PEER REVIEW HISTORY

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ARTICLE DETAILS

TITLE (PROVISIONAL)	Women's experiences of the renewed National Cervical Screening
	Program in Australia 12 months following implementation: a
	qualitative study
AUTHORS	Dodd, Rachael H; Mac, Olivia; McCaffery, Kirsten

VERSION 1 – REVIEW

REVIEWER	M Cruickshank
	Aberdeen Centre for Women's Health Research
	University of Aberdeen
	Aberdeen
	UK
REVIEW RETURNED	23-Apr-2020
GENERAL COMMENTS	This is an important topic and one where Australia have a lead in the introduction of primary HPV screening but also changing immediately to 5 year screening interval (unlike England). Elsewhere in the world, we have heard about women's concerns in Australia, the new HPV test and the extension of the screening interval so this study and its results are of international interest to those involved in screening including service users. With many other countries introducing HPV based screening, this is a useful insight with data collected one year into the running of the programme compared with asking women before they have participated.
	Pg 8. Most of the women were regular screeners. does this reflect the women signing up to the marketing company. It would add to the findings to understand results from women who were non- attenders or irregular attenders in the previous programme who have now attended or still not attended. Pg 4 article summary on limitations. Important limitations and

incidence of HPV and colposcopy workload. Is this a finding if only reported by one woman? pg 10: were the comments about communication to young women expressed by young women or the opinion of all or older women. I couldn't work this out from lines 39-40 on page 10.

responsible for their own health and self-care including opinions on

qualifications are given. I would also include the means of identifying women as they do appear to be a well informed group and this may represent those who are signed up to the market research company. The results also suggest that they be

I would be interested in patient or public input into the methodology/recruitment, results and their interpretation. I appreciate that there was not patient or public involvement and given the subject area, it would help to explain why or seek some appropriate input into the discussion.
pg12: the finding of stigma of HPV+ is an important finding as there has been such an exponential growth in information available in relation to vaccine, screening, cancer by a side means of media and other sources in last few years.
Pg 13: final paragraph. As a clinician, this is a very important point. Health professionals give clearer message not only when they have the knowledge and had time to understand and contextualise it but when they have had practice in discussing and explaining the information to others. These results that professionals have not yet reached that point and may need more support as well as time.
I would like to see some discussion, as well as the section on pg4 on the limitations and clear clinical message. What form of information, how can it be individualised and targeted?

	Kata Dala
REVIEWER	Katie Robb
	University of Glasgow, UK.
REVIEW RETURNED	30-Apr-2020
GENERAL COMMENTS	The manuscript provides an important insight in to women's experiences of the renewed National Cervical Screening Program in Australia. The work is timely and identifies potential targets to better meet the information needs of women attending the program. Overall, I believe the contribution is important and has been competently conducted. I have some minor comments which the authors may wish to consider. Abstract I appreciate you are limited by word count but is it possible to provide further information on what the 'renewed' programme involves and what the 'new test' is? The word 'test' is used several times in the abstract, does this refer only to the HPV test or also to the cervical screening test? Participants were sampled by test result, if words permit, can you say briefly what the groups were? Introduction or Methods - Figure 1 is helpful but it would also be useful to have slightly more context about the usual procedure for invitation (including what information is provided) and issuing of results in Australia. Is there a standardised approach or does it vary by region or Primary Care provider? Was there any mass media to inform the public about the change in the screening programme? This would be useful context in interpreting the results. Results Table 2: What is the difference between HPV+ don't know/unsure and Don't know/unsure result? Having read more, I realise that this probably means they don't know if they are 16/18/other or unsure. It would be helpful to clarify this in Table 2 and also throughout to be consistent in how the three HPV+ groups are labelled e.g. in Tables 1, 2, 3 Page 8 – How did the themes that emerged relate to the topics covered in the Topic Guide?

Page 8 – 'high information seekers' almost makes it sound like you measured this as a trait. Consider rewording?
Page 10 – line 36, 'Women spoke about the need for' this seems more of a general view about cervical screening than about
the changes to the programme. Or was it that they felt there needed to be more adverts on the changes to the programme?
Page 11 – line 42 typo over the phone
Discussion
Page 14 – 'mainly reported being told in their GP consultation' can you clarify if this was a consultation specific to cervical screening or were they there for another reason and the new changes were
flagged to them?
Briefly include the limitations of the research within the Discussion.

VERSION 1 – AUTHOR RESPONSE

Reviewer: 1 Reviewer Name: Margaret Cruickshank Institution and Country: Aberdeen Centre for Women's Health Research University of Aberdeen Aberdeen UK Please state any competing interests or state 'None declared': None declared

Please leave your comments for the authors below This is an important topic and one where Australia have a lead in the introduction of primary HPV screening but also changing immediately to 5 year screening interval (unlike England). Elsewhere in the world, we have heard about women's concerns in Australia, the new HPV test and the extension of the screening interval so this study and its results are of international interest to those involved in screening including service users. With many other countries introducing HPV based screening, this is a useful insight with data collected one year into the running of the programme compared with asking women before they have participated.

Pg 8. Most of the women were regular screeners. does this reflect the women signing up to the marketing company. It would add to the findings to understand results from women who were non-attenders or irregular attenders in the previous programme who have now attended or still not attended.

Thank you for your comment. Yes, most of the women interviewed were regular screeners and may well reflect the women who sign up to the market research company and of course who respond to surveys about screening. To be eligible however, women had to have had screening under the renewed program and this also may therefore have attracted regular screeners over non or irregular screeners. Screening uptake is high (68%; 2016-2018) so the vast majority of women are regular attenders and therefore the data represent the vast majority of women eligible for screening. But It is often difficult to recruit women who are non or irregular attenders, but you raise a great point and future research could focus specifically on under screeners. We have added this as a limitation in the discussion, page 16:

'Most women in the sample were regular screeners and so may not reflect the experiences of women who were previous non-attenders or irregular screeners in the old NCSP and have now had screening under the renewed NCSP.'

Pg 4 article summary on limitations. Important limitations and qualifications are given. I would also include the means of identifying women as they do appear to be a well informed group and this may represent those who are signed up to the market research company.

Thank you, we have now included this as a point in this section:

'The method by which women were recruited into the study may reflect women who are more wellinformed and therefore some caution is necessary when applying these findings to the whole population.'

The results also suggest that they be responsible for their own health and self-care including opinions on incidence of HPV and colposcopy workload. Is this a finding if only reported by one woman?

We wanted to include the view of this one woman to show the breadth of attitudes women expressed about the changes and also that some women were educated about the changes and their impact.

pg 10: were the comments about communication to young women expressed by young women or the opinion of all or older women. I couldn't work this out from lines 39-40 on page 10.

The quote is from an older woman, but this was expressed across all age groups. We have now made this clear in the results (page 10):

'In terms of preferences for information about the changes to the cervical screening program, women talked about the need for advertisement on television and in the media to reach a lot of women to encourage them to go for screening, with radio and internet advertisements more likely to reach younger women'

I would be interested in patient or public input into the methodology/recruitment, results and their interpretation. I appreciate that there was not patient or public involvement and given the subject area, it would help to explain why or seek some appropriate input into the discussion.

We appreciate your comment and we acknowledge the importance of patient or public involvement going forward. Although we did not directly involve patients and the public in this research project, we appreciate the importance and now involve them in our research going forward. Our wider research group (Wiser Healthcare) has a patient partner committee. We have presented this work to our Wiser Healthcare patient partner committee at our biannual national meetings where they have had the opportunity to comment on the design and findings of this research. We have now included this group in our acknowledgements, page 18:

'We thank the Wiser Healthcare patient partner committee for comments on the design and findings of this research during presentations of the work at Wiser Healthcare National meetings.'

pg12: the finding of stigma of HPV+ is an important finding as there has been such an exponential growth in information available in relation to vaccine, screening, cancer by a side means of media and other sources in last few years.

Thank you for this comment. We agree this is important.

Pg 13: final paragraph. As a clinician, this is a very important point. Health professionals give clearer message not only when they have the knowledge and had time to understand and contextualise it but when they have had practice in discussing and explaining the information to others. These results that professionals have not yet reached that point and may need more support as well as time.

Thank you for this comment. We agree this is important.

I would like to see some discussion, as well as the section on pg4 on the limitations and clear clinical

message. What form of information, how can it be individualised and targeted?

We have now included as expansion of the limitations on page 4 in the discussion (Page 16):

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

With regards to what form of information, how can it be individualised and targeted, we have now included a paragraph in the discussion, page 16:

'Clear messages to women about the reasons for a change in test, as well as information which normalises HPV and explains what their test results mean for them, are important to communicate and provide reassurance. These messages could be in the form of written or verbal communication, with the need for women testing HPV+ for the first time to receive individualised messages which acknowledge their previous normal test results.'

Reviewer: 2 Reviewer Name: Katie Robb Institution and Country: University of Glasgow, UK. Please state any competing interests or state 'None declared': None declared.

Please leave your comments for the authors below The manuscript provides an important insight in to women's experiences of the renewed National Cervical Screening Program in Australia. The work is timely and identifies potential targets to better meet the information needs of women attending the program. Overall, I believe the contribution is important and has been competently conducted. I have some minor comments which the authors may wish to consider.

Abstract

I appreciate you are limited by word count but is it possible to provide further information on what the 'renewed' programme involves and what the 'new test' is?

We have now included this in with the objective:

'Women aged 25 to 74 are now screened every five years with primary HPV screening.' The word 'test' is used several times in the abstract, does this refer only to the HPV test or also to the cervical screening test?

We have updated this to now state the cervical screening test (CST).

Participants were sampled by test result, if words permit, can you say briefly what the groups were?

We have now included these.

Introduction or Methods - Figure 1 is helpful but it would also be useful to have slightly more context about the usual procedure for invitation (including what information is provided) and issuing of results in Australia. Is there a standardised approach or does it vary by region or Primary Care provider? Was there any mass media to inform the public about the change in the screening programme? This would be useful context in interpreting the results.

We have now included details of the usual procedure and issuing of results. There was no mass media campaign to inform the public about the changes and despite the initial announcement of the changes by the Australian government in April 2014, the changes did not garner significant publicity until 2017 when a petition was set up against the changes: (Obermair et al (2018) 'It has saved thousands of lives, so why change it?' Content analysis of objections to cervical screening programme changes in Australia)

Page 5: 'Although there was an initial announcement of the changes by the Australian government in April 2014, there was no mass awareness campaign to inform the public. Significant publicity of the changes rose in early 2017 following a petition started against the changes.7'

¹Prior to the implementation of the Renewal, women were not invited for screening, but screened when due by their primary care provider. Once women had been screened, their details were recorded on their state or territory register and women overdue for screening would receive a reminder letter. Since the Renewal, details of women who have been screened will be recorded on the National Cancer Screening Register and they will receive an invitation letter for screening when they are due and reminder letters when they are overdue.

There is no standardised approach in Australia to informing women of their results, which varies by primary care provider.'

Results

Table 2: What is the difference between HPV+ don't know/unsure and Don't know/unsure result? Having read more, I realise that this probably means they don't know if they are 16/18/other or unsure. It would be helpful to clarify this in Table 2 and also throughout to be consistent in how the three HPV+ groups are labelled e.g. in Tables 1, 2, 3

The women who were HPV+ and unsure were those who did not know what type of HPV they had (now labelled HPV+ type unknown), but those who were don't know/unsure, were those who did not know their screening result at all (now labelled HPV status unknown). We have now ensured they are consistent across the 3 tables and clarified each result.

Page 8 - How did the themes that emerged relate to the topics covered in the Topic Guide?

We included the topic guide as a supplementary file. The themes that emerged reflected many of the topics included in the topic guide, but the themes were derived from the data in an inductive process and the topic guide was not used as a reference during the analysis and interpretation of the data. We have included some more detail in the methods, page 8:

'Themes were derived from the data in an inductive process and the topic guide was not used as a reference during the analysis and interpretation of the data.'

Page 8 – 'high information seekers' almost makes it sound like you measured this as a trait. Consider rewording?

We have now reworded this to: 'Women who were knowledgeable about the changes tended to have sought further information and done their own research.'

Page 10 – line 36, 'Women spoke about the need for...' this seems more of a general view about cervical screening than about the changes to the programme. Or was it that they felt there needed to be more adverts on the changes to the programme?

We have now clarified this in the manuscript (page 10):

'In terms of preferences for information about the changes to the cervical screening program, women talked about the need for advertisement on television and in the media to reach a lot of women to encourage them to go for screening, with radio and internet advertisements more likely to reach younger women'

Page 11 - line 42 typo over the phone

Thank you for bringing this to our attention. This has now been changed.

Discussion

Page 14 – 'mainly reported being told in their GP consultation' can you clarify if this was a consultation specific to cervical screening or were they there for another reason and the new changes were flagged to them?

We have now clarified this: 'Although this sample of women mainly reported being told in their GP consultation when they attended for screening about the changes in the test and the screening interval'

Briefly include the limitations of the research within the Discussion.

We have now included these in the discussion (Page 16):

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

VERSION 2 – REVIEW

REVIEWER	Margaret Cruickshank
	University of Aberdeen
	UK
REVIEW RETURNED	22-May-2020

GENERAL COMMENTS	Thank you for your revisions which have addressed the points I made in previous review. I think this is an important paper at this time when, although HPV primary screening has been halted due to Covid19, it will restart soon.
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REVIEWER	Katie Robb University of Glasgow
REVIEW RETURNED	04-Jun-2020

GENERAL COMMENTS Thank you for fully responding to my comments.
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