



Short communication

Getting the timing right: Women's views on the best time to announce changes to cancer screening policy recommendations

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ABSTRACT

In December 2017, the Australian National Cervical Screening Program (NCSP) changed from 2-yearly cervical cytology to 5-yearly primary human papillomavirus (HPV) testing, starting at age 25 and with an exit test when aged 70–74. Women showed limited awareness of these changes prior to their implementation. We explored women's preferences for how similar cancer screening changes could be communicated to the public in the future, including when, how, and using what methods. Six focus groups including 49 women aged 18–74 were conducted in November 2017. Focus groups were guided by information available on the NCSP website and information developed by the researchers. Generally, women suggested that communication of changes to cancer screening programs would ideally occur between 6 and 12 months ahead of their implementation and that they would like the opportunity to be involved in consultation about the changes. The NCSP website was described as answering basic questions, but also raising further questions for which there were no answers provided. Most groups preferred information which included evidence behind the changes and wanted an option of more information. Similar suggestions were made across all focus groups about how communications could be delivered, with recognition that the mode of delivery should differ by age. Women were still seeking information about the test itself and a symptom list, in order to be aware of these over the five-year period. These findings make an important and timely contribution which could help inform other countries considering making changes to their cancer screening programs in the future.

1. Introduction

Strong evidence supporting the superior ability of human papillomavirus (HPV)-based screening over cervical cytology to prevent cervical cancer (Ronco et al., 2014), along with evidence of a reducing incidence of HPV and cervical abnormalities (Drolet et al., 2019; Brotherton et al., 2016) in young women post HPV vaccination, resulted in transformative recommendations for the Australian National Cervical Screening Program (NCSP) (Medical Services Advisory Committee. National Cervical Screening Program Renewal: Evidence Review (Assessment Report). MSAC Application No., 1276). An initial announcement of the changes was made by the Australian government in April 2014, but no mass awareness campaign informed the public prior to its implementation. A petition against the changes in early 2017, started by an

Australian woman who was concerned and worried after being informed about the changes by her GP, gathered over 70,000 signatures, suggesting that there was a considerable amount of resistance (Obermair et al., 2018), which appeared to arise due to a lack of knowledge and understanding about the reasons behind the changes (Dodd et al., 2019). The NCSP used to recommend screening women aged 18–69 every two years with cytology-based screening. Since the “Renewal” of the NCSP, women are recommended to undergo five-yearly primary HPV screening, starting at age 25 and with an exit test between 70 and 74 (Medical Services Advisory Committee. National Cervical Screening Program Renewal: Evidence Review (Assessment Report). MSAC Application No., 1276).

Limited awareness of these updated recommendations were recorded in focus groups of Australian women held in the month prior to their

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implementation (Dodd et al., 2019). Using the case of Australia's NCSP, the aim of this study was to consider women's views on how similar changes to cancer screening programs could be more effectively communicated to the public in the future.

2. Methods

As previously described (Dodd et al., 2019), six focus groups were conducted with women aged 18–74 across three locations in Sydney, Australia. Each group consisted of 5–10 women, divided by eligible age ranges (18–30, 31–50 and 51–74 years) for both the previous (1991–2017, age 18–69) and current (2017–present, age 25–74 years) NCSP. Participants were recruited through a fully independent market and social research company (Taverner), who used random landline and location-known mobile samples drawn from SamplePages, and list based mobile samples drawn from an opt in privacy compliant list of consumers who had responded to various online lifestyle surveys.

Participants were first presented information from the Australian Department of Health National Cervical Screening Program website (Australian Government Department of Health. National Cervical Screening Program, 2017) available at the time of the focus groups and discussion was facilitated around this information. Participants were then presented with information developed by the research team to give further detail on the main changes (see [Supplementary information](#) for both sets of information). Further methodological detail are reported elsewhere (Dodd et al., 2019). The University of Sydney Human Research Ethics Committee reviewed and approved this study (project number 2017/489).

All sessions were audio recorded, professionally transcribed verbatim, and managed using NVivo V.11. Thematic analysis was conducted to identify main themes. A coding framework was developed by RHD, with input from KJM. Two researchers (RHD and BN) used this framework to analyse all transcripts for themes and codes which focused around women's information needs and preferences. These themes and codes were developed and applied to the data, and through numerous meetings an agreement was made on the overarching concepts that demonstrated women's information preferences towards changes to screening programs. The research team members work in the field of public health, with a special interest in reducing overdiagnosis and overtreatment (RHD, BN, KJM), and in cervical cancer prevention (RHD, JMLB, MAS).

3. Results

Forty-nine women participated across six focus groups. These women were aged 18–30 ($n = 16/49$, 32.7%), 31–50 ($n = 13/49$, 26.5%) and 51–74 ($n = 20/49$, 40.8%). Briefly, 44.9% of women had a university degree and 65.3% of women worked either full or part-time. The sample was diverse with regard to education, employment and country of birth. Demographic data are detailed elsewhere (Dodd et al., 2019).

3.1. Themes

Themes related to information needs and preferences which included when, how, by what methods and what further information could be communicated.

3.1.1. When should we consider communicating about changes to cancer screening programs?

The majority of women across all aged focus groups said these sorts of changes should be communicated 6–12 months in advance (Q1; [Table 1](#)), reinforcing the message as the implementation date gets closer. As the changes were due to be implemented in December 2017 (although the original implementation date was planned to be May 2017), "just before Christmas" was noted as a bad time to make the

Table 1
Supportive quotes from Focus Groups.

Themes	Support quotes
When should we communicate about changes to cancer screening programs?	<p>Q1: 6 months to a year. 6 months. Yeah, I think that too. Yeah, 6 months to a year. (FG4, 51–74 years old)</p> <p>Q2: And Christmas is coming up. And everybody's thinking about other things ... There's so much happening that really I think that's going to... Little bit the worst time of the year. (FG1, 51–74 years old)</p> <p>Q3: So, so say we didn't have the plebiscite, it would be like waking up, you know, the next day and finding out gay marriage has been approved and... there was nothing anyone could do or say anything about it. And it's like this has gone through and women don't have a say or, er, input into any of these changes. It's just done. (FG6, 31–50 years old)</p>
How should we communicate about changes?	<p>Q4: Could have been good to frame it in terms of a positive of the previous screening program as well. Like, that screening program was so successful that we're so confident knowing what we have to do to pick up cervical cancer that we know that this change is ok, and safe, and good. (FG2, 18–30 years old)</p> <p>Q5: I think it needs to be a combination of the two, because I think ... all the sort of data is just trying to convince people, yeah, we've done the science, here it is... assess it for yourselves. Um, whereas the first one was a lot more like, no, we've done the research, this is, this is what's happening. Um, so this one [research team developed information] was more focused on... er, convincing, or like... the evidence side. (FG2, 18–30 years old)</p> <p>Q6: I guess it makes it seem more reliable and more, like backs it up a bit better. Um, rather than just stating the facts ... Even if a person's not going to look it up, it's still... makes it look better. Or a bit more trustworthy, that's all. (FG2, 18–30 years old)</p> <p>Q7: And did they ... take it based on Australia's lifestyle and living conditions? Did they take it based on women living in America or Europe or England? (FG4, 51–74 years old)</p>
What information is still needed?	<p>Q8: I don't care if they elaborate a bit more about the testing. Like now we've got, you know, high voltage or technology machines and this is how they detect it. (FG3, 31–50 years old)</p> <p>Q9: Yes, exactly what are they screening for? What exactly is that? (FG1, 51–74 years old)</p> <p>Q10: Maybe even stats around well 99% are normal cervical cancers and then there's 1% that's... so there's a bit of context. Because the whole thing's rare right? So to say it's rare for under 25's ... I think getting cancer, or this type of cancer, I also feel that that's rare. So... it's not really, um, relative. (FG2, 18–30 years old)</p> <p>Q11: ...Or maybe for more information maybe, maybe have as section where, you know, symptoms, so you could sort of go, ahh... no, no, I'm all good, I haven't got that symptom. (FG5, 18–30 years old)</p>
What methods can we use to communicate with people?	<p>Q12: I swear I get better education on Facebook than I ever did at school. (FG5, 18–30 years old)</p> <p>Q13: I think that idea of the pharmacy putting information in their bag with their contraceptive is pretty good. (FG4, 51–74 years old)</p> <p>Q14: In fact, think of the Opal [transportation] card campaign, right? That was a phased thing and ... you were told all the time when the date would be... Um, so people had time to take on board and then... And even the people who thought it wouldn't work now love it (laughs). (FG1, 51–74 years old)</p>

changes due to women having other things to think about (Q2).

For these women, reasons for wanting to know about the changes before they happened included the need to limit the amount of wrong information conveyed, with its subsequent negative press and resultant negative opinions, and to maintain trust. Some women in the 51–74 year old focus groups also believed that there was another 'agenda' for not telling women earlier. They hypothesised the reasons for this could be to avoid all women rushing to get their Pap smear before the program changed and not being able to get an appointment, or conversely, wanting to avoid a situation where women delayed screening until the new program.

Some women in the 31–50 year old focus groups would have liked to have known about these potential changes before they had been confirmed so that they could give their opinion. They recognised that there was nothing they could do about it two weeks before implementation and believed women didn't have a say (Q3).

Mistrust in doctors was also reported across all focus groups, with

women not sure why doctors hadn't informed women about the changes over the last year when attending for their Pap smear, resulting in a loss of trust, 'why didn't they tell us?' (FG6).

3.1.2. How should we communicate about changes?

The information that women wanted to know was: what was changing, why was it changing, the benefits of the changes and anything they needed to do. More specifically women wanted to know further information so that when they went to the doctor and were told about the changes, they were better able to understand the reasons behind the changes. They believed this information should be framed positively and explain the similarities and differences between the old and new program (Q4).

Overall across all aged focus groups women viewed the information presented from the Department of Health (DoH) website to be quite straightforward, very easy and simple text, but they viewed it as not accessible to everyone such as those with a disability and from culturally and linguistically diverse (CALD) backgrounds. However, they expressed concerns regarding areas where the information was unclear, such as the purpose of the screening test and the research supporting the changes. The DoH website was said to 'answer the basic questions but it also opens up a lot of other questions' (FG3).

Most groups preferred the information developed by the research team. It was described as 'more thorough, but still accessible' (FG2). Most groups liked the numbers and statistics, along with the graphs, felt that it was a better explanation, liked that it explained the rationale for the changes (why the test is better, what had motivated the changes) and that it didn't oversimplify information. Women felt that this information portrayed a 'good news story' (FG4).

Table 2 provides an overview of women's responses towards the DoH information, to the information developed by the research team (both shown in Supplementary information) and their preferences between the two.

The majority of women spoke about the option of having more information available for those who want it. Those who liked a combination of both, thought the DoH information could have the research team developed information as additional information for those who want it. Overall, most groups agreed that there should always be an option to learn more such as through hyperlinks and separate pages of evidence. With both sets of information useful in their own ways, the information developed by the research team was said to provide the evidence (Q5), which some women wanted (Q6).

Women also wanted to know whether the research informing the changes was based on research conducted on the Australian population or another countries' context, such as the US (Q7).

3.1.3. What information is still needed?

Following both of the information presentations, women across all aged focus groups were still seeking information. Some of this was about the test itself, such as what it is testing for and how it is different (Q8 and Q9). Women wanted to see more evidence and research around why the age and interval had changed and for it to be explained that this cancer is 'rare' with some context given (Q10).

Further information was wanted on whether women could still have Pap smears and if this would be covered by Medicare. Due to the extended screening interval, some women also said they would like to also see a symptom list, in order to be aware of these over the five-year period (Q11).

3.1.4. What methods can we use to communicate with people?

In terms of how to communicate the changes, there were similar suggestions across all aged focus groups. General Practitioners (GPs) were endorsed as the most appropriate primary source, using electronic screens and installing pamphlets at GP surgeries, and the GPs themselves to make people aware of the changes in advance of them occurring. Doctor acceptability of the changes was perceived as essential,

Table 2

Overview of thoughts comparing two sets of information presented.

Department of Health website information	Research team developed information
Positives	
<ul style="list-style-type: none"> • Straightforward (FG1_51-74), easy to understand (FG2_18-30) • Very easy and simple text (FG1_51-74) • Bite-sized and visual information (FG1_51-74) • Answered how test is changing (FG2_18-30) • Liked information of no change in incidence/mortality in women aged 20–25, makes age change 'seem legit' (FG2_18-30) 	<ul style="list-style-type: none"> • More detail (FG2_18-30; FG3_31-50) • More thorough, but still accessible (FG2_18-30) • Clear, easy to understand (FG2_18-30; FG3_31-50; FG4_51-74; FG6_31-50; FG5_18-30) • Answered questions that remained from the DoH information (FG2_18-30; FG3_31-50; FG4_51-74; FG5_18-30), gives more background information (FG4_51-74) • 'Easier to read when it's broken up like that [with diagrams] rather than just text' (FG2_18-30) • Liked incidence/mortality table (FG5_18-30) • Makes more aware and want to find out more (FG3_31-50) • Reassured and understand 5 years (FG6_31-50) and exit test (FG3_31-50)
Negatives	
<ul style="list-style-type: none"> • Not accessible to everyone (e.g. those with disabilities, CALD backgrounds) (FG5_18-30) • Not clear about test and reasons for changes, about transition (FG2_18-30), whether can get extra tests if want (FG2_18-30; FG4_51-74), the exit test (FG6_31-50) • Would like more information on the research and evidence (FG2_18-30; FG4_51-74) • No information on what happens after test result (FG2_18-30; FG4_51-74) • Including previous guidelines confused younger women on when should go for a test (FG2_18-30) • Answers basic questions but opens up to lots of other questions (FG3_31-50) • Should be main pages of the website not frequently asked questions (FG6_31-50) • Not very specific; need to layout the purpose of test at some point (FG2_18-30) • 'Sounds like the party line to make you feel better, rather than providing any actual information' (FG5_18-30) 	<ul style="list-style-type: none"> • Pictures are distracting (FG5_18-30) • Need for a decision tree about when women need to be screened (FG5_18-30) • Intense information, not so easy to follow, headings don't match the table so not clear what it's showing; have to read statistics more thoroughly, need to concentrate to understand, harder to understand than first (FG1_51-74) • Needed explanation, % rather than 'very few people', hard to visualise 100,000, not understand oncogenic (FG2_18-30) • 'Dumbed down' the seriousness of HPV - screening women to detect two deaths in 100,000 (FG6_31-50) • Need to not say it's a change in test as from women's point of view it's exactly the same (FG5_18-30)
Preferred by FG1, 51–74 years old	FG2, 18–30 years old (combination of two); FG3, 31–50 years old; FG4, 51–74 years old; FG5, 18–30 years old; FG6, 31–50 years old

especially as they would be explaining to women why they would not need to return for screening for five years. Some women recognised that time with your GP is generally short and that 'when you go to a GP you go because you're sick ... then you're not really up for a discussion about all the other things that you need to do' (FG6).

Other suggestions chiefly arising from the 18–30 year old focus groups included a hotline, media (e.g. television, radio), social media (e.g. Facebook), internet campaigns, leaflets/posters (in places where women might see them e.g. shopping centres, public toilets), and information through Medicare (by email/letter/text). There was also recognition that the mode of delivery might differ by age; younger women may not see television advertisements as they are less likely to watch television and so social media may be more appropriate for younger women (Q12).

One suggestion was that younger women could receive information with their HPV vaccination or when collecting contraception (e.g. information placed in the prescription bag (Q13)).

Previous campaign strategies that some women perceived as successful were those for restricting smoking, the AIDS campaign, and the implementation of transportation (“Opal”) cards in Sydney (Q14).

5. Discussion

These findings demonstrate that timely public communication when changing well-established cancer screening programs is critical in order for the public to maintain trust and confidence in such programs. Previous research has identified people have concerns about missing cancers when less frequent screening is recommended (Obermair et al., 2020; Davidson et al., 2011). The findings from this study show that the public are interested in being involved in these decisions and being consulted through the progression of the policy change. The general public enthusiasm for cancer screening shown in previous studies needs to be considered (Waller et al., 2015; Schwartz, 2004).

Although women expressed that the ideal time for communicating changes to screening programs is between 6 and 12 months before implementation, many women also wanted to have been given an earlier opportunity to be consulted about potential program changes. As found previously with changes to breast cancer screening recommendations in the United States, where women felt they were being ‘excluded from the decision-making and policy process’ (Allen et al., 2013), these women felt the changes had been made without sufficient consultation. Including the end-user in research is becoming increasingly recognised as important (Miller et al., 2017) and this need for open consultation is also apparent when making changes to health policy. Despite formal consultation processes having taken place in relation to these policy changes, such as opportunities for feedback on the draft guidelines and consumer involvement in the working party, this did not appear to be well known suggesting a need for wider advertisement on public forums for future similar policy changes. Communicating the fact and type of consumer involvement throughout the process may also have helped address these concerns, noting an apparent need to further understand what level of consumer consultation women would prefer.

It is important to consider the major differences in how these age groups access information when deciding how to communicate with them. The need to focus efforts on digital channels for younger women and more traditional methods for older women is generalisable to cervical screening programs in other countries, as these programs typically span a large age range (e.g. 30–64 years of age). Although not until close to implementation, the Australian government focused their efforts on digital advertising through social media and sent information, posters and brochures to general practice. Many more resources are now available to women in Australia, with the most accessible website hosted by the Cancer Council (Mac et al., 2020; Cancer Council Australia, 2020).

In terms of providing the public with information about significant changes to cancer screening, trustworthy and evidence-based resources need to be developed prior to any announcements. These women endorsed GPs as key ambassadors and sources of information about the changes. Most women wanted to understand the rationale for the changes and have the option of accessing more information, including the research providing evidence for the changes. Providing this level of information could help prevent community backlash and online petitions against such changes.

To our knowledge this is the first study which provides an in-depth understanding of public preferences on how best to engage about changes to well-established screening programs. Our sample varied in age, education and screening history. Compared with 51.4% of the general female population, 65.3% of our sample had higher education so caution should be taken when interpreting their ease of understanding the information. The qualitative nature of focus groups enabled us to

explore optimal timings for communication of policy changes, but does not lend itself to generalisability, particularly as all women were sampled from Sydney, which is a large urban centre in Australia. Future research is particularly needed in diverse sociodemographic samples in other settings to reach women who are those more likely to be under-screened.

Overall, these findings can inform other countries considering making changes to their cervical screening programs, or other screening programs in the future. Careful consideration of the timing of public communication, as well as the framing of this information, is essential in avoiding negative press which has the potential to undermine confidence in the renewed program.

Ethical consideration

The University of Sydney Human Research Ethics Committee reviewed and approved this study (project number 2017/489).

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CRedit authorship contribution statement

Rachael H. Dodd: Conceptualization, Methodology, Formal analysis, Investigation, Writing - original draft. **Brooke Nickel:** Formal analysis, Investigation, Writing - review & editing. **Megan A. Smith:** Writing - review & editing. **Julia M.L. Brotherton:** Writing - review & editing. **Kirsten J. McCaffery:** Conceptualization, Methodology, Formal analysis, Writing - review & editing, Funding acquisition.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.pmedr.2020.101268>.

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