



Exploring Women's Experiences of Receiving their Cervical Screening Test Results: A Citizen Science Approach

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ABSTRACT

Background: The incidence and mortality of cervical cancer has steadily declined since the introduction of Australia's National Cervical Screening Program, however changes to the program in 2017 have caused some confusion among participants. We examined how women receive and interpret their results, and any outstanding information needs in light of screening program changes.

Methods: Women aged 25 years-74 years who received a cervical screening test after 2017 were recruited *via* social media and citizen science organizations. Participants answered short questionnaires providing demographic data, the mode of receiving cervical screening test results, interpretation of these results, levels of distress, whether additional information was sought, and if there were unanswered questions.

Results: The 465 participants reported wide variation in the process of result dissemination; the majority (43.4%) received their results verbally from a GP or practice nurse, and many reported seeking or wanting to receive additional information. This raises a number of key issues including the adoption of new media forms for communicating results, provision of scientific versus lay-person wording of results, and the potential to use existing healthcare portals to record and provide access to information.

Conclusion: Given the great variability in how women receive their results, there is a need to address the current standards of practice and consider women's information needs about their test results.

Keywords: Cancer; Communication; Early detection of cancer; Oncology; Papillomavirus infections; Screening; Test results

BACKGROUND

Cervical cancer incidence and mortality has steadily declined since the introduction of Australia's National Cervical Screening Program (NCSP) in 1991 and the introduction of the Human Papillomavirus (HPV) vaccine in 2007 [1]. HPV causes nearly all cervical cancers and some cancers of the vagina, vulva, penis, anus, and oropharynx [2] with HPV testing having much higher

sensitivity for cervical dysplasia than pap-smears, and comparable specificity [3]. HPV primary testing was commenced in 2017 as part of the Australian NCSP, and now women and others with a cervix are told if their cervical screen sample shows presence of HPV, stratified by high risk (HPV 16 and 18) and intermediate risk (HPV other) for developing cervical cancer in the next 5 years [4]. High risk HPV results lead to referral for colposcopy, while intermediate risk HPV types lead to

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re-screening in 1 years' time, unless the patient belongs to a high risk population, and if again positive for intermediate risk HPV, colposcopy [4]. Previously women and others with a cervix were simply told if pre-cancerous cell abnormalities were present on their Pap smear [5].

This information can be challenging to convey effectively, and may lead women to misunderstand or have misconceptions about their results. This is in part due to the sexually transmitted nature of HPV, with HPV positive results known to evoke anxiety, stigma, shame, and worries about partner fidelity [6-9] and in part because risk estimates have been shown to lead many individuals to believe their own risk is higher than the estimate [10]. Understanding women's interpretation of their HPV results may help inform interventions to prevent or reduce any negative psychological consequences of testing HPV positive.

Improving women's knowledge of HPV could be a key to improving psychological responses to an HPV positive result. HPV knowledge remains suboptimal, despite HPV vaccination being available for more than 10 years and screening being standard for 7. While the majority of women have heard of HPV, research suggests that a large number of women wrongly assume HPV positive and cervical cancer are synonymous [11,12], and experience confusion as to how the Pap smear and HPV test are related [13]. Citizen Science involves members of the public, or 'citizen scientists', in the process of gathering and making sense of data [14]. This type of research recognizes the voice, lived experience and expertise that community members can bring [15]. A citizen science approach was chosen for this study as we wanted citizen scientists to contribute to the research by directly sharing their results and experiences with us, their understanding of their results and what information needs they still have.

Health practitioners verbally explaining screening results and answering subsequent questions has been associated with better understanding [16]. General Practitioners (GPs) perform 80% of Australia's HPV tests [16], and there is evidence of significant variation in how women receive their screening test result, including whether written information is given and how this information is provided [17]. To our knowledge, no study has quantitatively explored how women receive their HPV test results, what written information is included, and their subsequent interpretation and understanding of what the results mean. The aim of this study was to explore how women receive their cervical screening test results, how they interpret their result, and their understanding of what the result meant.

METHODS

Participants and Recruitment

Participants were recruited *via* social media advertising (e.g., Facebook) and through citizen science organizations, including the Australian Citizen Science Association and the Join Us register. Recruitment ran from 08 October 2021 to 30 November 2021. Eligible participants were females aged 25 years to 74 years old and residing in Australia. Participants must have had a cervical screening test since December 2017 and remembered their screening result. If participants did not meet these

criteria, previously had a diagnosis of cervical cancer or had a hysterectomy, they were not eligible to take part in the study.

Data Collection

Study advertisements hosted a link to a survey on the Qualtrics platform, where participants were first able to view and download the participant information sheet. Participants provided their consent through the online survey.

Questionnaire Design or Methodology

The study used a citizen science approach [9], and the questionnaire was developed by the research team. Following consent, participants were asked whether they had the results of their most recent cervical screening test in a letter or another written format (i.e., email). If they did and were happy to do so, participants were asked to hide any identifying information and then to take a photograph of the letter/email and upload it to Qualtrics, a secure questionnaire platform. If participants no longer had, or did not receive their results letter/email, they were still eligible to take part in the study. Participants were then asked to complete a short questionnaire including demographics (including sex assigned at birth, with options being female or male) and questions exploring how they interpreted their screening result and what they understood their result to mean, presence of cervical abnormalities, recommendations for rescreening, how they felt when they received their screening test results, their perceived risk of developing cervical cancer, mode by which they received their screening test results (i.e. *via* their GP, by phone or by letter/email), whether they looked for any additional information or spoke to anyone about what their screening test result meant, and whether they have any unanswered questions about their screening result. Distress with receiving of results was measured using a 10 point scale, with options being 0 (no distress at all) to 10 (severe distress). Participants could upload their cervical screening results onto the survey platform for review. The questionnaire included a mix of closed scale and free text questions (Appendices) and took around 10 minutes to complete.

Data Analysis

Data were analyzed using SPSS (Version 27). Frequency analyses were used to analyze all categorical variables, whilst descriptive analyses were used to analyze all continuous variables. Content analysis was performed to analyze the free text responses to 2 questions: 'Thinking about the result of your most recent cervical screening test, please write what you understand your screening test result to mean' and 'Do you have any unanswered questions about your most recent cervical screening test result?' 2 members of the research team (AS, VC) became familiar with the content of the comments and made note of recurring themes for each question. The initial coding frameworks for each question were discussed with the research team and inter-rater reliability was calculated between AS and VC as 0.957 for the understanding of the test result and 0.924 for any unanswered questions, indicating appropriate reliability. 2 authors (AS, VC) then applied the coding framework to the remaining comments. A random sample (10%) was selected to validate similarity (RD). Frequency analyses were used to analyze responses.

RESULTS

Participant Demographics

572 participants accessed the questionnaire; 107 were excluded from analysis (55 did not complete the survey, 6 did not consent, 46 were not eligible). 465 participants were included in the final analysis. As indicated in **Table 1**, the majority of participants were between 25 years-39 years (44.5%) of age, and born in Australia (79.8%), with 5 participants (1.1%) identifying as Aboriginal. The majority of participants had completed their education at university degree level or higher (74%). Over half of participants (53.5%) reported not having been offered the HPV vaccine, while 117 (25.2%) received 3 doses, 52 (11.2%) received 2 doses, and 11 (1.4%) received one dose.

Table 1: Participant demographics

| Variable | n=465 (%) | Participant |
|--------------------------------------|---------------------------------|-------------|
| Age | 25-39 | 207 (44.5) |
| | 40-54 | 126 (27.1) |
| | 55-69 | 120 (25.8) |
| | 70-74 | 12 (2.6) |
| Country of birth | Australia | 371 (79.8) |
| | Other | 94 (20.2) |
| Aboriginal or Torres Strait Islander | No | 460 (98.9) |
| | Yes, Aboriginal | 5 (1.1) |
| Education | University degree or higher | 344 (74.0) |
| | Diploma or certificate | 80 (17.2) |
| | Trade apprenticeship | 7 (1.5) |
| | High School (Year 12) | 14 (3.0) |
| | High School (Year 10) | 20 (4.3) |
| | No school or other | 0 |
| Have you received the HPV vaccine? | Yes, 1 dose | 11 (2.4) |
| | Yes, 2 doses | 52 (11.2) |
| | Yes, 3 doses | 117 (25.2) |
| | No, have not been offered | 249 (53.5) |
| | No, offered but did not have it | 10 (2.2) |
| | Don't know | 3 (0.6) |
| | Can't remember | 8 (1.7) |
| Other | 15 (3.2) | |

Participant Results, Cervical Screening Test

The majority of participants (72.5%) received a 'negative' or 'normal' result following their cervical screening test (**Table 2**). 51 (10.9%) participants received a 'positive' or 'abnormal' test result. Of these, 14 indicated they were not advised of the 'type' of abnormal cell changes with 10 advised of 'possible high-grade squamous intraepithelial lesion/CIN2 or 3 [18].

A total of 77 (16.6%) participants were unable to state their result status. 51 (11%) participants were not told their result, 17 (3.7%) could not remember their result and 9 (1.9%) didn't know or were unsure of their result. Almost half of participants (47.7%) reported not being informed of their risk for significant cervical abnormalities, while a third (33.3%) reported that they were low risk (**Table 2**). Most participants (64.9%) were advised to be rescreened in 5 years, however 59 (12.7%) were not told this information. Participants commonly received their cervical screening test results verbally from a General Practitioner (GP) or practice nurse (43.4%) or *via* a letter delivered through the mail (23%) (**Table 2**). Of the 21 (4.5%) participants who uploaded their results, 2 were identified as cervical biopsy results and were excluded from the analysis. Of the remaining 19, 9 results were delivered in a letter from a medical practice, 4 in a pathology report, 3 in an email from a medical practice and 3 in a text message from a medical practice.

Table 2: Participant results, Cervical screening test

| Questionnaire | n=465 (%)* | |
|---|-------------------------------------|------------|
| How did you receive the results of your cervical screening test (tick all that apply)?* | By letter in the post | 107 (23.0) |
| | By letter at the GP | 13 (2.8) |
| | Text message | 28 (6.0) |
| | By telephone | 78 (16.8) |
| | By email | 10 (2.2) |
| | Verbally from GP or practice nurse | 202 (43.4) |
| | Don't know/can't remember | 36 (7.7) |
| | Other | 39 (8.4) |
| | By GP/Doctor/next appointment | 5 (1.1) |
| | Told would only receive if abnormal | 9 (1.9) |
| | By Gynaecologist/ Surgeon | 7 (1.5) |
| | Had to call and ask myself | 3 (0.7) |
| | Didn't receive results/ Don't know | 12 (2.6) |
| | Online/myGov/Login portal | 3 (0.7) |
| Wasn't told this information | 14 (3.0) | |
| Can't remember | 7 (1.5) | |
| Don't know/unsure | 5 (1.1) | |
| Other | 0 | |
| Please indicate what you were told your risk is for significant cervical abnormalities | Low risk | 155 (33.3) |
| | Intermediate risk | 27 (5.8) |
| | High risk | 11 (2.4) |
| | Wasn't told this information | 222 (47.7) |

| | | | | |
|--|---|------------|--|----------|
| What recommendation were you given for when you should be screened next? | Can't remember | 31 (6.7) | Email from GP, nurse, practice | 3 (15.8) |
| | Don't know/unsure | 19 (4.1) | Text from GP, nurse, practice | 3 (15.8) |
| | Refer for colposcopy | 31 (6.7) | * Multiple codes could be applied to each participant's free-text response | |
| | Rescreen in 12 months | 53 (11.4) | | |
| | Rescreen in 5 years | 302 (64.9) | | |
| | Wasn't told this information | 59 (12.7) | | |
| | Can't remember | 14 (3.0) | | |
| | Don't know/unsure | 5 (1.1) | | |
| | Rescreen due to unsatisfactory sample | 1 (0.2) | | |
| | Participants who uploaded test results: | | 21 (4.5) | |
| Excluded: | Cervical biopsy results | 2 | | |
| Test results analysed: | | 19 (4.1) | | |
| | Pathology report | 4 (21.0) | | |
| | Letter from GP, nurse, practice | 9 (47.4) | | |

Participant Understanding of Results

After receiving their results, around half of participants (52%) believed their chances of developing cervical cancer in the next 10 years were average compared to a woman of the same age. Approximately half of participants (50.3%) felt no distress at all upon receiving their results, with a mean distress level of 1.88 from a range of 0 (no distress) to 10 (severe distress). As indicated in **Table 3**, the majority of participants who uploaded their results clearly understood the meaning of their results, and 2 participants miscomprehended the survey question, describing what the test was rather than what their results meant. Participants were asked to interpret the meaning of their test result (**Table 4**), with the most common response codes being a 'Negative Result' (23.2%), 'All clear/good/OK' (15.3%), 'Cancer Absent' (13.6%) and 'HPV-negative' (12.0%). Only 0.4% of responses were coded as 'Unsure of Result Meaning'.

Table 3: Participant results, Uploaded results comprehension (n=19)

| # | Type | Result uploaded by participant | Participant interpretation of uploaded result | Correct interpretation: yes (y), no (n), unclear |
|----|--------------|---|--|--|
| 1 | Text Message | Cervical screening normal. Repeat in 5 years. | That everything was normal | y |
| 2 | Text Message | Pap normal. Repeat in 5 years. | Negative, no abnormalities | y |
| 3 | Email | Result low risk. Do not have HPV infection. Due for next screen in 5 years. | Normal Result no HPV virus detected | y |
| 4 | Email | Test was negative. Next text in 5 years. | Negative cells detected, return in 5 years | y |
| 5 | Letter | Low risk. Recall in 5 years. | Swab of cervix to test for HPV infection | UNCLEAR |
| 6 | Letter | Low risk. Normal. Rescreen in 5 years | I was at low risk of cervical cancer | y |
| 7 | Path Report | High risk. Refer for colposcopy assessment. | I have HPV and need further investigation | y |
| 8 | Text Message | Result is intermediate. Repeat test in 1 year. | At risk-need testing next year | y |
| 9 | Email | High risk virus, possible low-grade abnormality. Repeat test in 1 year. | Have high risk HPV virus | y |
| 10 | Path Report | Low risk. Rescreen in 5 years. | No abnormalities, nothing to worry about, get tested in 5 years | y |
| 11 | Letter | Negative (normal). Next screen in 5 years. | The results were normal, no issues | y |
| 12 | Letter | Low risk. Rescreen in 5 years. | No abnormalities detected on this occasion and overall, I am in a low-risk group. | y |
| 13 | Letter | High risk. Specialist referral advised. | Abnormal | y |
| 14 | Path Report | HPV 18 positive. High risk. No evidence of squamous intraepithelial lesion. | HPV 18 positive but no evidence of cancer cells | y |
| 15 | Path Report | Oncogenic HPV not detected. No abnormality. Rescreen in 5 years. | That HPV was not detected nor were abnormal cells found, therefore I can return to 5 yearly pap smears. It means that I am at a low risk of cervical cancer. | y |

| | | | | |
|----|--------|--|---|---------|
| 16 | Letter | Low risk. Rescreen in 5 years. | That there are no abnormal cells and nothing to worry about | y |
| 17 | Letter | Negative (normal). | Testing for abnormalities leading to cervical cancer. | UNCLEAR |
| 18 | Letter | Negative. Follow-up in 5 years. | To be clear of HPV and not showing any abnormalities. | y |
| 19 | Letter | Negative (normal). Next screen in 5 years. | I'm negative for HPV and everything is normal | y |

Table 4: Participants self-reported understanding of their cervical screening results, with free-text responses coded by authors

| Description | n =465* | Percentage (%)* |
|--|---------|-----------------|
| Cancer absent/pre-cancer absent | 77 | 13.60% |
| Check for cancer | 4 | 0.70% |
| Did not receive results | 13 | 2.30% |
| Low Risk/low grade | 10 | 1.80% |
| High Risk/high grade | 8 | 1.40% |
| HPV-positive | 30 | 5.30% |
| HPV-negative | 68 | 12.00% |
| Positive result | 3 | 0.50% |
| Negative result** | 132 | 23.20% |
| All clear/good/OK | 87 | 15.30% |
| Normal result | 49 | 8.60% |
| Abnormal cells | 15 | 2.60% |
| Describing the test procedure or process | 28 | 4.90% |
| Awareness of follow-up process | 39 | 6.90% |
| Results well explained | 1 | 0.20% |
| Unsure of result meaning | 2 | 0.40% |
| Response not valid/completed | 1 | 0.20% |
| Not all clear/not good/not OK | 1 | 0.20% |

*Multiple codes could be applied to each participants' free-text response

**Includes 'no abnormalities' 'no abnormal cells'

Participant Self-reported Information Needs

Over one third (35.4%, n=118) of participants stated they looked for extra information or spoke to someone about what their cervical screening test results meant, with 74 (15.9%) stating they have unanswered questions about their test result. Participants were asked what unanswered questions they had regarding their test result (Table 5). Upon coding of responses, 18.5% sought clarification of their results, 16.3% desired further information and 14.1% expressed confusion around changes to screening guidelines.

Table 5: Participants' unanswered questions pertaining to their cervical cancer screening results, with free-text responses coded by authors

| Description | n=465* | Percentage (%)* |
|--|--------|-----------------|
| Results not clarified/not understood/confusion about meaning | 17 | 18.50% |

| | | |
|--|----|--------|
| Need for more information/would like to know more | 15 | 16.30% |
| Confusion around understanding changes to new screening guidelines | 13 | 14.10% |
| Did not receive results/was not told results | 10 | 10.90% |
| Follow up processes | 9 | 9.80% |
| Miscellaneous, Other | 9 | 9.80% |
| Accuracy of results/reliability/sensitivity | 7 | 7.60% |
| Lack of knowledge/awareness about HPV (various) | 5 | 5.40% |
| Confusion/lack of understanding of a HPV+result | 4 | 4.40% |
| Not knowing the result was part of negative result process 'no news good news' | 2 | 2.20% |
| Would like to know results | 1 | 1.10% |

*Multiple codes could be applied to each free-text response

DISCUSSION

The aim of this study was to explore how women receive their cervical screening test results, how they interpreted their result, and their understanding of what their result meant. Overall, there were inconsistencies in the process of results dissemination; the results and supplementary information participants received was highly variable, as was the method by which participants received their results. This study also identified participants' need for extra information upon receiving and interpreting results. While only a limited number of participants uploaded their results as part of the study, a clear lack of consistency in HPV test result delivery was apparent. This raises a number of key issues, including: Adoption of new media forms for results communication (mobile phones specifically), language used in results communication (scientific versus lay person wording), personal health record keeping (physical versus digital), and the potential use of existing healthcare portals to record and access information (My Health Record, for example) [19-21].

The majority of participants received their results verbally from a GP or practice nurse however the mode of communication varied.

There is a growing reliance on digital modes of communication,

and research has shown that while text messaging is acceptable, there is still greater value in phone calls to patients to deliver results [13,14]. Text messages are indeed an immediate way of delivering results, however research shows this is not the preferred method of receiving bad news or news which patients do not understand; in-person visits are preferred [15]. The majority of participants understood their test results most commonly delivered as 'normal/abnormal' or 'negative/positive'. Where result terminology was not consistent, there is a need to re-examine the language used in results communication to explain the relationship between HPV status and cervical cancer. Of note, some women received pathology reports as their results, and although these women reported understanding what their results meant, this may not be appropriate delivery of results, especially for women with low health literacy. Further, despite high education levels many women expressed that they had unanswered questions across a broad range of topics, related not only to their result, but to the test itself [16]. A couple of participants also described how 'no news was good news', in that they presumed that by not being explicitly communicated their result, this indicated that their result was normal and there was nothing to worry about. This however is not a rigorously used technique and some women may simply have not received a result in error. Again, standardized result communication is warranted to ensure testing is equitable and responsible [22-25]. Some participants were unsure of their test result or HPV vaccine status. This raises the question on how we store personal health information. In Australia, there has been underwhelming uptake and lack of trust in the digital platform. My Health Record [17,18] and when used internationally, mobile health apps for cervical cancer lack standardized quality assessment tools [19]. Ensuring that patients and their health professionals have a platform in which they can access their previous screening results, might be a strategy in which patients can feel empowered about their own health.

STUDY LIMITATIONS

Although this study sought to explore women's receipt of cervical screening results, many did not have a copy of their results to upload and therefore the majority of the data is self-reported. Importantly, this study did not assess the health literacy levels and language needs of participants which may have impacted results comprehension, knowledge and awareness. This study also did not assess the place of residence of participants which may have impacted service access. This was a very highly educated sample and biased towards those online with good digital literacy and high trust.

CLINICAL IMPLICATIONS

This study highlights the need for consistency in the reporting of cervical screening results to inform women on their level of risk and next steps, particularly since the introduction of primary HPV testing and extended screening intervals. Alongside a copy of the results, whether these are given verbally, digitally, or through the mail, the information needs of women in this study support the need for written resources to aid in result interpretation.

CONCLUSION

This study used a citizen science approach to explore how women receive their cervical screening results, what written information was included, and their subsequent interpretation and understanding of what their results meant. Given the great variability in how women received their results, there is a need to address the current standards of practice and to consider women's information needs about their test results.

DECLARATIONS AND ETHICS STATEMENTS

Ethical Approval

This study was approved by the University of Sydney Human Research Ethics Committee [2021/626].

Data Availability Statement for Basic Data Sharing Policy

The data that support the findings of this study are available from the corresponding author upon reasonable request.

Competing Interests

The authors declare there are no competing interests.

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