

## PEER REVIEW HISTORY

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## ARTICLE DETAILS

<b>TITLE (PROVISIONAL)</b>	Examining the information needed for acceptance of de-intensified screening programs: qualitative focus groups about cervical screening in Australia
<b>AUTHORS</b>	Dodd, Rachael; Nickel, Brooke; Wortley, Sally; Bonner, Carissa; Hersch, Jolyn; McCaffery, Kirsten

## VERSION 1 – REVIEW

<b>REVIEWER</b>	D van der Waal Radboud university medical center, the Netherlands
<b>REVIEW RETURNED</b>	24-Feb-2019

<b>GENERAL COMMENTS</b>	<p>In general, I believe the topic of this article is interesting and relevant. However, I do still have some minor comments:</p> <ul style="list-style-type: none"><li>- Methods, page 5: I understand why you excluded women who are not fluent in English, but do you have any idea if this concerns a large group? This may affect the generalisability of your results.</li><li>- Methods, page 7: 'Accuracy of the HPV test compared to the Pap smear'. I think the term 'Pap smear' might be a bit confusing in this context, considering you use a smear with HPV testing as well. I would suggest using Pap test.</li><li>- Methods, page 7, outline of the presentation: Based on the presentation, I'm wondering if the focus groups were actually performed in a 'nondirective' way or not? For example, mentioning the concerns that had already been raised by women and the FAQ may certainly have a strong influence on the discussion? I also noticed in the Results section that there was no distinction between, for example, concerns that came up spontaneously and the ones that were discussed in response to the presentation.</li><li>- Discussion, page 13: 'The findings suggest that if information and the rationale for change is presented clearly women will likely accept de-intensified screening programs.' I think your results show what women want/need to know, but you didn't really assess how it should be presented to them (e.g. in what kind of format)? I think the communication aspect was somewhat neglected here.</li><li>- Discussion, page 14: 'These reactions are not surprising given that research has shown a high public enthusiasm for screening.' What are the participation rates in Australia?</li><li>- Discussion, page 15: 'Findings from this study can be used to consider processes for de-implementation' I would prefer the term de-intensification. I don't think de-implementation of any of these screening programmes is currently justified, nor will it be in the near future. Of course, HPV vaccination may certainly decrease the need for cervical screening, but there is still a long way to go.</li><li>- Discussion, page 16: You mention HPV vaccination at several points in the article. Could you please add information on when HPV</li></ul>
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	<p>vaccination was introduced in Australia? Have these women already reached the screening age? What is the coverage of HPV vaccination in Australia?</p> <p>- Table 2: 'Note: some items had a small amount of missing data.' Why not present the missings as a separate category?</p> <p>- Table 4: 'Are women your age eligible for free cervical screening?' Am I correct in assuming that these questions, prior to focus groups, are about the old screening programme? Perhaps clarify this in your table? Furthermore, were all the questions in table 4 multiple choice questions? If so, what were the other answer options (e.g. for the screening interval)? Were they very different? This may determine how easy or difficult it is to answer the question.</p> <p>- Presentation: I was surprised to see that there was only one slide on what happens after a positive HPV test. I also believe that you may want to add this information to table 1 of your manuscript.</p>
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<b>REVIEWER</b>	Melissa Shepherd University of Montevallo USA
<b>REVIEW RETURNED</b>	03-Mar-2019

<b>GENERAL COMMENTS</b>	<p>I think work on understanding hesitancy for de-intensified screening programs is very important. I appreciate the fact that this was qualitative research.</p> <p>I had a few minor concerns that can easily be addressed. One concern is the use of the word "internationally." Under the strengths and limitations sections you write: "These findings make an important and timely contribution to the potential communication strategies for countries internationally updating cervical screening programs." Countries are not internationally updating the programs; rather many countries are updating their programs at the national level. Under the introduction you write: "The study aimed to explore women's understanding of the reduced program and its acceptability, with the view of generating insights to guide communication about de-intensification of future screening program changes internationally," and in the discussion you write: "These findings make an important and timely contribution to the potential communication strategies for countries internationally updating cervical cancer screening." I would feel more comfortable if the word internationally was committed. Again, I think it could be interpreted as the programs being updated at the international level which is inaccurate. Alternatively, it might be interpreted as this qualitative research done in Australia can inform how practitioners in other countries talk to patients about the new screening guidelines. I think this would be overstating especially since you are careful to write in the abstract and discussion that a limitation of qualitative research is its generalizability. Another concern is the reporting of the details of the new screening program. I think details of the new screening program (e.g., less frequent testing and the use of the HPV test) should be explained in the introduction. I think the reader can piece the information together by reading methods and results, but I don't think the reader should have to hunt for the information in manuscript or online. As an international reader, I am only familiar with the US guidelines. Furthermore, you may have Australian readers for whom this is not their area of expertise.</p>
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<b>REVIEWER</b>	Kine Pedersen University of Oslo, Norway
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<b>REVIEW RETURNED</b>	30-May-2019
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<b>GENERAL COMMENTS</b>	<p>Thank you for the invitation to review this paper. This is a well written paper that addresses an important issue in cancer screening policy - namely, communicating changes in the screening program to the target population. The paper investigates this issue within the context of deintensifying the Australian CC screening program in 2017, and highlights important topics for communicating these changes. In the years to come, countries that have implemented the HPV vaccine will have to consider deintensifying the screening program, and communication to the target population will be essential for ensuring acceptance of the population.</p> <p>Although I think the paper is good and does not need revision, if anything; the authors could have discussed the Wilson and Jungner criterion that the screening program should be deemed acceptable to the population, and how communication strategies relates to this. Furthermore, a discussion of how these results may help decision makers elsewhere in communicating deintensified screening would be helpful. Should all countries conduct focus group studies before designing their communication strategy?</p>
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### VERSION 1 – AUTHOR RESPONSE

Reviewer(s)' Comments to Author:

Reviewer: 1

Reviewer Name: D van der Waal

Institution and Country: Radboud university medical center, the Netherlands Please state any competing interests or state 'None declared': None declared

Please leave your comments for the authors below In general, I believe the topic of this article is interesting and relevant. However, I do still have some minor comments:

- Methods, page 5: I understand why you excluded women who are not fluent in English, but do you have any idea if this concerns a large group? This may affect the generalisability of your results. From previous research we have conducted 1) Obermair H; Dodd RH; Bonner C; Jansen J; Carter S; McCaffery K. (2018) "It has saved thousands of lives, so why change it?" Content analysis of objections to cervical screening programme changes in Australia. *BMJ Open*, 8:e019171 and 2) Dodd RH; Obermair H; McCaffery K. (2019) A thematic analysis of attitudes toward changes to cervical screening in Australia. *JMIR Cancer*;5(1):e12307, we know that these concerns about changes to the screening program are widespread among women in Australia (over 70,000 women signed the petition and 20,000 commented).

This research is referenced in the introduction on page 5: 'Our own research to the proposed changes to the Australian NCSP identified strong concerns about the increased interval between cervical screens 10,11 principally due to the perception that this would miss cancers and put women's lives at risk.' This data came from a petition which was set up prior to the changes being implemented which expressed concerns in comments to the petition in the shape of 20,000 women. The concerns we found in these focus groups were similar to those found in comments to the petition. In addition, around 40% of the participants included in these focus groups were born outside of Australia and while the inclusion criteria stipulated fluency in English that does not mean that the current study does not include a diverse range of views from a broad sample of the population.

We have added this as a limitation in the 'strengths and limitations section':

'As this was a qualitative study, we cannot express the findings as generalisable across the whole population and we could only include English-speaking women due to the nature of the methodology.'

Methods, page 7: 'Accuracy of the HPV test compared to the Pap smear'. I think the term 'Pap smear' might be a bit confusing in this context, considering you use a smear with HPV testing as well. I would suggest using Pap test.

Thank you for your suggestion. We have changed any instance of 'Pap smear' to 'Pap test'.

- Methods, page 7, outline of the presentation: Based on the presentation, I'm wondering if the focus groups were actually performed in a 'nondirective' way or not? For example, mentioning the concerns that had already been raised by women and the FAQ may certainly have a strong influence on the discussion? I also noticed in the Results section that there was no distinction between, for example, concerns that came up spontaneously and the ones that were discussed in response to the presentation.

Thank you for seeking clarification on this. We first presented women with information about what the changes to the cervical screening program were, and then asked them what advantages and concerns they could see about the changes to the program, what they wanted to know to make them feel comfortable with the changes and whether there was any more information they would like (first 4 slides after the welcome in supplementary information), before we mentioned any other concerns. Most of the concerns women brought up in the groups were then covered on slide 10, with women in the focus groups also bringing up more detailed concerns, particularly how to transition into the new program.

We wanted to present women with information which was already available on the National Cervical Screening Program (Department of Health) website, to gauge whether the information was adequate to meet their needs. The information about the frequently asked questions was provided to provoke discussion and any questions about the program came up organically throughout the discussions about each change. Our presentation and focus group topic guide were independently reviewed by three experts and a consumer representative (patient advocate). We do therefore believe these focus groups were conducted in a 'nondirective' manner as women were encouraged to speak freely throughout and to also answer each other's queries.

- Discussion, page 13: 'The findings suggest that if information and the rationale for change is presented clearly women will likely accept de-intensified screening programs.' I think your results show what women want/need to know, but you didn't really assess how it should be presented to them (e.g. in what kind of format)? I think the communication aspect was somewhat neglected here. Thank you for your observation. We did also ask women in the groups how they think this information should be communicated to people. We have now included this in the results on page 16: How to communicate these changes?

'In terms of how to communicate these changes, verbal explanations from your general practitioner (GP) and through schools were suggested across all groups. Additionally, younger age groups suggested focusing communication more through social media (e.g. Facebook, Instagram), websites and email, and the older age groups through posters, TV adverts and public awareness campaigns.' In addition, the sentence 'Further quantitative research is needed to test optimum formats for presenting this information' has been added on page 20 in response to another reviewer comment.

- Discussion, page 14: 'These reactions are not surprising given that research has shown a high public enthusiasm for screening.' What are the participation rates in Australia?

We have now included the uptake rates of cervical screening in Australia (page 19): 'These reactions are not surprising given that research has shown a high public enthusiasm for screening, 13,14 with 56% cervical screening uptake in women aged 20-69, 15 women have spent much of their lives being told about the importance of having regular screening and early detection, and believe 'more care is better care'. 16'

- Discussion, page 15: 'Findings from this study can be used to consider processes for de-implementation' I would prefer the term de-intensification. I don't think de-implementation of any of these screening programmes is currently justified, nor will it be in the near future. Of course, HPV vaccination may certainly decrease the need for cervical screening, but there is still a long way to go. Thank you for this comment. We have used deintensification all the way through and have changed this instance also.

- Discussion, page 16: You mention HPV vaccination at several points in the article. Could you please add information on when HPV vaccination was introduced in Australia? Have these women already reached the screening age? What is the coverage of HPV vaccination in Australia?

We have now included some further information in the introduction about the HPV vaccination program and the coverage rates on page 4.

'A recent example of de-intensification of cancer screening comes from Australia, where the National Cervical Screening Program (NCSP) was revised in 2017 to include an older age of invitation for screening, less frequent testing and primary HPV screening. A national school-based program for the HPV vaccination was introduced in 2007 for school-aged girls (aged 12-13) plus a 2 year catch up program for girls aged 13-26 and in 2013 for school-aged boys. Current national uptake rates for 3 doses are 80.2% for females and 75.9% for males. 6 The changes encompassed new recommendations based on evidence of potential harms attributed to the previous screening regimen,7 as well as the changing landscape due to the uptake of the human papillomavirus (HPV) vaccination and the development of new screening technology (Table 1).'

Those women at the lower end of the age who were vaccinated as part of the 2 year catch up program in 2007 (ages 13-26), would have reached screening age for the old program in 2012, but only this year for the new program. So those females first to be vaccinated in 2007 as part of the national school-based program will be invited for screening in 2019/2020.

- Table 2: 'Note: some items had a small amount of missing data.' Why not present the missings as a separate category?

We have now included under each variable a 'missing' category.

- Table 4: 'Are women your age eligible for free cervical screening?' Am I correct in assuming that these questions, prior to focus groups, are about the old screening programme? Perhaps clarify this in your table? Furthermore, were all the questions in table 4 multiple choice questions? If so, what were the other answer options (e.g. for the screening interval)? Were they very different? This may determine how easy or difficult it is to answer the question.

Thank you for this question and clarification. Yes, the questions prior to the focus groups was about the old screening program and this has now been clarified by adding 'Prior to focus groups (old screening program)'. Also, the questions were all multiple choice and the response options have now been shown in table 4.

- Presentation: I was surprised to see that there was only one slide on what happens after a positive HPV test. I also believe that you may want to add this information to table 1 of your manuscript.

Thank you for this suggestion. We have now added this to Table 1.

Reviewer: 2

Reviewer Name: Melissa Shepherd

Institution and Country: University of Montevallo USA Please state any competing interests or state 'None declared': None

Please leave your comments for the authors below I think work on understanding hesitancy for de-intensified screening programs is very important. I appreciate the fact that this was qualitative research.

I had a few minor concerns that can easily be addressed. One concern is the use of the word "internationally." Under the strengths and limitations sections you write: "These findings make an important and timely contribution to the potential communication strategies for countries internationally updating cervical screening programs." Countries are not internationally updating the programs; rather many countries are updating their programs at the national level. Under the introduction you write: "The study aimed to explore women's understanding of the reduced program and its acceptability, with the view of generating insights to guide communication about de-intensification of future screening program changes internationally," and in the discussion you write: "These findings make an important and timely contribution to the potential communication strategies for countries internationally updating cervical cancer screening." I would feel more comfortable if the word internationally was committed. Again, I think it could be interpreted as the programs being updated at the international level which is inaccurate. Alternatively, it might be interpreted as this qualitative research done in Australia can inform how practitioners in other countries talk to patients about the new screening guidelines. I think this would be overstating especially since you are careful to write in the abstract and discussion that a limitation of qualitative research is its generalizability. We have now changed 'internationally' in the strengths and limitations to read: 'These findings make an important and timely contribution to the potential communication strategies for countries updating their national cervical screening programs.' And in the introduction to 'The study aimed to explore women's understanding of the reduced program and its acceptability, with the view of generating insights to guide communication about de-intensification of future national screening program changes in other countries.'

Another concern is the reporting of the details of the new screening program. I think details of the new screening program (e.g., less frequent testing and the use of the HPV test) should be explained in the introduction. I think the reader can piece the information together by reading methods and results, but I don't think the reader should have to hunt for the information in manuscript or online. As an international reader, I am only familiar with the US guidelines. Furthermore, you may have Australian readers for whom this is not their area of expertise.

We have given details of the new screening program in Table 1, but have now also included this in the text. 'A recent example of de-intensification of cancer screening comes from Australia, where the National Cervical Screening Program (NCSP) was revised in 2017 to include an older age of invitation for screening, less frequent testing and primary HPV screening (Table 1).'

Reviewer: 3

Reviewer Name: Kine Pedersen

Institution and Country: University of Oslo, Norway Please state any competing interests or state 'None declared': None declared.

Please leave your comments for the authors below Thank you for the invitation to review this paper. This is a well written paper that addresses an important issue in cancer screening policy - namely, communicating changes in the screening program to the target population. The paper investigates this issue within the context of deintensifying the Australian CC screening program in 2017, and highlights important topics for communicating these changes. In the years to come, countries that have implemented the HPV vaccine will have to consider deintensifying the screening program, and communication to the target population will be essential for ensuring acceptance of the population.

Although I think the paper is good and does not need revision, if anything; the authors could have discussed the Wilson and Jungner criterion that the screening program should be deemed acceptable to the population, and how communication strategies relates to this. Furthermore, a discussion of how these results may help decision makers elsewhere in communicating deintensified screening would be helpful. Should all countries conduct focus group studies before designing their communication strategy?

Thank you for this suggestion. We have now acknowledged the Wilson and Junger criterion that screening programs should be deemed acceptable to the population (page 19): ‘Screening programs will continue to need reviewing to ensure benefits outweigh harms and are deemed acceptable to the population, as stated by Wilson and Junger.<sup>3</sup> Findings from this study can be used to consider processes for de-intensification of screening programs in the future and how to develop communication strategies so that changes to screening programs are deemed acceptable to the population.’

We have also included recommendation for other countries (page 20): ‘Other countries needing to design communication strategies for deintensified screening should consider involving members of the public in their development to ensure the information presented is meeting information needs and ensuring confidence in the screening program is maintained. Further quantitative research is needed to test optimum formats for presenting this information.’

### VERSION 2 – REVIEW

<b>REVIEWER</b>	D vd Waal Radboudumc, the Netherlands
<b>REVIEW RETURNED</b>	22-Jul-2019
<b>GENERAL COMMENTS</b>	All comments have been adequately addressed, no further comments.