasis on factual information from organisations over personal anecdotes.[14] The general practitioner is a trusted and valued source of information and should provide interventional health education with eligible women.[15,16] More research should occur in general practice to develop and evaluate interventions in order to improve cervical screening. Finally, financial concerns prevented women from participating in screening. Women incur a cost with cervical screening unlike bowel or breast screening. Government policymakers should reassess the costs involved in cervical screening and consider expanding the availability of bulk-billed services.

Screening participation is influenced by personal and practitioner factors. A woman's personal factors include: to be healthy, to be there for family, history of abnormal smears or cancer. A woman's comfort in her relationship with her practitioner influenced her screening behaviour. This was determined by trust in her regular doctor, gender preference and a general feeling of comfort. A previous qualitative literature review similarly discussed that screening provides reassurance of health. Though unlike this study, it also iterated that the test was uncomfortable, embarrassing and previous negative experiences hindered participation.[17] This may be as the literature review encompassed studies that included under-screened populations, while this study only included two under-screened women.

This study provides timely qualitative research on participant's perceptions of the new NCSP and will provide valuable data on these changes. Researchers conducted interviews using a piloted interview template until theoretical data saturation. It was also conducted in parallel to a quantitative study as an explanatory component and allowed for data triangulation. The use of convenience and snowball sampling at one private regional general practice may have led to a skewed representation of the population and may not include high risk groups for cervical cancer.

Conclusion

Women are apprehensive about the new changes to the NCSP, as they believe that increased screening intervals and primary HPV testing may lead to missed cervical cancers. Personal and practitioner factors affect screening participation, with emphasis on maintaining good health and feeling 'comfortable' with their doctor. Cervical cancer participation could be improved by increasing education about cervical cancer and the new NCSP through schools, advertising campaigns and the general practitioner. It was also emphasised that the cost and accessibility of screening should be revised.

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Author Statement

AN designed the study, conducted interviews, transcribed interviews, coded data, conducted thematic analysis and was primary author of the manuscript. RB assisted with logistical considerations for data collection at the general practice. JB assisted with study design, designing the interview template, reviewed thematic analysis and provided intellectual input into the manuscripts. CH assisted with study design, creating the interview template and provided intellectual input into the manuscripts.

Conflicts of Interests

None declared

Data Statement

Technical appendix, statistical code, and dataset available from the Dryad repository, doi:10.5061/dryad.7m0cfxppx

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Tables

Table 1: Demographic Tables

Participant	Age	Screening Status[1]
P1	41	Well-screened
P2	42	Under-screened
P3	43	Well-screened
P4	53	Well-screened
P5	30	Well-screened
P6	55	Well-screened
P7	58	Well-screened
P8	33	Well-screened
P9	20	Well-screened
P10	22	Well-screened
P11	57	Well-screened
P12	36	Well-screened
P13	38	Well-screened
P14	35	Under-screened

Notes: [1]Participants were considered well-screened if they had participated in screening the last two years. Under-screened participants had not been screened in over two years or had never been screened.

Table 2: Themes and Illustrative Quotes

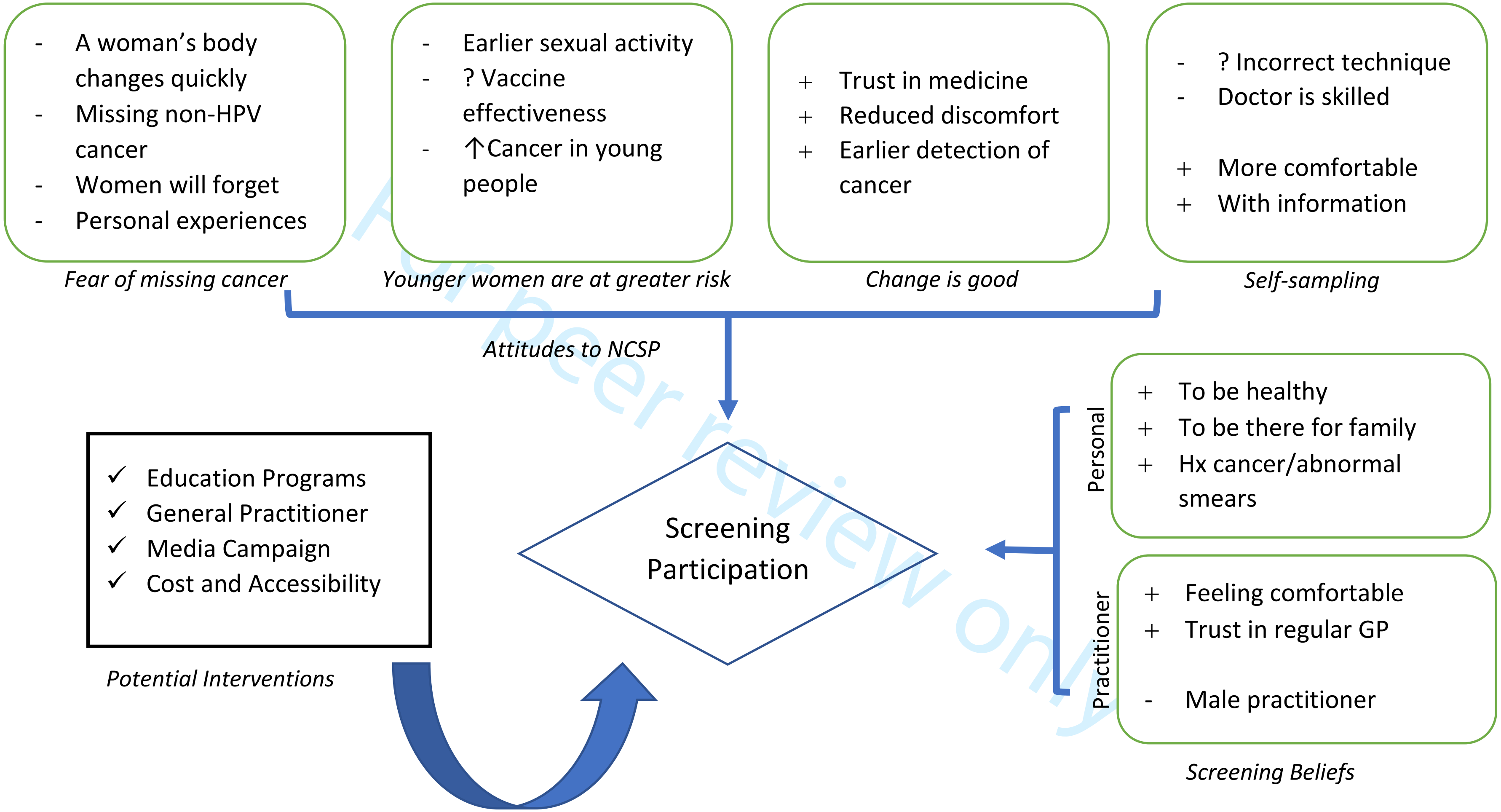
Theme			
Attitudes to NCSP	Fear of missing cancer		
		A woman's body changes quickly	So obviously, it's important to try and catch it early and a couple of years can make a huge difference. So, I think it probably would have been better if they left it the way that it was. (P10) But like stretching it out that bit further, it worries me that is something going to happen and by the time they come around to screening again, is it going to be too late for me? (P4)
		Missing non-HPV cancer	If we miss that 1%, what's that out of 100? That's still one person. One person out of every hundred we're missing, that's sad. That's someone's mother, someone's daughter. (P12) I would think put some women at risk, that are not exposed to HPV and would get it otherwise. (P2)
		Women will forget	And then it will get to that five years and people will still go, 'Well I'll just wait another 6 months.' (P5) I think there will be too many people that get complacent and I think because of it too many people will get sick. (P12)

	Personal Experiences	Considering that I've had smears that have been not… a little bit concerning, I'd be concerned about that. (P8) A friend of mine got cervical cancer when she was 21… If they didn't catch it early, she'd be dead. (P2)
Younger women are at greater risk		
	Earlier sexual activity	A lot of children are starting to have sex at 13,14. At 25, for some kids that's over 10 years that kids are sexually active before they have screening. (P3)
	Vaccine effectiveness	Depends on how good the vaccination is and the stats around how effective that is. Because we know that vaccinations aren't 100%. (P8) Maybe that's what contributed to the 25 age testing that a lot of younger women have had the Gardasil vaccine but even then, a lot of parents won't let their kids have that. (P5)
	More young people have cancer	And I've heard that there has been cases of younger ones getting cervical cancer. Stuff that normally you don't see til you are older and now coming up in younger women. (P4) I think younger people are at higher risk. (P2)
Change is good		
	Trust in medicine	I think I've got faith in the doctors because there must be a reason as to why they are doing that. (P11)

		Reduced discomfort	Well I like the idea of not having to go back every 2 years and not be in that uncomfortable position. (P14)
		Earlier detection of cancer	I guess it starts somewhere doesn't it. If they pick up one thing, they can prevent it from leading to something else. (P13)
Screening Beliefs	Personal		
		To be healthy	Just because I want to be healthy, like I go to the dentist and have a normal check up every year. This is part of the routine. (P11)
		To be there for family	It wouldn't just affect me, it would affect my whole family. I couldn't be selfish like that, to not get it done for whatever reason. Because, once you're gone… you've left and not destroyed but you've upset your whole family by not going to look after yourself when it's just a simple test. (P4)
		Hx cancer/abnormal smears	My grandma got really sick with cancer and so it kind of has impacted me to make sure I try and look after myself. (P10) A long time ago I did have an abnormal smear. So, I guess knowing that, not wanting to go through that again making sure I'm keeping on top of that, so it doesn't happen again. (P13)

	Practitioner	
	Feeling comfortable	As long as I felt comfortable with the doctor. Their bedside manner was nice, they were clean, the instruments they used was sterile, they followed all their proper PPE precautions. (P12)
	Trust in regular GP	I always just go to my GP. (P9) …. because I had been going to him for a long time. (P4)
	Male Practitioner	I just feel more comfortable with a female because I'm female (P11)
Potential Interventions	Education Programs	And that the girls should be learning about it at school in their health and wellness classes as well so that as maturing adults they are aware of what is going on in their own bodies. (P3) Kids these days get information from their friends, if their parents don't talk to them about it. So, if you are one of those parents that doesn't, your children are going to take information from their friends that might be incorrect. (P5)
	General Practitioner	The GP would be good. You listen to them. Even if they give you a piece of paper, you go read that. (P6) I do think that it would be a good idea that when you are having a pap smear the doctor talks to you about the relationship between cervical cancer and other issues and stuff (P3)

	Media Campaign	So just put it on my Facebook screen or my Instagram or something like that. So then, y'know that I can click on it and it's private. (P2) It's something that should be spoken about more, y'know. And I just think advertising on tv would be a strong starting point (P12) I feel like people need to hear about the stories of people actually having cancer. I think the scare factor is pretty effective for young people. (P8)
	Improving cost and accessibility	I think anything to do with those tests (cervical screening) should come with a bulk billing visit for women because it is a deterrent for going to your GP. (P5) And if you did like pop up clinics because you know they always have pop up Red Cross Blood Van (P9)


- A woman's body changes quickly
- Missing non-HPV cancer
- Women will forget
- Personal experiences
Fear of missing cancer
- Earlier sexual activity
- ? Vaccine effectiveness
- ↑Cancer in young people
Younger women are at greater risk
+ Trust in medicine
+ Reduced discomfort
+ Earlier detection of cancer
Change is good
- ? Incorrect technique
- Doctor is skilled
+ More comfortable
+ With information
Self-sampling
Attitudes to NCSP
✓ Education Programs
✓ General Practitioner
✓ Media Campaign
✓ Cost and Accessibility
Potential Interventions
Screening Participation
Personal
+ To be healthy
+ To be there for family
+ Hx cancer/abnormal smears
Practitioner
+ Feeling comfortable
+ Trust in regular GP
- Male practitioner
Screening Beliefs

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	3
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	3
Occupation	3	What was their occupation at the time of the study?	3
Gender	4	Was the researcher male or female?	3
Experience and training	5	What experience or training did the researcher have?	3
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	3
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	3
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	3
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	4
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	3
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	3
Sample size	12	How many participants were in the study?	4
Non-participation	13	How many people refused to participate or dropped out? Reasons?	4
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	3
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	3
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	4
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	3
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	3
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	3
Field notes	20	Were field notes made during and/or after the inter view or focus group?	3
Duration	21	What was the duration of the inter views or focus group?	3
Data saturation	22	Was data saturation discussed?	3
Transcripts returned	23	Were transcripts returned to participants for comment and/or	3

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	4
Description of the coding tree	25	Did authors provide a description of the coding tree?	4
Derivation of themes	26	Were themes identified in advance or derived from the data?	4
Software	27	What software, if applicable, was used to manage the data?	4
Participant checking	28	Did participants provide feedback on the findings?	4
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	15-19
Data and findings consistent	30	Was there consistency between the data presented and the findings?	10-14
Clarity of major themes	31	Were major themes clearly presented in the findings?	10-14
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	10-14

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.

Knowledge and perspectives of the new National Cervical Screening Program: a semi-structured interview study of North Queensland women – "I could be that one percent"

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Knowledge and perspectives of the new National Cervical Screening Program: a semi-structured interview study of North Queensland women – "I could be that one percent"

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Word count 3888 words

Abstract

Objectives

To investigate women's understanding and attitudes towards the National Cervical Screening Program (NCSP) and to explore methods to improve screening participation.

Design

Semi-structured face to face interviews were conducted through convenience and snowball sampling. Thematic analysis occurred using the interpretivist framework.

Setting

A private general practice in North Queensland.

Participants

Women between the ages of 18 to 74 who attended the general practice were eligible to participate. Fourteen women between 20 and 58 years old were interviewed.

Results

Participants were concerned that the new NCSP would miss cancer due to longer screening intervals and reliance on primary HPV testing. They believed that young women are at increased risk of cervical cancer, due to perceived HPV vaccine ineffectiveness and parent objection to vaccination. Most participants were not agreeable to self-sampling and preferred their doctor to perform screening. Personal and practitioner beliefs influenced a woman's screening participation. Personal factors include being healthy for themselves and their family, previous abnormal smears and family history of cancer. Emphasis was placed on feeling 'comfortable' with their practitioner which included patient rapport and gender preference. Proposed methods to improve cervical screening included education programs, advertising campaigns, general practitioner interventions and improving accessibility.

Conclusions

It is apparent that women are hesitant about the new NCSP. However, when provided with additional information they were more amenable to the changes. This highlights the need to improve awareness of cervical screening and the new NCSP.

Article Summary

Strengths and limitations of this study

- Interviews explored participants' attitudes towards the new NCSP, where there is currently little research.
- Individual interviews were conducted until theoretical data saturation and the interview template was piloted.
- Convenience and snowball sampling through a private general practice may have led to inaccurate sample representation.
- Most participants were well-screened for cervical cancer, which may not be inclusive of high risk groups.
- The study was completed in an outer regional centre and may not apply to the general Australian population.

Background

While the National Cervical Screening program (NCSP) has more than halved cervical cancer mortality, only 54-56% of eligible Australian women[1] participated in screening between January 2016-June 2017. This is especially concerning as over 90% of women diagnosed with cervical cancer were under-screened or never-screened.[2] Women from lower socioeconomic status, rural areas or those that identify as Aboriginal and Torres Strait Islander have lower screening participation rates and higher cervical cancer mortality.[1] Recently, the NCSP has been changed and has moved away from traditional pap smears towards a 5 yearly cervical screening test (CST) with for Human Papilloma Virus (HPV) and reflex cytology.[2] Australian women begin cervical screening at 25 years old and have an exit CST from 70-74 years old. Women over 30 years who have never been or are currently under-screened are also eligible for self-sampling, consisting of a high vaginal swab for HPV.[2,3]

As per the World Health Organisation guidelines, there has been a global shift to HPV-based cervical screening.[4] Worldwide, countries including the United Kingdom, Ireland, Netherlands and Turkey have implemented national HPV-based cervical screening, with many more transitioning towards primary HPV testing.[5,6] Previous international studies stated most women are unaware of the use of primary HPV testing[7] and that some women may experience a negative emotional response towards primary HPV testing as it is a sexually transmitted infection[8,9]. Due to the recent nature of changes to cervical screening, there is limited qualitative literature assessing Australian women's attitudes towards the new NCSP. One Australian study used thematic analysis of an online petition against the new NCSP, revealing that the greatest concerns were missing cancer due to prolonged screening intervals and the delay in screening age.[10]

The researchers' primary aim is to explore North Queensland women's awareness and perceptions of the new NCSP. Knowledge of cervical cancer, factors that affect screening participation and methods to improve screening awareness were also investigated.

Methods

Authors followed the Consolidated Criteria for Reporting Qualitative Health Research (COREQ).

Patient selection and setting

Women between 18-74 years old who attended a specific North Queensland general practice were eligible for this study with convenience and snowball sampling. This project was conducted with a concurrent quantitative survey. Receptionists provided waiting room surveys and an expression of interest form for a follow-up interview. Quantitative results collected through waiting room surveys will be published separately. The interviews were advertised on the practice's Facebook page and participants were encouraged to promote the study to their family and friends. Women who expressed interest were contacted by phone or email.

Data collection

A semi-structured, face-to-face individual interview was conducted at the participant's convenience at their home or a hospital meeting room between March and April 2019. The average length of the interview was 20 minutes. All interviews were conducted by the primary author, a female medical student (AN) with training in qualitative research. The interviewer (AN) may have some personal bias as she is eligible for cervical screening. No participants were known to AN and participants were aware that this interview was part of an Honours project.

The piloted interview guide included questions about knowledge of cervical cancer and screening, opinions regarding the NCSP, barriers to screening and thoughts to improve screening participation.

During the interview, participants were asked their opinions of the new NCSP, both with their baseline knowledge and after the interviewer provided basic information on the program. Additionally, the interviewer determined screening status in the interview. Screening status was defined using the previous guidelines due to the current transition to the new NCSP. A 'well-screened' participant had undergone cervical screening in the last two years while, an 'under-screened' participant was overdue for screening.

The interview guide (Appendix 1) was developed after analysis of the existing literature[11,12] and discussion amongst the investigators, including a general practitioner and a research officer, both experienced in qualitative research. Prior to the interview, participants signed a consent form for the interview to be audio recorded. The interviews were transcribed verbatim, including notes on non-verbal cues and were uploaded to nVivo. Transcribed interviews were not returned to participants for comments as there was no ambiguity that required clarification. Further, some methodological literature suggests it may provide little benefit to improving data accuracy and it may lead to misrepresentation of the original data.[13] No repeat interviews were conducted. Data collection continued until theoretical data saturation was achieved.

Patient and public involvement

No participants were involved with the development of this study protocol or data analysis.

Data analysis

Transcribed interviews were analysed using NVivo 12[14] using thematic analysis and the interpretivist paradigm. Data was analysed under relevant headings, for example 'Attitudes towards NCSP' and 'Factors affecting screening participation' but no themes were predetermined. AN completed line-by-line coding to identify the preliminary themes and codes in the data, which was validated by another author (JB) with no significant changes to coding required. Data was further analysed to cluster themes under the appropriate research questions to create a thematic schema.

Ethical Considerations

Ethical approval was provided by the James Cook University Human Research Ethics Committee (H7465). Participants completed a consent form that stated that they agreed to a recorded interview.

Results

Participant Characteristics

Twenty-eight women expressed interest to be interviewed and were contacted by phone or email. Fourteen women consented to be interviewed, with four participants identified by convenience sampling and ten by snowball recruitment. Table 1 displays individual participant characteristics. The age of participants ranged between 20 and 58 years old. Most women participated in screening and only two were considered under-screened as per the previous NCSP.

Themes

Thematic analysis revealed three major themes on participant's attitudes towards the NCSP: 'Fear of missing cancer',' younger women are at greater risk,' 'self-sampling' and 'change is good'. Screening beliefs were subdivided into personal and practitioner factors. Based on participants' suggestions, four potential intervention strategies emerged. Table 2 displays illustrative quotes for these themes. A thematic schema depicting conceptual links throughout the themes is displayed in Figure 1.

Knowledge of Cervical Cancer and NCSP

Participants identified genetics and infection as the main causes of cervical cancer. Most participants did not specify HPV as the main cause of cervical cancer but when asked, participants were frequently aware of the link between HPV and cervical cancer. Hormones, contraceptive pill, smoking and toxins were listed by participants as causes of cervical cancer. Women considered family history and sexual activity the main risk factors for cervical cancer. Other risk factors included not participating in regular screening, previous abnormal smears and being unvaccinated. Participants believed abnormal bleeding and pain were symptoms of cervical screening though, many women were unsure of the symptoms. Bloating, abnormal discharge and pain during sex (dyspareunia) were also reported by some participants as symptoms of cervical cancer.

Participants understood that cervical screening occurs using pap smears and often could describe that pap smears look for abnormal cells. Some participants were aware of the change to screening and could correctly identify that screening was now 5-yearly. Women stated that cervical screening should occur in their early twenties and some said that it began with the onset of sexual activity.

Attitudes towards the new NCSP

FEAR OF MISSING CANCER

Participants were anxious that 5 years was 'a long time for cancer to grow' (P12) and may lead to more women diagnosed with cancer. More regular screening was identified as having 'a better chance of picking something up' (P14) as 'things in our body change very quickly' (P1). There were fears that increased screening intervals may miss cancer, as clinicians may not always get a 'clear swab' (P8) and hence more regular screening was preferable. Additionally, participants were apprehensive that primary HPV testing would miss cancer caused by ‘things other than HPV’ (P9). They were uncomfortable with the CST not testing for abnormal cells as ‘I could be that one percent’ (P12) with cervical cancer not caused by HPV. Subsequently, some participants preferred co-testing for both HPV and abnormal cells to receive the benefits of both screening methods.

Women believed that ‘every 2 years is easy enough to recall but not 5 years’ (P12) and may not remember to participate in screening, due to increased screening intervals. Participants were concerned that increased screening intervals will make women more ‘complacent’ (P12) in their screening behaviour and will delay screening even longer. They proposed that increased intervals required a register to provide appropriate reminders to women. A participant stated that increased intervals may also affect the feasibility of contacting patients, as after five years ‘not everyone lives at the same address’ (P7).

Those with a history of previous abnormal smears thought 5 yearly screening was ‘a little bit concerning’ (P8). Participants who had family or friends with cervical cancer were concerned by the increased screening interval as ‘they didn’t pick up hers until it was too late’ (P4). One participant negatively viewed delaying screening until a woman is 25 years, as her friend was diagnosed with cervical cancer earlier than this, and ‘if they didn’t catch it early, she’d be dead’ (P2). These personal experiences with abnormal smears or cervical cancer made women more ‘paranoid’ (P4) about cervical cancer.

YOUNG WOMEN ARE AT GREATER RISK

Participants perceived that commencing screening from 25 years old, placed women at increased risk for cancer due to earlier sexual activity of young women. Participants stated that children are ‘having sex a lot younger nowadays’ (P13). They highlighted that as young women are sexually active from their early teens, it may be ‘over 10 years that kids are sexually active before they have screening’ (P3). Participants also believed that delaying cervical screening would prevent opportunistic testing for sexually transmitted infections in young women.

While some women identified that the introduction of the Gardasil vaccination was beneficial in reducing cervical cancer incidence, there was also a perception that ‘a lot of parents won’t let their kids have that’ (P5). This raised concerns as to whether unvaccinated women would be protected under the new NCSP in the future. Additionally, participants feared that ‘even though you are vaccinated you can still get diseases’ (P7) and believed that delaying screening will lead to cervical cancer being missed in women under 25 years. Some participants thought that patients diagnosed with cancer are becoming ‘younger and younger’ (P2). Younger women were described to be at ‘higher risk’ (P2) of cervical cancer and participants felt that earlier detection of cervical cancer in women would improve their survival rates.

CHANGE IS GOOD

Several participants expressed their ‘faith in the doctors’ (P11) and believed that screening would not have changed without underlying improvements in science. They perceived that ‘testing is that good’ (P7) if screening intervals have increased from every 2 years to 5 years. Participants highlighted that HPV testing is a positive change as it would ‘catch it (HPV)’ (P11) before abnormal cells became detectable by a traditional pap smear. They accepted that if HPV was ‘linked so strongly’ (P9) with cervical cancer, primary HPV testing was a beneficial change to cervical screening. After participants were provided information on the new NCSP and cervical cancer’s slow progression, they were more receptive towards the new guidelines. An additional benefit of the new NCSP was that reduced screening would ‘make life easier’ (P6) for women, as cervical screening was described as ‘uncomfortable’ (P14) by participants.

SELF-SAMPLING

Participants were generally hesitant to accept self-sampling as they did not ‘feel confident enough in myself’ (P14) to administer the test. This stemmed from the fear of incorrectly completing the test as they may not ‘swab far enough’ (P5) or that ‘it might be contaminated’ (P4). Doctors were thought to be better equipped to perform cervical screening as they had appropriate training to ensure it was ‘done properly’ (P8). It was perceived that doctors had better visualisation of the cervix as they used a speculum and would take a sample from ‘the right places’ (P3).

Nonetheless, participants acknowledged that self-sampling would provide women ‘more privacy’ (P10) and could improve screening participation. The test was deemed to be ‘less invasive’ (P5) than traditional cervical screening, especially for those who have had previous negative experiences with cervical screening. Participants often had the misconception that self-sampling required a cervical swab. When informed it was in fact, a high-vaginal swab more participants reported they would consider self-sampling. Some participants indicated that they would complete self-sampling if they were provided instructions or shown by a practitioner. Women highlighted that technological improvements allowed for ‘smaller traces’ (P2) of HPV to be detected and this made self-sampling more acceptable.

Factors affecting screening participation

PERSONAL

Participants explained that cervical screening was a part of their normal health ‘routine’ (P11). Screening allowed them to have ‘peace of mind’ that they were healthy, and it allowed them to receive ‘further help’ (P1) if required. Many women emphasised that their family was the key reason they had cervical screening. They described their sense of responsibility to their family who required them to ‘make the right choices’ (P3) by undergoing screening. Participants disclosed that cancer could destroy their families and thus they chose to screen. A woman’s personal experiences with cancer shaped her willingness to participate in cervical screening. A history of abnormal smears motivated women to ‘keep on top’ (P13) of their screening to prevent re-occurrence. Women with a family history of cancer had firsthand experience as to how it devastated their families, which motivated them to undergo regular cervical screening.

PRACTITIONER

Several participants described feeling ‘comfortable’ (P10) with their general practitioner as a facilitator to screening participation. This feeling of being ‘comfortable’ was influenced by the doctor’s bedside manner, professional behaviour and hygienic technique throughout the procedure. Some women expressed that they trusted their regular doctor due to their pre-existing relationship, as they have known them for a ‘long time’ (P4). Participants frequently mentioned their practitioner’s gender when discussing screening participation. Most participants indicated that they are more ‘comfortable’ with a female doctor as she ‘has the same bits’ (P2). However, some women had no gender preference as cervical screening is ‘just something that happens’ (P7) and one participant thought that ‘once you have a few kids, you’re over it’ (P4).

Improving CST Awareness and Participation

Cost and Accessibility

A lack of bulk-billed services in regional areas was identified by women as a key barrier to cervical screening participation. The cost of cervical screening was a ‘deterrent’ (P5) for attending the general practitioner for screening, especially in low socioeconomic women as ‘their priority is probably not money for them, it’s going to be feeding their children’ (P5). Participants also emphasised that cervical screening is not bulk-billed, unlike breast and bowel cancer. Women expressed the need for increased accessibility of cervical screening, especially in regional communities. It was suggested that cervical screening should have ‘pop-up’ (P9) clinics, as seen with blood donation and breast screening.

Media Campaigns

The role of a media campaign to potentially increase cervical screening awareness was discussed by participants. Participants proposed that television advertisements should be aired to encourage discussion about screening. Social media was deemed to be a valuable platform to educate women about cervical screening due to its ‘really big role in young women’s lives’ (P9) and the interaction remained ‘private’ (P2). Women also suggested that an ambassador should lead the discussion on cervical cancer, such as in England when a celebrity ‘found out on Big Brother that she had cervical cancer’ (P3). Participants expressed that it is important to hear personal stories from survivors as it provides a ‘scare factor’ (P8) and would encourage screening.

Education Programs

Participants explained the importance of education to improve screening participation, especially in schools through sex education to ensure young women have the ‘right information’ (P5) about HPV and cervical cancer. Education programs should inform women about the purpose of the Gardasil vaccine, the NCSP and symptoms of cervical cancer. Participants believed that education will reduce any fears related to screening and solidify ‘how important it is’ (P12). It was also suggested that education sessions should also occur at universities, playgroups and the workplace.

General Practitioner

Participants emphasised the importance of their general practitioner as a trusted source of information about cervical screening as ‘you listen to them’ (P6). It was indicated that general practitioners should facilitate opportunistic discussions about screening, especially when a woman turned 25 years old. Practices should display information in the waiting rooms and provide written information such as pamphlets or fact sheets, with this information being ‘very direct, black and white’ (P1) to increase the likelihood that a woman will read it. It was also proposed that general practices should provide information by phone or email.

Discussion

It became apparent that women were hesitant about the new NCSP, as they were apprehensive that screening will miss cancers due to primary HPV testing and increased screening intervals. A Canadian study by *Ogilvie et al.* stated that primary HPV testing was acceptable, though acceptability decreased when combined with increased screening intervals.[15] Participants’ objections towards the change in screening may be due to the general public’s fatalistic view of cancer and belief that frequent testing leads to earlier diagnosis.[16] A qualitative Irish study highlighted that even when women understood HPV causes cancer, they were anxious about screening changes due to their attachment to traditional pap smears.[17] Participants were afraid that the new program would endanger young women as they were perceived to be at increased risk of cervical cancer. This was due to participant concerns that young women are becoming sexually active earlier and queries over the effectiveness of the Gardasil vaccine. In reality however, women over 50 years are at higher risk for cervical cancer and this misconception of age related risk may indicate the need for more patient education.[18] Moreover, the new screening program is predicted to have a greater impact in cervical cancer mortality in unvaccinated cohorts (36%) over vaccinated cohorts (29%).[19]

It is noteworthy that participants became accepting of HPV after they were provided additional information explaining the new NCSP. This is congruent with *Waller et al*[20] who described that women's anxieties surrounding HPV reduces as health literacy increases. Participants suggested a variety of methods to improve screening including education programs concentrating on young women. Minimal education about cervical cancer and HPV occurs in schools and parents perceived it is not their responsibility to educate their children on this topic, though school-based education programs were an acceptable solution to this.[21] Media and social media campaigns were proposed to increase awareness. Participants suggested the use of cancer survivors as ambassadors, though past research suggested an emphasis on information from organisations over personal anecdotes.[22] The general practitioner is a trusted and valued source of information and should provide interventional health education with eligible women.[23,24] A systematic literature review explains that patient's likelihood to participant in preventive screening is linked directly to the quality of discussion between clinician and patient, with an emphasis on shared decision making rather than a simple recommendation.[25] More research should occur in general practice to develop and evaluate interventions in an Australian context in order to improve cervical screening.

Finally, logistical concerns prevented women from participating in screening. Previous literature demonstrates that reducing economic and geographic barriers improve disadvantaged women's likelihood to participate in cervical screening.[26] Unlike other government mandated screening programs such as bowel and breast screening, for cervical cancer screening women bear the burden of cost when attending their appointment with their general practitioner. Government policymakers should reassess the costs involved in cervical screening and consider expanding the availability of bulk-billed services.

Screening participation is influenced by personal and practitioner factors. A woman's personal factors include: to be healthy, to be there for family, history of abnormal smears or cancer. A woman's comfort in her relationship with her practitioner influenced her screening behaviour. This was determined by trust in her regular doctor, gender preference and a general feeling of comfort. A previous qualitative literature review similarly discussed that screening provides reassurance of health. Though unlike this study, it also iterated that the test was uncomfortable, embarrassing and previous negative experiences hindered participation.[27] This may be as the literature review encompassed studies that included under-screened populations, while this study only included two under-screened women.

This study provides timely qualitative research on participant's perceptions of the new NCSP and will provide valuable data on these changes. Researchers conducted interviews using a piloted interview template until theoretical data saturation. It was also conducted in parallel to a quantitative study as an explanatory component and allowed for data triangulation. However, sampling at one private regional general practice may have led to a skewed representation of the population and may not include high risk groups for cervical cancer. In addition, snowball sampling may have led to women with more positive health seeking behaviours to participate in this project. The use of the interpretivist paradigm may allow for the impact of the primary researcher bias (AN) though, this was minimised by a second author (JB) validating thematic analysis.

Conclusion

Women are apprehensive about the new changes to the NCSP, as they believe that increased screening intervals and primary HPV testing may lead to missed cervical cancers. Personal and practitioner factors affect screening participation, with emphasis on maintaining good health and feeling 'comfortable' with their doctor. Cervical cancer participation could be improved by increasing education about cervical cancer and the new NCSP through schools, advertising campaigns and the general practitioner. It was also emphasised that the cost and accessibility of screening should be revised.

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Author Statement

AN designed the study, conducted interviews, transcribed interviews, coded data, conducted thematic analysis and was primary author of the manuscript. RB assisted with logistical considerations for data collection at the general practice. JB assisted with study design, designing the interview template, reviewed thematic analysis and provided intellectual input into the manuscripts. CH assisted with study design, creating the interview template and provided intellectual input into the manuscripts.

Conflicts of Interests

None declared

Data Statement

Data are available upon reasonable request

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Table 1: Demographic Tables

Participant	**Age**	**Screening Status**[1]
P1	41	Well-screened
P2	42	Under-screened
P3	43	Well-screened
P4	53	Well-screened
P5	30	Well-screened
P6	55	Well-screened
P7	58	Well-screened
P8	33	Well-screened
P9	20	Well-screened
P10	22	Well-screened
P11	57	Well-screened
P12	36	Well-screened
P13	38	Well-screened
P14	35	Under-screened

Notes: [1]Participants were considered well-screened if they had not participated in screening the last two years. Under-screened participants had not been screened in over two years or had never been screened.

Table 2: Themes and Illustrative Quotes

Theme			
Attitudes to NCSP	Fear of missing cancer		
		A woman's body changes quickly	So obviously, it's important to try and catch it early and a couple of years can make a huge difference. So, I think it probably would have been better if they left it the way that it was. (P10) But like stretching it out that bit further, it worries me that is something going to happen and by the time they come around to screening again, is it going to be too late for me? (P4)
		Missing non-HPV cancer	If we miss that 1%, what's that out of 100? That's still one person. One person out of every hundred we're missing, that's sad. That's someone's mother, someone's daughter. (P12) I would think put some women at risk, that are not exposed to HPV and would get it otherwise. (P2)
		Women will forget	And then it will get to that five years and people will still go, 'Well I'll just wait another 6 months.' (P5) I think there will be too many people that get complacent and I think because of it too many people will get sick. (P12)
		Personal Experiences	Considering that I've had smears that have been not… a little bit concerning, I'd be concerned about that. (P8) A friend of mine got cervical cancer when she was 21… If they didn't catch it early, she'd be dead. (P2)
	Younger women are at greater risk		
		Earlier sexual activity	A lot of children are starting to have sex at 13,14. At 25, for some kids that's over 10 years that kids are sexually active before they have screening. (P3)
		Vaccine effectiveness	Depends on how good the vaccination is and the stats around how effective that is. Because we know that vaccinations aren't 100%. (P8)

			Maybe that’s what contributed to the 25 age testing that a lot of younger women have had the Gardasil vaccine but even then, a lot of parents won’t let their kids have that. (P5)
		More young people have cancer	And I’ve heard that there has been cases of younger ones getting cervical cancer. Stuff that normally you don’t see til you are older and now coming up in younger women. (P4) I think younger people are at higher risk. (P2)
	The changes are good		
		Trust in medicine	I think I’ve got faith in the doctors because there must be a reason as to why they are doing that. (P11)
		Reduced discomfort	Well I like the idea of not having to go back every 2 years and not be in that uncomfortable position. (P14)
		Earlier detection of cancer	I guess it starts somewhere doesn’t it. If they pick up one thing, they can prevent it from leading to something else. (P13)
Screening Beliefs	Personal		
		To be healthy	Just because I want to be healthy, like I go to the dentist and have a normal check up every year. This is part of the routine. (P11)
		To be there for family	It wouldn’t just affect me, it would affect my whole family. I couldn’t be selfish like that, to not get it done for whatever reason. Because, once you’re gone… you’ve left and not destroyed but you’ve upset your whole family by not going to look after yourself when it’s just a simple test. (P4)
		Hx cancer/abnormal smears	My grandma got really sick with cancer and so it kind of has impacted me to make sure I try and look after myself. (P10) A long time ago I did have an abnormal smear. So, I guess knowing that, not wanting to go through that again making sure I’m keeping on top of that, so it doesn’t happen again. (P13)

	Practitioner	
	Feeling comfortable	As long as I felt comfortable with the doctor. Their bedside manner was nice, they were clean, the instruments they used was sterile, they followed all their proper PPE precautions. (P12)
	Trust in regular GP	I always just go to my GP. (P9) …. because I had been going to him for a long time. (P4)
	Male Practitioner	I just feel more comfortable with a female because I'm female (P11)
Potential Interventions	Education Programs	And that the girls should be learning about it at school in their health and wellness classes as well so that as maturing adults they are aware of what is going on in their own bodies. (P3) Kids these days get information from their friends, if their parents don't talk to them about it. So, if you are one of those parents that doesn't, your children are going to take information from their friends that might be incorrect. (P5)
	General Practitioner	The GP would be good. You listen to them. Even if they give you a piece of paper, you go read that. (P6) I do think that it would be a good idea that when you are having a pap smear the doctor talks to you about the relationship between cervical cancer and other issues and stuff (P3)
	Media Campaign	So just put it on my Facebook screen or my Instagram or something like that. So then, y'know that I can click on it and it's private. (P2) It's something that should be spoken about more, y'know. And I just think advertising on tv would be a strong starting point (P12) I feel like people need to hear about the stories of people actually having cancer. I think the scare factor is pretty effective for young people. (P8)
	Improving cost and accessibility	I think anything to do with those tests (cervical screening) should come with a bulk billing visit for women because it is a deterrent for going to your GP. (P5)

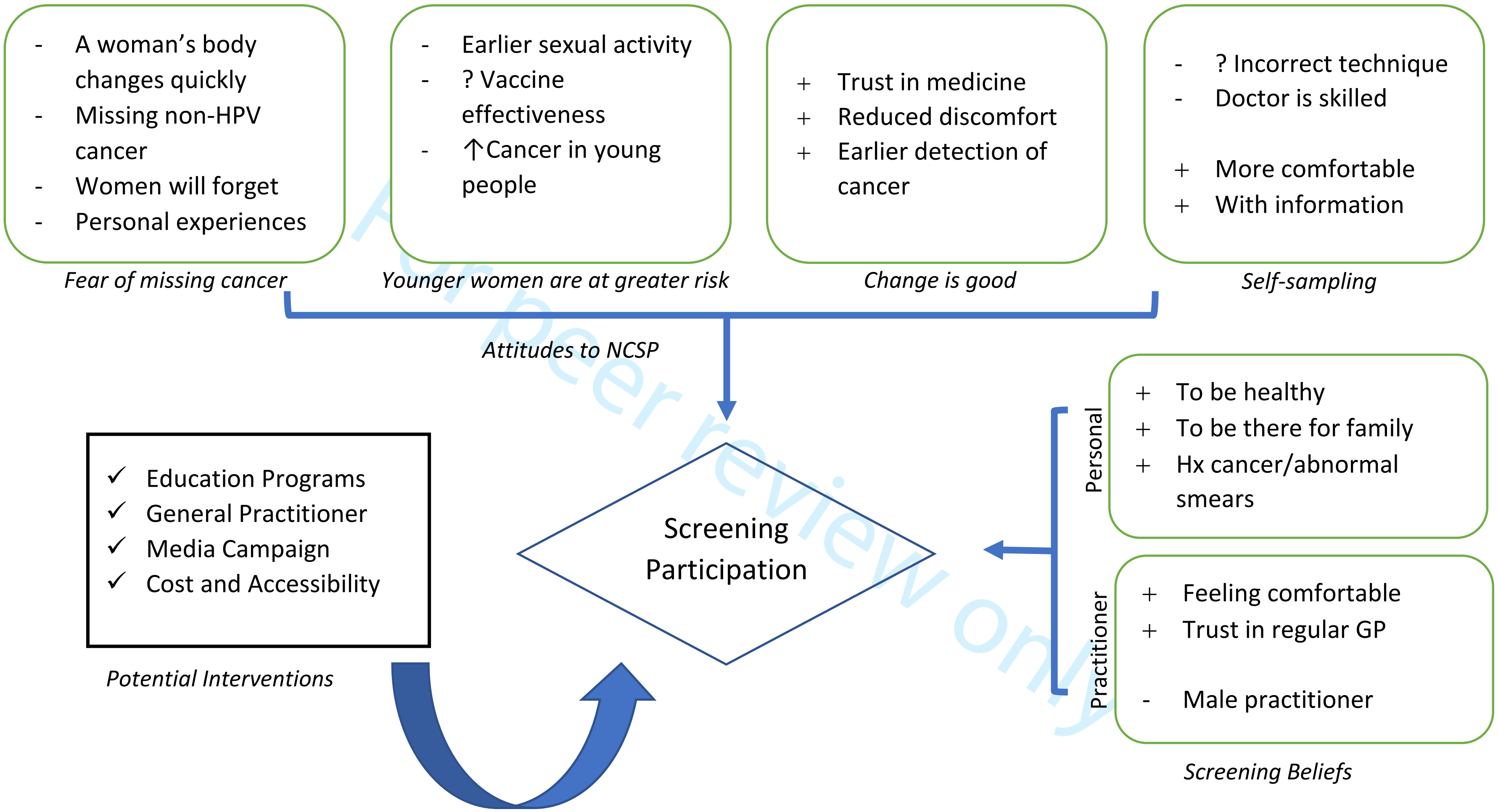
	And if you did like pop up clinics because you know they always have pop up Red Cross Blood Van (P9)

Figures

Figure 1: Relationship between identified themes

Appendix

Appendix 1: Piloted semi-structured interview guide


- A woman's body changes quickly
- Missing non-HPV cancer
- Women will forget
- Personal experiences
Fear of missing cancer
- Earlier sexual activity
- ? Vaccine effectiveness
- ↑Cancer in young people
Younger women are at greater risk
+ Trust in medicine
+ Reduced discomfort
+ Earlier detection of cancer
Change is good
- ? Incorrect technique
- Doctor is skilled
+ More comfortable
+ With information
Self-sampling
Attitudes to NCSP
✓ Education Programs
✓ General Practitioner
✓ Media Campaign
✓ Cost and Accessibility
Potential Interventions
Screening Participation
Personal
+ To be healthy
+ To be there for family
+ Hx cancer/abnormal smears
Practitioner
+ Feeling comfortable
+ Trust in regular GP
- Male practitioner
Screening Beliefs

Interview Template- Women's perceptions and understanding of cervical cancer and its screening

1. What do you know about cervical cancer?

    a. What do you think causes cervical cancer?

    b. What do you think are the symptoms of cervical cancer?

    c. What do you believe makes you more at risk for cervical cancer?

    d. How do you think HPV (wart virus) is related to cervical cancer?

2. What do you know about cervical cancer screening?

3. Cervical cancer screening has changed from every 2 years to every 5 years as of December 2017. How do you feel about that?

    a. How do you feel about starting screening at 25 years old instead of 18 years old?
    b. Do you feel about screening every 5 years instead of 2 years?
    c. As part of the new cervical cancer guidelines, some women will be allowed to take their own sample. How comfortable do you feel about the possibility that you can take your own sample?
    d. How do you feel about new screening tests looking for HPV (wart virus) first rather than looking at abnormal cells?

4. I am going to provide you some information about the new cervical screening program

    Cervical cancer is caused by Human papilloma virus (HPV), which high school students are now being vaccinated for. This virus also causes genital warts, anal cancer and throat cancer. HPV is contracted through sex and very common amongst those who are sexually active. Those who are infected with HPV may have some abnormal changes, but they often clear the infection themselves over a year or two. It takes about 10 years for abnormalities caused by this virus to cause cancer, this is quite rare.
    Although it will feel the same for you, the way your sample is stored and tested is different. It looks for HPV virus first and only if this is present will you have your smear looked at under a microscope. It is expected that the changes to the National Cervical Screening Program will protect up to 30% more women from cervical cancer. The new Cervical Screening Test is a more accurate, effective and safe test to have every five years instead of the two yearly Pap test.
    Source:

http://www.cancerscreening.gov.au/internet/screening/publishing.nsf/Content/D0EA98D0745313FACA2581D3001A6950/$File/DL-Brochure-Larger-Print-version.pdf

   a. Does this change your opinion about the changes to cervical screening?
   b. Do you feel comfortable with testing for HPV first?
   c. Do you feel it is safe to be tested every five years and to start testing later?

5. How comfortable do you feel with getting a pap smear/cervical cancer screen?
   a. Why do you choose or choose not to participate in cervical cancer screening?
   b. Do you have any personal factors that impact your decision?
   c. Does the doctor performing the test impact your decision?

6. How would you feel if your GP told you that you had ‘wart virus’?
   a. Would you prefer if your doctor called it HPV or wart virus and why?

7. What would you like to know about cervical cancer? How would you like to find out about this?

8. What would you like to know about cervical screening? How would you like to find out about this?

9. How do you think participation in cervical cancer screening could be improved?

10. Do you have any questions, concerns or a final statement?

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	3
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	3
Occupation	3	What was their occupation at the time of the study?	3
Gender	4	Was the researcher male or female?	3
Experience and training	5	What experience or training did the researcher have?	3
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	3
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	3
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	3
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	4
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	3
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	3
Sample size	12	How many participants were in the study?	4
Non-participation	13	How many people refused to participate or dropped out? Reasons?	4
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	3
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	3
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	4
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	3
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	3
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	3
Field notes	20	Were field notes made during and/or after the inter view or focus group?	3
Duration	21	What was the duration of the inter views or focus group?	3
Data saturation	22	Was data saturation discussed?	3
Transcripts returned	23	Were transcripts returned to participants for comment and/or	3

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	4
Description of the coding tree	25	Did authors provide a description of the coding tree?	4
Derivation of themes	26	Were themes identified in advance or derived from the data?	4
Software	27	What software, if applicable, was used to manage the data?	4
Participant checking	28	Did participants provide feedback on the findings?	4
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	15-19
Data and findings consistent	30	Was there consistency between the data presented and the findings?	10-14
Clarity of major themes	31	Were major themes clearly presented in the findings?	10-14
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	10-14

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.