



# Cervical screening communications for young Māori, Pacific and Asian women

## Key findings and implications

11 April 2019



**ALLEN+CLARKE**

## ACKNOWLEDGEMENTS

We would like to thank all the women we met with who took the time to engage with us and share their experience and thoughts about how to improve the communication about cervical screening and what is important to them. We would also like to thank the organisations who helped us organise the focus groups.

### About *Allen + Clarke*

Allen and Clarke Policy and Regulatory Specialists Limited (*Allen + Clarke*) is a consultancy firm with offices in Wellington, New Zealand and Melbourne, Australia. We specialise in policy and programme development and implementation, research and evaluation, business change, operational management and risk, and secretariat and programme support services. A key component of our work is undertaking reviews and developing and implementing policies that improve the outcomes for the public. Founded in 2001, the company is owned and managed by senior staff and has a team of approximately fifty other senior evaluation and policy practitioners, analysts and project support staff. Our company works extensively for a range of government agencies in New Zealand, and international clients and non-government organisations in the Pacific and Asia. More information about our work can be found on our website: [www.allenandclarke.co.nz](http://www.allenandclarke.co.nz).

<b>Document status:</b>	Final Report
<b>Version and date:</b>	V 3.0; 11/04/19
<b>Author(s):</b>	Fiona Scott-Melton
<b>Filing Location:</b>	W:\MOH Public Health\2018 Cervical screening research\04 Deliverables\Reports\Submitted final reports
<b>Peer / technical review:</b>	Anna Scanlen
<b>Verification that QA changes made:</b>	Fiona Scott-Melton
<b>Proof read:</b>	Anna Gribble
<b>Formatting:</b>	Fiona Scott-Melton
<b>Final QA check and approved for release:</b>	Anna Gribble, Practice Lead, Secretariat

*Allen + Clarke* has been independently certified as compliant with ISO9001:2015 Quality Management Systems

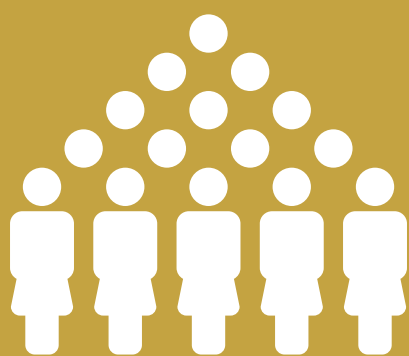


## CONTENTS

<b>ACKNOWLEDGEMENTS</b>	<b>ii</b>
<i>About Allen + Clarke</i>	ii
<b>KEY FINDINGS</b>	<b>1</b>
<b>EXECUTIVE SUMMARY</b>	<b>5</b>
Approach	5
Key findings	5
Conclusion	7
<b>1. INTRODUCTION</b>	<b>9</b>
1.1. Purpose	9
1.2. Methodology	9
1.3. Structure of this report	11
<b>2. BARRIERS EXPERIENCED BY YOUNG MĀORI, PACIFIC AND ASIAN WOMEN</b>	<b>12</b>
2.1. Insufficient provision of information on cervical screening	12
2.2. Young women want cervical health talk to be normalised	13
2.3. Young women need to feel sufficiently prepared to engage in screening	15
2.4. Experiences of health services is an important influence	17
<b>3. PREFERENCES ON APPROACHES TO COMMUNICATION</b>	<b>21</b>
3.1. Young women need to see themselves represented in promotions	21
3.2. A multi-level approach to cervical screening communication is needed	22
3.3. Information about cervical screening needs to be simple and relatable	27
3.4. Different strategies to answer young women’s questions is needed	30
<b>4. CONCLUSIONS</b>	<b>32</b>
<b>REFERENCES</b>	<b>34</b>
<b>APPENDIX 1: TERMS OF REFERENCE FOR THE RAPID REVIEW OF COMMUNICATING CERVICAL SCREENING TO YOUNG WOMEN</b>	<b>37</b>
<b>APPENDIX 2: CERVICAL SCREENING FOCUS GROUP GUIDE</b>	<b>40</b>

# KEY FINDINGS

## Insufficient provision of information on cervical screening



Insufficient provision of necessary information contributed to a **lack of understanding** and **confusion**.

This was one of the most **significant barriers** for young Māori, Pacific and Asian women.

Most young women felt they did not have the **necessary information** to give informed **consent**, including young women **did not know** why it was important to be **screened**.

The combination of lack of **information**, **misinformation** and **confusion** suggests health practitioners and providers should not assume young women have a good understanding of their bodies and cervical health needs.

# Young women want cervical health talk to be normalised



Not living in an environment in which cervical health is discussed **openly**, contributed to the young women's **lack of understanding** about cervical health.

Feeling uncomfortable talking about cervical health meant these young women experienced **shyness** and **embarrassment** when trying to gather information.

All the young women expressed a desire for cervical health 'talk' to be **normalised**.

# Young women need to feel sufficiently prepared, mentally and logistically, to engage in screening



There are a range of mental, physical and **logistical challenges** that the young women needed to work through to attend a cervical screening appointment.

**Cost and transport** are the most significant logistical challenges to attending an appointment.

Addressing these challenges could **increase engagement** rates in the programme for young Māori, Pacific and Asian women.

# Experiences of the health system is important



Negative scening experiences **reduce** young women's willingness to **engage** and remain engaged in the programme.

Trust in the New Zealand health system needs to be **built**, especially with young Asian women, if engagement in the programme is **likely to improve**.

Young Māori, Pacific and Asian women need **positive experiences**, as defined by them.

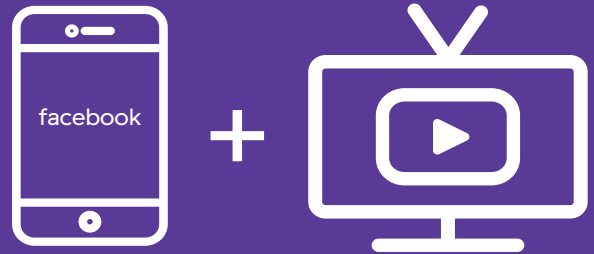
# Representation is crucial



All of the women wanted to see themselves **reflected** back at them in **publicity** and **education materials**.

They wanted to see:  
**Young like me**  
**Looks like me**  
**Dresses like me**  
**Talks like me**  
**Same interests as me**  
**Then I know it's about me**

## Multi-level approach needed



There is no one size fits all, rather there needs to be a multi-level, **no wrong door**, approach to information.

Information needs to be provided where they are. For young wāhine Māori **building relationships** is important.

Popular approaches for receiving information included **social media**, campaigns and advertisements on TV, YouTube, and Facebook.

## Information needs to be simple and relatable



Both Māori and Pacific young women preferred more **direct text, visual approaches** and a **relationship-based** approach.

Information needs to provide an outline of the entire process, choices you can make, explain the **costs, risks** and **benefits**.

Care needs to be taken in the **extent risks** and **benefits** are **explained**.

## Provide variety of options to get questions answered



Preferences included searching Google, **frequently asked questions**, online chat, someone at GP surgery.

Implication is that promotional material needs to both **reflect** the women and **meet them** where they are.



## EXECUTIVE SUMMARY

The Ministry of Health (the Ministry) is preparing to change the age to start cervical screening from 20 to 25 years of age. A key focus of this change is to continue to improve equitable access to cervical screening for Māori, Pacific and Asian women.

### Approach

*Allen and Clarke* was commissioned by the Ministry to identify effective approaches to communicate with young Māori, Pacific and Asian women about participating in the National Cervical Screening Programme (the Programme). A two-phase exploratory research project was undertaken, the first component was a rapid literature review.

A total of nine focus groups were held across New Zealand, three groups each for Māori, Pacific and Asian women aged 20 to 30 years. Key themes from the literature review were used to inform the questions at the focus groups with a view to testing their applicability specifically for young Māori, Pacific and Asian women. The key areas explored in the focus groups included:

- challenges to engaging in organised cervical screening;
- effective communication methods for informing young women about cervical screening;
- preferences for accessing and receiving information; and
- how to make a difference and engage young women in organised cervical screening.

All the focus group findings were in line with the literature review. Broadly, the findings identified key barriers young Māori, Pacific and Asian women experience when engaging in organised cervical screening, the impact of these barriers and preferences on the approach to communication about cervical screening. The findings also highlighted key areas the Ministry could consider changing in their approach to engaging young Māori, Pacific and Asian women and encouraging participation in the Programme.

### Key findings

#### Insufficient provision of information on cervical screening

Findings from the focus groups indicated that there is an opportunity to more effectively inform women and increase knowledge about cervical cancer, cervical screening and cervical health as this is a major barrier for getting young women to engage in the Programme. Insufficient provision of necessary information was a significant factor in the lack of knowledge, misinformation and confusion among the young women. This was particularly the case for those young women who had never been screened. A significant number of these women had heard that the screening procedure was painful, which had left them with an expectation that they would have a similar experience. This, along with lack of information on the importance and relevance of screening for this age group, contributed to expressions of unwillingness to engage in the Programme. Moreover, many of the young women interviewed felt that they did not have the necessary information to give informed consent to be screened.



### **Young women want cervical health talk to be normalised**

Findings from the focus groups indicated that the link between cervical cancer, sexuality and sex has made the subject of cervical screening taboo and as a result was not to be talked about. This was especially the case if young women were not married and lived in communities where sex before marriage was discouraged. Not discussing cervical health and screening contributed to the lack of young women's understanding and a sense of shyness and embarrassment about making open attempts to gain information. There was a strong emphasis on normalising the topic of cervical screening, with suggestions that a media campaign could raise awareness and help enable necessary conversations with and between young women.

### **Young women need to feel sufficiently prepared, mentally and logistically, to engage in screening**

Findings from focus groups showed that there were a range of logistical accessibility issues that acted as barriers to the young women engaging in the Programme. Cost and transport were particularly significant challenges for the young women. There was general consensus that making cervical screening free both at GP surgeries and health clinics would help improve participation rates. The young women made a range of suggestions including providing transport or bringing screening to them, providing out-of-hours, early morning or weekend appointments and making it into a social occasion with food so that the experience was more relaxed.

### **Experiences of the health system is important**

Findings from the focus groups showed at a service provision level negative experiences of the New Zealand health system either in connection to cervical screening or more broadly contributed to a reluctance to engage in the Programme. A strong theme among young Asian women was a lack of trust in the New Zealand health system. Across the focus groups, some young women shared negative screening experiences, including feeling pain, not being adequately talked through the process and opportunistic screening which left them feeling like a tick-box exercise. A positive screening experience was defined as having someone to talk them through the process, being gentle, using lubrication, having a sense of humour and understanding their needs. Additionally, some young Māori and Pacific women wanted to attend in a group with other family members as this would create an opportunity to support each other.

### **Young women need to see themselves represented in promotions**

Findings from the focus groups highlighted that all the young women wanted to see themselves represented in promotional material. This signalled that the information concerned them. However, there was some diversity among the young women's preferences with some young women wanting to see only their ethnic group and others wanting broader representation. Moreover, young Māori and Pacific women placed importance on a whānau approach, including men and children, rather than individual well-being.

### **Multi-level approach to cervical screening communication is needed**

Findings from the focus group indicated that a multi-level approach to providing information was needed; there was no one-size fits all. This meant that there needed to be varying levels of information (from high level to more detailed information) provided across a range of platforms. Recommended options for receiving information included social media platforms such as Instagram, Facebook and WeChat, campaigns and advertisements which could be shown on

television, YouTube, Facebook and GP surgeries. All the young women wanted people they could relate to, were role models and that came from their community appearing in campaigns and advertisements. In addition, there was general agreement that a cervical screening awareness week or day could be effective in raising awareness. For promoting that it was time to be screened, the young women preferred text or email over receiving a letter or telephone call.

### **Information about cervical screening needs to be simple and relatable**

The literature review provided limited insight to determine the most effective information and messages to encourage engagement in screening. Although there were some indications that explanations of the value of cervical screening could be motivating. Findings from the focus groups showed that information about cervical screening needed to be in everyday language, simple and relatable. Key information that needed to be provided included a step-by-step explanation of the process and how to access a provider, screening options, the risks involved (including the procedure) and the benefits of being screened. Most of the young women could not relate to a risk of dying from cervical screening, however, a risk of potentially losing the ability to have a baby resonated. A strong theme was the need for testimonials of other women's experiences, particularly from role models in their community. For many Asian women for whom English was not their first language, it would be useful to have written material provided in their mother tongue. This made the information more accessible and was considered a more inclusive approach.

### **Different strategies to answer young women's question is needed**

Focus group findings showed that young women had a variety of preferences when seeking information to answer questions. A reoccurring theme was that information needed to come from a trusted source. Preferred approaches included Google, Frequently Asked Questions, online chat, provision of weblinks, health practitioners and members of their community.

## **Conclusion**

Young Māori, Pacific and Asian women encountered a range of barriers which reduced the likelihood of their participation in the Programme. The most significant barriers were insufficient provision of information, cervical health not being discussed openly, cost, transport and negative service provision experiences. There are a range of changes that could help reduce these barriers, including:

- health practitioners and providers providing young women with more education about their bodies, cervical health, the need to be screened and the choices the young women can make;
- cervical health talk being normalised through increased publicity;
- service provision of the Programme being changed (e.g., making screening free, providing transport options and offering a wider range of appointment times); and
- young Māori, Pacific and Asian women being given a positive experience as defined by them.

For communication, a multi-level approach is required to improve the Programme's accessibility and support increased uptake of cervical screening. This includes:

- making the intended audience clear by representing the young women in images, such as age, ethnicity and using a whānau approach;
- providing information through social media, campaigns and advertisements. Role models from the young women's communities need to be used;
- using everyday language, making information succinct and relatable; and
- making a variety of trustworthy options available to answer young women's questions.

# 1. INTRODUCTION

## 1.1. Purpose

Young women aged 20-29 years old have lower cervical screening coverage than older women, especially for those who identify as Māori, Pacific, or Asian (Ministry of Health, 2019). Evidence shows that Māori and Pacific women have a higher burden of disease in relation to cervical cancer (Ministry of Health, 2016). A key focus for the Ministry of Health's (the Ministry) National Screening Unit (NSU) is to continue to improve equitable access to cervical screening for Māori, Pacific and Asian women.

*Allen + Clarke* was commissioned by the Ministry to identify effective approaches to communicate with young Māori, Pacific and Asian women about participating in cervical screening. Cervical cancer is associated with persistent infection of certain strains of HPV. In women aged under 25 years, human papilloma virus (HPV) infection and cell changes are common but will usually resolve without treatment. To avoid unnecessary treatment in this cohort, the NSU is preparing to raise the screening start age from 20 to 25 years within the current cytology-based cervical screening programme (the Programme). This change is expected to occur in mid-2019. Findings from *Allen + Clarke's* research will be used to inform the NSU's strategy for bringing Māori, Pacific and Asian women aged 25 years into the Programme.

## 1.2. Methodology

The research used a combination of a rapid literature review (the evidence review) and focus groups with young Māori, Pacific and Asian women.

### 1.2.1. Rapid literature review

The rapid literature review looked at:

- barriers to participating cervical screening for young Māori, Pacific and Asian women;
- communication approaches and strategies for cervical screening for young Māori, Pacific and Asian women;
- information and messages to support decision-making on participation in cervical screening for young Māori, Pacific and Asian women; and
- general health promotion communication approaches that could potentially inform approaches for cervical screening communication and messaging for young Māori, Pacific and Asian women.

Information from 44 sources, including journal articles, grey literature, and Ministry documents were reviewed. Documents included were full text material available in English and published from 2008 to the present.

The most significant limitation of the documents sourced for the rapid literature review was the lack of information specifically about young women in Aotearoa/New Zealand. Studies around communication strategies and participation in cervical screening for ethnic minority groups (in particular Māori, Pacific and Asian women) tended to cover all ages. There was also a significant lack of kaupapa Māori, by Pacific for Pacific, and research on Asian women in New Zealand on cervical screening communication strategies.

A full description of the approach to the rapid literature review is set out in *Appendix 1*.

### 1.2.2. Focus groups

To further understand how best to communicate with young Māori, Pacific and Asian women about cervical screening, we facilitated focus groups. The following criteria was used to select focus group sites:

- areas which had a higher density of Māori, Pacific and Asian populations;
- spread across New Zealand (e.g. three locations in the North Island, one location in the South Island);
- mixture of urban and rural;
- socio-economic status, with a focus on those living in under-resourced communities (i.e. NZDep index 9/10); and
- social and cultural groups (e.g. family or whānau, church, small community health providers).

A snowball approach to recruitment was used. Initial reach-outs were made to a mums and babies' group, a drugs and alcohol group, church-based group, small community-based health providers and individuals with strong community connections. These initial reach-outs led to individual young women recruiting family members, friends and other personal connections through Facebook and word-of-mouth. This led to a mixture of mums, tertiary students and working young women attending the focus groups; some of which already knew each other. The young women were aged 20-30 years old.

Importance was placed on creating a comfortable environment. This included providing kai (food), holding the focus groups in premises that the young women felt comfortable, making it clear that the young women were welcome to bring children and having a support person available to help with children if desired.

The project team carried out nine focus groups across New Zealand. This was made up of:

- three focus groups with young wāhine Māori. Each focus group was facilitated by the same wāhine Māori. The number of young wāhine Māori that attended the focus groups varied, i.e. n=12, 5 and 11.
- three focus groups with young Pacific women. Each focus group was facilitated by the same Pacific woman. The number of young Pacific women that attended was fairly uniform across the focus groups, i.e. n= 10, 12, 12.
- three focus groups with young Asian women. Each focus group was facilitated by an Asian woman (i.e. South Korean, Sri Lankan and Chinese) with support from the project lead. Two focus groups were made up of a mixture of Asian ethnicities<sup>1</sup> and one focus group was made up of Chinese young women. The facilitator for the Chinese focus group was a health translator who facilitated the focus group in Chinese and translated for note taking purposes. The number of young Asian women that attended was fairly uniform across the focus groups, i.e. n= 9, 10, 10.

---

<sup>1</sup> Ethnicity of the Asian women who attended the focus groups included Chinese, Malaysian-Chinese, Korean, Thai, Sri Lankan, Indian, Fiji Indian

Key themes from the rapid literature review were used to inform the questions at the focus groups with a view to testing their applicability. The following four key areas were explored:

- challenges young women faced when deciding to engage with organised cervical screening;
- what ways of communicating would be most effective in getting information about cervical screening programme;
- how young women preferred to get information, and to access information to have their questions answered; and
- what would make a difference for young women to engage in organised cervical screening.

The focus groups involved a mixture of small group and larger group exercises, which involved a process of questions and answers. One small group exercise involved commenting on current Ministry pamphlets on cervical screening. At each focus group one researcher kept notes of the discussions. The focus group guide is set out in *Appendix 2*. Notes from the focus groups were thematically coded. This information was then used to identify key findings, which were presented to the Ministry as part of testing their validity.

### **1.3. Structure of this report**

This report includes three main sections:

- key barriers young Māori, Pacific and Asian women experience when engaging in organised cervical screening and their impact (*Section 2*);
- young Māori, Pacific and Asian women's preferences on approaches to communication (*Section 3*); and
- what the Ministry needs to do to help improve young Māori, Pacific and Asian women's engagement in the Programme (*Section 4*)

## 2. BARRIERS EXPERIENCED BY YOUNG MĀORI, PACIFIC AND ASIAN WOMEN

*Section 2* discusses focus groups findings on the main barriers that young Māori, Pacific and Asian women experience that reduce the likelihood of them engaging in the Programme. These barriers included insufficient provision of information on cervical screening and cervical cancer, cervical health was not openly discussed in their communities, there are a range of logistical challenges which make attending cervical screening appointments challenging, and there are a range of individual and contextual barriers which exacerbate the situation.

### 2.1. Insufficient provision of information on cervical screening

*Section 2.1* discusses findings from the focus groups about the prevalence of a lack of provision of necessary information about cervical screening and cervical cancer and the implication for young Māori, Pacific and Asian women engaging in the Programme.

#### **Findings from the literature review**

The literature review showed that a lack of knowledge about cervical cancer, cervical screening and services was a major barrier for getting women to engage in cervical screening programmes (Kaneko, 2018; Women's Health Research Centre, 2018; Chan & So, 2017; Lee & Lee, 2017; National Cervical Screening Programme, 2017; Phoenix Research, 2015; Oshima & Maezawa, 2013; PHO Performance Programme, 2013; Shea et al., 2013; Bartholomew, 2011; Yoo et al., 2011). In New Zealand, the National Cervical Screening Programme (2017) indicated that particularly for Māori it was important that health professionals and providers were trained to build their ability to educate women about their bodies, health, and the need for cervical screening (Ministry of Health, 2016). This was supported in the international literature on cervical screening communication strategies for indigenous women ((Maar et al., 2016 ).

In keeping with the literature review, *Allen + Clarke's* focus group research found that a lack of provision of necessary information was a significant factor in the lack of understanding and misinformation about cervical cancer and cervical screening evident all the focus groups. This was one of the most significant barriers to women engaging in the Programme, particularly for young women who had never been screened.

#### **2.1.1. Lack of knowledge contributes to disinterest in the Programme**

Young women we spoke with in the focus groups were uncertain about where the cervix was and why it was important to be screened. Many of the young women were not sure if they had received the HPV vaccine or what HPV and vaccination meant for their cervical health. This lack of knowledge about cervical cancer and cervical screening contributed to a fear of pain and discomfort and the unknown. A significant number of the women had heard that the screening procedure was painful and shared that stories of negative screening experiences spread quickly through their community. These were stories they overheard in discussions between older women, leaving them with an expectation that everyone's experience was the same. This, accompanied with insufficient understanding of the importance of being screened, contributed to expressions of unwillingness or disinterest in engaging in the Programme.

Most of the young women felt that they did not have the necessary information to give informed consent to be screened. In addition to this, most of the women were unclear about where they could get information from. Across the focus groups, the women commented that around them



they did not see information around about cervical screening, cervical cancer or cervical health. This contributed to a lack of awareness of the Programme and why it was important.

### 2.1.2. Misinformation and confusion compounds lack of knowledge issues

Misinformation and confusion about cervical cancer and cervical screening compounded the issue of lack of information and understanding.

Cost was consistently a source of confusion and concern. Asking about the cost of cervical screening was also considered embarrassing. Some of the women thought that it was free based on ethnicity and/or age, or depending on which clinic you attended. Some women felt that a health practitioner had given them the wrong information or had failed to provide an adequate explanation. This included GP surgeries charging family members for screening, when the young women thought that it was free due to their ethnicity.

Other areas of general confusion included who needed to be screened, the relationship between sexual activity, HPV vaccination and screening (e.g. did you need to have a baby first and at what age should you receive the HPV vaccine). Sometimes misinformation came from within a young woman's own community or family.

One young woman shared that a family member had told her you only need the HPV vaccine once you're sexually active. School told her otherwise. She found this very confusing and wasn't sure who she should believe.

The combination of lack of information, misinformation and confusion suggests that health practitioners and providers should not assume that young women have a good understanding of their bodies and cervical health needs. In addition to the Ministry of Health's (2016) suggestion that for Māori in particular health education needed to be improved, this research found young Māori, Pacific and Asian women not only needed but wanted more education about their body, health and the need to be screened. This is discussed more in *section 3.3*.

## 2.2. Young women want cervical health talk to be normalised

*Section 2.2.* discusses findings from the focus groups that talking about cervical health is a topic that is not openly discussed in the young women's families, whānau and communities. This contributes to a lack of knowledge and understanding about the importance of cervical screening, and the desire of the young women for such talk to be normalised.

### Findings from the literature review

Several studies have shown that the link between cervical cancer, sexuality and sex has made the subject of cervical screening taboo or stigmatised and as a result was not to be talked about (National Cervical Screening Programme, 2017; Frost et al., 2016; Phoenix Research, 2015; Bartholomew, 2011). This can be especially the case if young women are not married and living in communities where sex before marriage is discouraged. Reflecting the taboo nature of the topic, Phoenix Research (2015) found that cultural sensitivity (e.g. modesty) in messaging about women's bodies in the context of health of "female" parts of the (lower) body was important for Māori, Pacific and Asian women; however, the need for such cultural sensitivity can depend on women's individual attitudes and beliefs about their bodies.

### 2.2.1. Cervical health not being openly discussed contributes to lack of understanding

In keeping with the literature review, the focus group research found that, across the different ethnic groups, talking about cervical health was taboo, especially for young women who were not married. Being taboo contributed to their lack of understanding about cervical health as it created a world of silence around them. This meant that cervical health and cervical screening was not discussed directly with them. However, experiences across the women were not uniform. While most women shared that talking about the cervix and that area of the body at home was taboo, a small number of women talked about a level of openness about cervical health within their home (e.g. conversations that mothers had with aunties or even more directly with them as young women). Sometimes increased openness was driven by the loss of a close family member to cervical cancer.

Nevertheless, these women's broader cultural contexts were those where cervical health 'talk' was taboo. This left almost all the young women with a deep sense of privacy around cervical health as a potential topic of conversation with family and friends. Although, one young wāhine Māori shared that her husband sometimes checked in front of friends and family if she was up-to-date with being screened. While this was viewed as a sign that her husband was a good man caring for his whānau, some of the women expressed potential embarrassment at being asked quite so publicly.

Holding a deep sense of privacy about cervical talk left the women with a sense of shyness and embarrassment if they were to openly attempt to gain information about cervical screening. Many young Pacific women shared that due to the taboo nature of cervical talk, especially for unmarried women, they would not want to be seen gathering information about cervical screening for fear of generating parental disappointment.

Direct feedback about cervical screening included that:

- it's not discussed by my parents or members of my community or any group that I'm connected with
- I might hear about it, but it's not discussed.
- To pick up a pamphlet would be embarrassing. Who might see me? If my parents found out there'd be awkward questions as I'm not supposed to be having sex.
- I'm not at that stage of life yet, this is something for when you're married.

### 2.2.2. Cervical health talk needs to be normalised

#### Findings from the literature review

Research has shown that normalising screening and removing taboos was important for women in general (Ministry of Health, 2016) and for Māori, Pacific and Asian women in particular (Phoenix Research, 2015). A study of Chinese women in the US and Australia found women who were less concerned with modesty and were more comfortable with talking about their body were more likely to be screened (Chan & So, 2017).

Bethune and Lewis (2009) found that a social marketing approach used in New Zealand had successfully increased awareness and understanding of cervical cancer among Māori and Pacific women. The approach was found to have encouraged discussion of cervical cancer among Māori and Pacific women by 'breaking the ice' and creating a gateway to talk about a previously taboo topic. Pivotal to the approach was the use of humour, specifically through using television as a marketing tool.

In keeping with the literature review, this focus group research found that the young women expressed a strong desire for cervical health ‘talk’ to be normalised. This was reflected in suggestions that cervical screening and cervical cancer needed to be publicised more and that it needed a presence in the media to create more awareness.

Young women with children talked about wanting to make a difference for their daughters to help create a world in which it was normal to discuss such women’s health topics. Normalising talking about cervical health was seen by the young women as crucial for making a change and for improving women’s health.

Almost all the women felt cervical screening should be talked about more openly. They believed this would give young women such as themselves more confidence in the topic, including more hope and courage to discuss it. They wanted to have a laugh about it, to have a good feeling about cervical screening as opposed to finding it daunting, which is the present state.

### **2.3. Young women need to feel sufficiently prepared to engage in screening**

*Section 2.3* discusses findings from the focus groups that there are a range of mental, physical and logistical challenges that young Māori, Pacific and Asian women need to work through to attend a cervical screening appointment.

#### **Findings from the literature review**

The literature showed that there are a range of logistical accessibility issues that act as barriers to women engaging in cervical screening programmes (Women’s Health Research Centre, 2018; Chan & So, 2017; Lee & Lee, 2017; PHO Performance Programme, 2013; Bartholomew, 2011). Issues identified included the cost of the appointment and screening test, an ability to get an appointment at an appropriate time, clinic opening times and an inability to take time off work to attend, family commitments such as childcare and lack of transport.

#### **2.3.1. Cost and transport challenges reduce likelihood of being screened**

Focus groups highlighted that the cost of being screened and transport were particularly significant barriers for young Māori, Pacific and Asian women. There was general consensus that making cervical screening free would increase participation in the Programme. Some young women with children shared that if they needed to choose between buying petrol, getting something for their children or being screened, they would put petrol and their children’s needs before their own health. As one young woman said, “\$5 is a lot of money for some people”. A further complicating factor for some young women was owing money at their GP surgery, which meant they were less likely to visit the surgery until they could afford to pay the outstanding bill. Many young women suggested if it was that important to be screened for cervical cancer then the government should make it free. Doing this would reinforce to the young women the importance of cervical screening.

Building on findings from the literature that under-utilisation of health services or only going to the doctor when sick was a barrier for Asian women (Ho, 2013, in National Cervical Screening Programme, 2017), this focus group research found that this was also the case for young Māori and Pacific young women. Most of the young women shared they would not visit a GP for screening alone. Rather, they tended to visit their GP surgery when they had multiple health issues that needed to be addressed. From the women's point of view, this approach reduced the overall costs and brought a potential sense of value for money.

Although some young women cautioned that if an appointment took too long, the doctor could charge them for an additional appointment.

Some Asian young women shared that by the time they visited a health centre they were suffering with a number of health issues. Addressing these issues were a priority, which meant that any promotion about cervical screening they were exposed to was pushed aside while more immediate health issues were addressed.

Transport and how to get to a clinic was a further significant logistical barrier. Many of the young women, especially those living in more rural areas, commented that having sufficient petrol or not having a vehicle to get to the clinic was challenging. In Auckland, finding money for public transport when rents were high, was seen as challenging. Some of the young women explained that needing to ask for transport to a cervical screening appointment was a source of shame and it was not something they were willing to do. They believed that the clinic needed to offer to help get them there.

### 2.3.2. Mental, physical and logistical preparation is required to attend a cervical screening appointment

In addition to cost and transport, findings from the focus groups found that attending a cervical screening appointment involved a combination of mental, physical and logistical coordination. While there were some differences between the different ethnic groups, there were many commonalities in the preparation involved.

- **Mental preparation** included thinking about childcare, worrying about whether they could get an appointment at a good time, thinking about where they were in their menstrual cycle, considering whether the appointment needed to be rescheduled due to another engagement, worrying about the possible results and whether they could afford it. For women undergoing screening for the first time, there was an additional burden of fear of the unknown, worrying about the process and for some Asian young women uncertainty about how to enter into the health system;
- **Physical preparation** included making sure they were clean, having showered, making sure they had the right clothes on. Being physically prepared was especially important for young wāhine Māori who placed great importance of being clean and physically prepared; and
- **Logistical preparation** included organising kids, making time available during a busy working day, and organising transport.

To reduce these barriers, the young women made a range of suggestions. These included:

- Bring cervical screening to them (e.g. cervical screen takers could attend mums and babies support group, a small van could travel around rural areas that both advertised and offered cervical screening, use the breast screening van and bring it to workplaces such as factories where the sick bay could be used).
- Make appointments available at a time that worked for the young women (e.g. make weekend and after-hour appointments available, make morning appointments more available (this was noted as particularly important for young wāhine Māori).
- Have someone available to look after babies and small children while the women are being screened (*NB* one young woman shared her experience of taking along her young son to an appointment and she found that his curiosity around what was happening to his mum had made things a little awkward as he kept engaging with the procedure, wanting to know what was being done to his mum and why);
- Make it a social occasion with food available (e.g. holding morning tea where the women could attend as a group or a screening party a bit like a Tupperware party).
- In focus groups where self-testing was discussed, some young women liked the idea of testing themselves in the convenience of their own home. At the same time, others aired concerns about the efficacy of self-testing. They were worried that they may not get the correct area, making the test invalid as a result. How would they know they hadn't missed something?

In almost all of the focus groups, the idea of an incentive system to encourage the women to address the barriers they faced was discussed. The women made a wide range of suggestions including receiving hand cream, mascara, T-shirts or petrol vouchers; however, one young woman questioned the ethics of such an approach. She felt that there was a risk of short circuiting informed consent, with women opting to receive a 'treat' that they may not otherwise be able to afford rather than weighing up the pros and cons of being screened.

## 2.4. Experiences of health services is an important influence

*Section 2.4* discusses findings from the focus groups that there are additional barriers at an individual and contextual level that young Māori, Pacific and Asian women encountered when engaging with GP surgeries or the broader health system. These experiences reduced the likelihood of the women engaging in or remaining in the Programme.

### 2.4.1. Negative screening experiences put young women off

#### **Findings from the literature review**

Studies have shown that negative screening experiences, such as pain or discomfort from the procedure acted as a barrier to being screened (Women's Health Research Centre, 2018; Chan & So, 2017; Phoenix Research, 2015; Cook et al., 2014; PHO Performance Programme, 2013). Opportunistic cervical screening processes (i.e. where a health practitioner or GP engages a woman to participate in screening at an appointment for something else) can be a potential barrier to future screening (Phoenix Research, 2015).

Similar to the literature review, focus group findings showed that cervical screening experiences make a difference to the women's willingness to engage and remain engaged in the Programme.

A number of the women shared either personal stories of negative experiences or what they had heard from older women. Many of these 'stories' were about experiencing pain and/or discomfort. It was assumed that everyone would have the same experience. Some women talked about cervical screen takers using hot water instead of lubrication. Other negative experiences included:

- health practitioners not taking the time to talk young women through what was involved and why cervical screening was important;
- opportunistic screening experiences which had left them feeling like a tick box exercise rather than as a person who health practitioners cared about; and
- being repeatedly asked about being screened, feeling pressurised, even though the young women felt they had been clear that 'now was not a good time': Māori and Asian young women, in particular, felt that the doctor or nurse needed to find a good time for them, not for the health practitioner.

Almost all of the young women with such experiences indicated that it had left them with a reluctance to be screened again. In comparison, many of the young women talked about the difference a positive experience made. A positive experience was defined as having someone who talked them through the process (including while carrying out the screening test), being gentle, using lubrication, having a sense of humour, and understanding them. Positive experiences made the young women feel more comfortable with engaging in cervical screening in the future.

#### **2.4.2. Relationship with the screen taker can be important**

##### **Findings from the literature review**

The literature review showed a lack of a culturally competent workforce and/or appropriate support services (including having the desired gender or ethnicity of smear takers available) was a significant barrier (Women's Health Research Centre, 2018; Cook et al., 2014; Harris, Cormack, et al., 2012 and Ho, 2013, in National Cervical Screening Programme, 2017; Phoenix Research, 2015; Bartholomew, 2011). In their kaupapa Māori research, Cook et al. (2014) suggested that in order to be culturally safe, health providers need to ensure that women are recognised as whole beings, relationships between women and staff are close and there is a connection (which helps to reduce feeling whakamā), communication is prioritised, and health professionals actively practice responsive listening.

In addition to this, friends can potentially have a role in supporting their friends to participate. A study by Phoenix Research (2015) identified that due to scant information about cervical screening shared between friends, Māori, Pacific and Asian women were less likely to be encouraged by their friends to participate in cervical screening. However, another study found that Pacific women were more likely than Māori to support their friends to have a cervical smear (National Social Marketing Centre, 2011, in National Cervical Screening Programme, 2017). For Asian women, some studies found recommendations from friends encouraged them to undergo cervical screening (Chan & So, 2017; Oshima & Maezawa, 2013; Bartholomew, 2011).



Focus groups found that for some young women, having a relationship with the screen taker was important. For many young Māori and Pacific women, this was important in terms of gathering information (see *section 3.2.3*). Sometimes this extended to having a relationship with the person doing the screening. This was particularly the case for young wāhine Māori, where whakawhanaungatanga, that is building a relationship with the screen taker, was important.

As one young wāhine Māori pointed out, she did not want to attend a clinic where it was free as she didn't have a relationship with them. Instead, she wanted to visit her GP who she knew and trusted. The problem was, her GP was not free.

Building such relationships may occur over several visits. For some young women pre-existing relationships with their GP and the importance they placed on this, meant they were reluctant to attend clinics that were free as opposed to their GP which meant a cost was incurred.

However, sometimes the way GP surgeries and clinics were administratively organised made achieving a relationship with specific health practitioners challenging. For example, on the day appointment systems where the young women saw different doctors depending on who was available, meant that the young women had not developed a relationship with a particular health practitioner. These women did not know that they could choose between a man or woman doing their screening, were unclear how they could organise for a woman to do it, and did not have a relationship with someone at the surgery to discuss cervical screening.

In addition to this, some young Māori and Pacific women expressed a desire to be able to attend in a group. They felt such an approach would create an opportunity to support each other. Most wāhine Māori thought that they would like to go with their sisters, cousins and mums. This would create a feeling that they were in it together, where they would provide each other moral support.

In contrast, other young women expressed a desire for anonymity. This was particularly the case for young unmarried women where there was a cultural expectation of not having sex before marriage. These young women expressed concerns about privacy and others finding out. Young Asian women also expressed concerns about going to someone they already knew, especially someone who was the same ethnicity as them. This was because their community was so small, sometimes the family GP was also a family friend. In these situations the relationship was a little too close for something so private. Also, in keeping with findings from the literature that young Asian women reported lacking confidence in receiving a cervical smear from a male physician (Ghotbi & Anai, 2012; Kaneko, 2018), young Asian women in focus groups also placed importance on a woman doing their screening. This was a priority over having a relationship with their doctor.

### **2.4.3. Distrust in the health system reduces willingness to engage in the Programme**

#### **Findings from the literature review**

The literature showed that Asian people in New Zealand met some specific barriers to engaging in the New Zealand health system. One barrier was lack of prioritisation of Asian people in the New Zealand health system (Ho, 2013, in National Cervical Screening Programme, 2017). Another was a perceived lack of understanding of specific challenges for south Asian and Muslim women who had immigrated to New Zealand (such as lack of social support, different social norms) (Bartholomew, 2011). Similarly, findings from the Women's Health Research Centre research (2018) found mistrust of the health system and/or government was a barrier to cervical screening for Māori women.



In keeping with the literature review, findings from the focus groups highlighted that a significant barrier for many Asian young women was a lack of trust in the New Zealand health system. All the women who had immigrated to New Zealand talked about how differently the health system here worked from what they were used to back 'home'. For example, some young Indian women talked about how doctors in India were more action-based (e.g. ready provision of antibiotics, access to care in tertiary not primary care settings). Also, young Chinese women expected a more preventative focus than they had experienced here and talked about having annual full health checks in China as normal. The need for a specific health check was foreign to them.

These issues were further exacerbated by GPs being too busy, also nurses. Some young Asian women felt that their GP didn't take enough time to explain things to them. Their complaints included that they needed time to talk health concerns through, that the communication wasn't there and that they didn't feel listened to. They all agreed, when things went wrong in New Zealand, were missed, these stories spread quickly through their community.

These young women found it difficult to know how to navigate the system in New Zealand. They felt shocked when they first arrived and had found it difficult to know where to start, how to engage with the system. They commented that there was no step-by-step guide to explain how the health system worked or who to engage with. A further challenge for some young Asian women who had migrated to New Zealand was uncertainty about their eligibility for cervical screening, especially if they were an international student.

Additionally, most of the young Asian women felt that the health system in New Zealand did not understand the health needs of Asian women. Some young Asian women shared that they felt the New Zealand health system did not understand what they were going through. As one young woman said

*"I need somebody of the same background, they would understand. My doctor needs to be culturally competent, someone I can relate to."*

They felt that there was a mismatch of approach and communication, which led to a mistrust in the system. Some of these women, as reflected above, said they would like to be seen by an Asian doctor for an Asian approach to healthcare.

### 3. PREFERENCES ON APPROACHES TO COMMUNICATION

Section 3 section discusses focus group findings on the different approaches to communication that young Māori, Pacific and Asian women indicated would be most likely to reach them and support improvements in their knowledge. This included the importance of seeing themselves represented in promotional material, the need for a multi-level approach to cervical screening communication, that the information provided needs to be simple and relatable, and a range of ways to access and receive information needs to be available for the young women to get their questions answered.

#### 3.1. Young women need to see themselves represented in promotions

Section 3.1 discusses findings from the focus groups that young Māori, Pacific and Asian women needed to see themselves represented in promotional material to recognise that the information concerned them. This included the importance some young women placed on having a family/whānau approach to such material.

**Findings from the literature review**

The literature review indicated that it was vital that women from ethnic minorities are involved in the development and planning of communication initiatives to ensure that strategies are culturally appropriate, clear and relevant. This included developing health literacy content and ways to reach people. This theme came through strongly in a number of documents, particularly for Māori (Cram, 2014; Women’s Health Research Centre, 2016, 2018). In an unpublished document review, it was noted that Māori women wanted wāhine and community leaders to lead and develop communication strategies, messaging, and resources – a by Māori for Māori approach (Raukura Hauora O Tainui, 1994, in National Cervical Screening Programme, 2017). A study of young Asian women in the United States, (Gor et al., 2011) found educational materials needed to be culturally and linguistically appropriate. This included recognising and considering existing contextual factors and barriers to screening, such as cultural emphasis on family rather than individual well-being, gender-specific beliefs about modesty and religious beliefs.

Similar to findings from the literature review, focus groups highlighted that all the young women wanted to see themselves represented in cervical screening promotions. Seeing themselves gave the message that it included them. As one Asian young woman explained:

*“if I see Māori, Pacific and/or European then I think it as an issue about them, not me. If you include Asian people, then I know it’s about me”.*

There was some diversity among the young women’s preferences regarding images in promotional material. While some young women wanted to see only their ethnic group, others wanted it to be mixed, to see broader representation of young women. One of the reasons for this was that some of the young women felt that when they saw only their ethnic group they felt that that it portrayed a message that they were not complying with what they were supposed to do for their health. There was a sense that they were being “nagged”.

*Young like me*  
*Looks like me*  
*Dresses like me*  
*Talks like me*  
*Same interests as me*

This feeling was exacerbated by images in which the women looked stern or appeared to be looking down on the reader/audience.

### 3.1.1. Representing whānau is important for Māori and Pacific young women

#### **Findings from the literature review**

A study carried out by the Women's Health Research Centre (2018) found for Māori women a whole-of-whānau approach to public health campaigns with whānau-inclusive messaging was important.

Similar to the findings of the literature review, the focus groups found that young wāhine Māori wanted a whānau approach to promotional images. They wanted to see the entire family, including different generations, used for promoting cervical screening. Some young wāhine Māori felt that it needed to be 'mixed up more'. They wanted to see a 10 year old girl who was due her HPV vaccine mixed in with women at different stages in their life. They suggested this could even be made into a video.

A recurring theme across many of the focus groups with Māori and Pacific young women was the desire to have men represented in promotional materials. This was particularly prevalent among young married women with children. There was some differences in focus.

- Young Pacific women placed importance on the need to educate men about the importance of cervical screening.
- Young wāhine Māori focused on the inclusion of men as part of the importance they placed on whānau.

Both Māori and Pacific young women believed that men had an important role in normalising cervical health 'talk' and in supporting women to look after their health. In contrast, having photos that focused on individual women, missed the importance these women placed on family, whānau and interconnectedness.

### 3.2. A multi-level approach to cervical screening communication is needed

*Section 3.2* discusses the need to use a variety of communication channels to effectively communicate information about cervical screening, cervical health and cervical cancer to young Māori, Pacific and Asian women. This included a range of options that the young women suggested as potentially fruitful approaches to improving the Ministry's reach in communicating with them.

#### **Findings from the literature review**

Findings from the literature review indicated that communication strategies to encourage screening should take a multi-level approach. Potential approaches identified included public health promotion campaigns (Women's Health Research Centre, 2018; Cram, 2014; Gao, 2008 in National Cervical Screening Programme, 2017), social marketing campaign (Bethune & Lewis, 2009), text messaging (Lee et al., 2014; PHO Performance Programme, 2013), telephone calls (PHO Performance Programme, 2013), letters from healthcare organisations (Chan & So, 2017; PHO Performance Programme, 2013), and pamphlets (Gao, 2008 in National Cervical Screening Programme, 2017).

In keeping with the literature review, the focus groups found that a multi-level approach to providing information was needed: there is no one-size-fits-all approach, rather a 'no wrong door' approach to information with multiple entry points is needed. This refers to:

- providing varying levels of information (from high level to more detailed information), and
- providing this information across different platforms.

Within each focus group, the young women expressed a desire for differing types and amounts of information to be provided. Also, across the different priority populations, preferred platforms for receiving information varied. Adopting a multi-level approach to providing information would enable the young women to select the best approach(es) to getting information that meets their needs and desires. Differences in preferred approaches are discussed in the following sections.

### 3.2.1. Some traditional communication channels were appealing

#### **Findings from the literature review**

Schmidt-Grimminger et al. (2013) reported on a study of young indigenous American women in 2009, looking at their HPV knowledge, beliefs and attitudes towards HPV and HPV vaccination. The authors found these young women desired more information and favoured traditional forms of communication to receive messages. This included healthcare providers, family, media and print materials. A study by Phoenix Research (2009) found the most popular communication approach for the public to receive information about cancer screening was mass media campaigns or advertising. A study in Auckland indicated that pamphlets about cervical screening had encouraged Chinese women to have a smear test (Gao 2008, in National Cervical Screening Programme, 2017). Some research indicated that communication about cervical screening needed to be age appropriate. Indigenous First Nations women in Canada thought that education around cervical screening should begin at a young age (Maar et al., 2016). Another study that looked at factors associated with cervical screening among Korean women supported the need for age specific interventions (Chang et al., 2017).

Most young women felt cervical screening needed to have a greater presence generally.

Focus group findings showed that some traditional forms of communication had appeal to young Māori, Pacific and Asian women. There was widespread agreement that there needed to be more campaigns and advertisements on television. Some young women suggested that such adverts could also be played in GP surgeries, which young women would see while waiting for their appointment. All the young women placed importance on the people who appeared in these adverts. They needed to be someone they could relate to, people they recognised, and people that come from their community.

Another suggestion was to have an advert that showed a role play of the process of going to be screened, and to promote screening as part of a normal day. Some young women felt such a role play should show the entire process from making the appointment to being screened. Young Māori and Pacific women suggested that such advertisements should be played at times of the day when they were most likely to be watching television, such as before a netball game or Shortland Street.

Other elements of a campaign suggested:

- more use of posters;
- having fridge magnets as a prompt;
- messages could be included on tampon or condom packets; and
- having a cervical screening awareness day or week.

There was general agreement that a potentially effective means of improving awareness was through a cervical screening awareness week or day. This would be a time when more emphasis was placed on publicity and raising public awareness of its importance

In contrast to these findings, responses to hardcopy communications material, especially pamphlets were mixed. While some young Asian women liked the idea of pamphlets, most young women felt that information needed to be provided where they were. This was reflected in such statements as

*“women our age don’t look at pamphlets, we’re on our phones. You need to provide information where we are.”*

In keeping with the importance placed on whānau, young Māori and Pacific women felt that the Ministry should continue to have pamphlets for the older generation, for their mums and aunties.

### 3.2.2. Social media was a popular option

#### Findings from the literature review

The literature review showed that use of social media and its efficacy has not been widely explored. A literature review carried out by Brusse et al. (2014) found while social media and mobile software applications aimed at indigenous Australians showed “great promise”, there was little evidence of its efficacy. The authors suggested that for social media to be a successful tool for communicating about health issues, health organisations needed a better understanding of how social media and technology could be better used to reach and make a difference to their service. While in New Zealand the ‘smear your me’, a community-funded and wāhine-driven health campaign focusing on wāhine Māori and families involved in kapa haka, was potentially effective; however, there has been no formal evaluation of the effectiveness of this campaign.

A systematic review carried out by Chou et al. (2013) found Web 2.0 (such as social media) tools for health promotion had changed communication. In particular, in the online environment providing information had changed from a unidirectional and read-only approach to multidirectional communication that was characterised by participation, collaboration and openness; however, a key research question facing these changes was the issue of the inequalities that exist in access to technologies that had been observed.

In keeping with the literature review findings, the focus groups found that the use of social media as an approach was a popular choice. This was particularly the case for young women without children and Asian women. The recommended social media platforms were Facebook, Instagram

Suggestions varied between young Pacific, Māori and Asian women.

- Young Pacific women wanted basketball players, netball players or someone like Valerie Adams.
- Young wāhine Māori wanted the Silver Ferns, netball or Warriors for men.
- Young Asian women wanted well-known Korean, Chinese or Indian public figures (e.g. musicians or actresses).

and WeChat (for Chinese young women). Almost all the women thought that information could be provided through the use of YouTube and Facebook advertisements; however, there is a risk that unless the Ministry pays for advertising specifically focused towards engaging young Māori, Pacific and Asian women, some will not see these advertisements as their viewing habits among other things will not trigger the algorithms to show the required content.

In some of the focus groups with young Māori and Pacific women, the social media campaign in New Zealand ‘smear your mea’ was discussed. This campaign generates awareness of cervical screening through social media messaging, posting pictures and announcing smear campaigns and events. In keeping with the importance the young women placed on representation, this focus group research found that the ‘smear your mea’ campaign had more resonance with young wāhine Māori living among communities with a strong kapa haka emphasis. In contrast, the campaign did not resonate with some young Pacific women, who found the slogan ‘smear your mea’ potentially rude.

Across the focus groups many young women expressed a desire for the information to be multidirectional. That is, these young women wanted to have opportunities to participate in promoting cervical screening through social media. This reflected their desire for cervical health ‘talk’ to be normalised and their willingness to help make this happen.

**Suggestions included:**

- Use hashtags (eg., #timetoscreen), or
- Run competitions with the hashtag (eg., find the ribbon or add a photo of oneself with the ribbon).

**3.2.3. Some young women wanted a relationship-based approach to accessing the Programme**

**Findings from the literature review**

The literature review found it was important for health professionals and providers to develop trusting relationships with Māori, Pacific, and indigenous First Nations women having cervical screening (Women’s Health Research Centre, 2018; Folaki & Matheson, 2015, in National Cervical Screening Programme, 2017; Cook et al., 2014). Similarly, Chan & So (2017) found that Asian women from Australia and America who received a recommendation from a health professional were encouraged to have cervical screening. This was also noted for Auckland-based Chinese women in a document review (Gao, 2008, in National Cervical Screening Programme, 2017). For Pacific women, group-based communications, for example a group of Pacific women meeting with health practitioners (Sligo, 1989, in National Cervical Screening Programme, 2017) and education (Mishra et al., 2009) could help encourage participation in screening.

Similar to the literature review, focus groups found that the women, especially young wāhine Māori with tamariki, placed importance on a more relationship-based approach for gaining information. These young women placed importance on information coming from people they trust. This was reflected in the desire for smear takers to attend mums and babies’ support group meetings (see section 2.3.2). These young women not only wanted it to be made logistically easier to be screened, they wanted to develop a relationship with a screen taker, to be able to have any questions answered by them and to develop trust. This would make them feel more comfortable.

Some young women also felt that health practitioners needed to reach-out to schools and social events to raise awareness of the importance of cervical screening in communities. Furthermore,



they felt that cervical health ‘talk’ should be included in sex education as part of women looking after themselves. School was seen as a neutral space, where parents did not have the same level of oversight over what they were doing and where the girls could talk more freely. The young women felt that this education could start in Years 7 or 8 (11, 12 years old) and continue through high school.

Another suggestion was for health practitioners to attend community events that were already in existence. For example, some young Chinese women thought that an annual Asian Health Day, an event which a range of agencies attended, created an opportunity for health practitioners to share information directly with their community. Such approaches were thought to create an opportunity to build relationships and trust with health practitioners.

In addition to health practitioners, some young women, especially Pacific, placed importance on information coming from role models. These role models were slightly older than them, people they respected, looked up to and followed on social media/blogs. The young women felt that an endorsement promoting the importance of cervical screening from such well-respected women from their own community would send a strong signal about the need to be screened.

#### **3.2.4. Text, emails and telephone calls were preferred over letters**

##### **Findings from the literature review**

The literature review showed that, generally, text messaging was seen as a useful form of communication to encourage cervical screening for Māori, Pacific and Asian women. A study of Korean-American young women had found text messaging was popular for accessing cervical screening services as well as a communication tool for education (Lee et al., 2014); however, there was little evidence of the efficacy of text messaging as a tool in terms of influencing positive health outcomes (Yeager & Menachemi, 2011).

Other approaches to encourage Māori, Pacific and Asian women to participate in cervical screening were telephone calls and letters from healthcare organisations (PHO Performance Programme, 2013). In Australia, Chan & So (2017) had found letters from healthcare organisations had encouraged Asian women to be screened.

This focus group research found that approximately half of the participants had not received an invitation to be screened from their health practitioner. In some cases, this was because they sat outside of the “health system”. For example, many of these young women were international students who had not enrolled at a GP surgery. Additionally, some young women who were enrolled at their GP surgery could not recall ever being invited to be screened.

Across the focus groups, there was a lack of consensus about the preferred approach to receive prompts to be screened. While some young women liked the idea of email, making such statements as “that would get them every time”, other young women disagreed, stating that they were “not big on using email”. Some Pacific young women did not like the idea of being emailed as they were concerned that their parents may see the email.

The other approach the young women tended to suggest was text messaging, however, as one young woman pointed out, a risk with text messages was that their number may have changed. A few young women also reported that they had received several text reminders to be screened but that this had not led to them book a test. These text messages were received with a level of



ambivalence. One young woman explained that each time she received a text message reminder, she told herself that she would organise to be screened next time. Her ambivalence was in part driven by a belief that the opportunity to be screened was always there. She told us that she had never organised an appointment.

The young women were more ambivalent about telephone calls. Some young women thought that a phone call from their GP clinic could work for encouraging them to be screened. While others, as stated above, preferred email or text. Generally, the young women were not keen on receiving a letter, but, as with pamphlets, some young Māori and Pacific women felt letters would be appropriate for their mums and aunties.

### 3.3. Information about cervical screening needs to be simple and relatable

*Section 3.3* discusses findings from the focus groups concerning the need for information about cervical screening, cervical health and cervical cancer to be in everyday language, simple, and relatable. Included are suggestions from the women about the types of messages the information should carry, the need for messages to resonate with them, and for written materials to be available in other languages for young Māori and Asian women.

#### **Findings from the literature review**

The literature review provided little insight to determine the most effective information and messages to encourage young Māori, Pacific and Asian women to initiate screening. However, literature that explored information and messaging in communications around cervical screening was inextricably linked with communication approaches.

Phoenix Research (2015) found that the idea of wellness was powerful and motivating and something that Māori, Pacific and Asian women wanted to move towards. Furthermore, Phoenix Research reported that messages should have a prevention focus. The ideal portrayal of cervical screening was a health check, to show 'that everything's alright down there'. They noted that women wanted to feel supported and cared for by the brand or entity representing cervical screening. The authors suggested information and messaging around cervical screening should not:

- make reference to connotations of a burden of health responsibility on Māori, Pacific and Asian women
- include compliance as a key message, as it undermines self-responsibility for future participation in screening
- nag: cervical screening reminders can be seen as nagging, and
- give prominence to links between sex and cervical screening (eg., HPV as the cause of cervical cancer): this aspect of cervical cancer screening should be addressed appropriately and with care in secondary communication strategies.

Information and having knowledge that asymptomatic women should be screened was found to be motivating for Chinese women in Auckland (Gao, 2008, in National Cervical Screening Programme, 2017). Similarly, a study of Indigenous First Nations women noted that explanation of the value of cervical screening motivated this group (Maar et al., 2016). In New Zealand it was found that messages about how effective the National Cervical Screening Programme is could be motivating (Phoenix Research, 2015).

In keeping with the literature review, the focus groups found that young women wanted more information about the reasons why they should be screened, what the procedure involved and what choices were available to them. They wanted the information to cover a range of areas:

- A step-by-step explanation of the process (i.e., what one woman referred to as the “*life cycle of having a smear test*”): this information should start with when a woman enters the system, such as setting up an appointment or gathering information, through to when she has been screened and when follow-up screening should be undertaken.
- What screening options exist: all the women wanted to know what choices they could make, such as what choices they could make around who carried out the procedure.
- The risks involved, both in terms of the risks of the procedure itself and the risks to their health if they decided not to be screened.
- The benefits of being screened: some young women wanted to know if there were any particular health benefits from being screened, such as reassurance that their cervix was healthy; however, a few women raised concerns that the screening programme could not provide 100% assuredness that their cervix was healthy and they felt the lack of certainty would leave them with a nagging doubt about their health and as a result undermine a key benefit of being screened.

Generally, messaging about the risk of dying from cervical cancer did not resonate with young women. The young women we spoke with saw themselves as young and healthy, and dying of cancer felt like something that happened to the older generation, not to them. However, the link between cervical cancer and losing the ability to have a baby was a message that resonated. Such messaging would be highly motivating as having a baby was important and fitted with their stage of life. This was especially the case for young Māori, Pacific and Indian women.

### 3.3.1. Messages need to be succinct and resonate with young women

#### **Findings from the literature review**

Phoenix Research (2015) noted that vocabulary in messaging needs to be relevant and user friendly. They found the use of the word “screening”, along with poorly understood clinical terms such as abnormal cells or pre-cancerous cells, contributed to confusion with cervical screening being thought of as cancer detection, not as a prevention strategy. Their study showed Māori, Pacific and Asian women wanted better communication messages about the nature of the procedure and any discomfort they might experience.

All the young women wanted messages to be in everyday language and placed importance on the avoidance of clinical words and phrases as they were not easily understood. Both Māori and Pacific young women talked about their preference for written messages to be “*to the point*”. They also wanted more diagrams and images to be used. There was a lack of consensus on how far initial information should go. While some young women wanted information to include messages about what happens if you get an abnormal result, other young women felt this was a step too far and that the information should be limited to the process of being screened.

Suggestions for better messaging about cervical screening included:

- Use bullet points;
- Use heading and subheadings;
- Explain the process, including where to go, what to expect and who can carry out the procedure;
- Be clear about the risks and benefits (*NB there was a lack of consensus between the women about how much information around risks and benefits should be included in information introducing cervical screening*);
- Provide high level information with a link to a website for more information;
- Use slogans that transmit a message of care; and
- Use fear tactics such as those used on cigarette packets or in some advertising. Messages could be included on tampon or condom packets.

At the same time as wanting information to be to the point, focus group participants wanted the information to be engaging, to be something they could relate to. Most of the young women wanted other women's experiences to be shared with them, short vignettes that explained what it was like. For some young Pacific women this was important, as they felt that being provided with information only was not believable. There was general agreement that such stories needed to be heartfelt, to have more meaning.

### 3.3.2. Messages need to be available in different languages

#### **Findings from the literature review**

Studies have shown that for Asian women, language and lack of awareness of translation services was a barrier for engaging in the cervical screening programme (Ho, 2013, Lovell et al., 2007, in National Cervical Screening Programme, 2017; Bartholomew, 2011). Messages or communication about cervical screening should be in a language that people understand, which is particularly important given the diversity of cultures and languages in Asian populations (Gor et al., 2011). Chan and So (2017) found Asian women with less proficiency in an official language had a lower level of exposure to publicly available health information.

Focus groups highlighted that all the young Asian women felt it was important to address language barriers. They said that it would be helpful to have some information translated into the languages they spoke. This was partly because while young Asian women may speak English, this did not mean they could easily read it. A further challenge was not understanding medical terms or concepts. Most of the Asian women felt that English versions of the information needed to have key words translated into their language as this would be more meaningful. They also expressed a sense that the use of their own language felt more inclusive, it carried another message that this information was important and it applied to them.

Some young wāhine Māori also felt that written information should include Te Reo Māori. These young women suggested information should be presented in English first, followed by a Te Reo

Māori translation. The need for written information to be in Pacific languages was not discussed in the focus groups with young Pacific women.

### 3.4. Different strategies to answer young women's questions is needed

Section 3.4 discusses the ideas raised by focus group participants about the different strategies the Ministry could consider using to assist young Māori, Pacific and Asian women to get their questions answered

#### Findings from the literature review

The literature showed many Asian young people seek health information from the internet. In a United States study focused on young Asian American women, Frost et al. (2016) found that because the young women wanted their health issues to remain confidential, many chose to access health information from the internet. This was despite knowing the information may be inaccurate. The study concluded that diversified strategies needed to be used to communicate and connect young Asian women with sexual and reproductive health care information. Another study found Asian-Americans were more likely to trust information that was shared directly from health organisations; however, they were more likely to access health information from the Internet (Alber et al., 2018).

While a New Zealand-based study found sources of knowledge about cervical screening should be credible, reputable, friendly and well-informed (Phoenix Research, 2015). Findings from the study showed 30 percent of participants that that being told personally was a good way to reach New Zealand women about health-related issues, however, Māori and Pacific people were especially unlikely to suggest this.

In keeping with the literature, this focus group research found that the young women expressed a variety of preferences when seeking information to answer questions. Some of these differences existed between Māori, Pacific and Asian young women. An underpinning theme was that the information needed to come from a trusted source. Preferred approaches for getting questions about cervical screening answered are described below.

- **Google:** most young women said the first place they would search for answers to their questions was Google; however, the information needed to come from a trusted source, such as a government department or a website with good reviews. It also needed to be the first option that appeared as sometimes they found it challenging to find the information they were looking for. For example, some young women had attempted to find out more about cervical screening before attending the focus group, but had struggled to find the information they were looking for.
- **FAQ:** most of the women liked the idea of having frequently asked questions (FAQ) made available: they saw this as a quick and easy way of accessing information and finding answers to their particular questions.
- **Online chat:** this was particularly popular with Asian young women and some young Asian women felt that online chat was more private and that it gave them time to think.
- **Online applications (apps):** A few young wāhine Māori suggested that information could be provided in apps for women's health that already existed. Many of these apps provided reminders of when they were in their menstrual cycle. These young women felt

that it would be helpful to receive prompts and reminders about cervical health and screening in these or similar apps.

- **Weblink at the end of pamphlets:** Some young Māori and Asian women suggested that pamphlets should be kept short and focused with a weblink at the end of them to make it easy for young women to get more information if desired.
- **Someone at the GP surgery:** Some young Māori and Asian women suggested that it would be helpful to have someone at the health clinic or hauora to talk to. Seeking information in this way needed to be free.
- **Someone from within their community:** Both young Māori and Pacific young women felt they would like to get additional information from a trusted member of their community and/or their family and friends. This was in keeping with the importance these young women placed on relationships.

Almost all the young women said they would not use the freephone number; however, many young Māori and Pacific women were concerned that this service remained available for the older generation.

## 4. CONCLUSIONS

Findings from the focus group indicate that young Māori, Pacific and Asian women encounter a range of barriers that reduce the likelihood of them engaging in the Programme. The most significant of these barriers was the prevalence of a lack of clear and relatable information relating to cervical screening. This, combined with misinformation and confusion, contributed to fears of pain and discomfort and of the unknown. It also meant that the young women did not have clarity on the importance of cervical screening. These findings indicate that there is an opportunity for the Programme, health practitioners and providers to consider providing young Māori, Pacific and Asian women with more education about their bodies, cervical health and the need to be screened. The young women also need to know what choices they can make and many of the women placed importance on being able to choose a woman to be the screen taker.

A contributing factor to these young women feeling unfamiliar with cervical screening was that talking about cervical health was taboo in many communities, especially for unmarried young Māori, Pacific, and Indian women. This meant that not only was cervical health and screening not discussed but the women experienced shyness and embarrassment if they were to make open attempts to gain information. All the women expressed a desire for cervical health 'talk' to be normalised. To enable this to happen, cervical health, cervical screening and cervical cancer needs to be publicised more, including have a greater presence in the media. This could help the young women to start talking about these topics more openly.

This research found that to attend a cervical screening appointment the young women needed to engage in a combination of mental, physical and logistical coordination that could be challenging. These challenges included cost, transport, appointments being available at a time that worked for the young women, and having someone to look after young children. Suggestions to address these barriers included making it free to attend screening appointments both at GP surgeries and health clinics, providing transport or bringing the screening to them, providing out-of-hour appointments and making it into a social occasion with food. Making these types of changes could lead to improved participation rates in the Programme.

At a service provision level, negative experiences of the New Zealand health system either in connection to cervical screening or more broadly contributed to a reluctance to engage in the Programme. In contrast positive experiences increased the young women's willingness to engage and to remain engaged in the Programme. The young women defined a positive experience as having someone to talk them through the process, being gentle, using lubrication, having a sense of humour and understanding their needs. For some young women it was also important that they had a pre-existing relationship with the screen taker. These findings suggest that it is important that young Māori, Pacific and Asian have a positive experience, as defined by them, in order to increase the likelihood of their ongoing engagement in the Programme.

Findings from the focus groups indicates that a multi-level approach to communication is required to improve the Ministry's reach and support increased uptake of cervical screening.

Across the focus groups, the young women suggested a range of approaches to communication that would improve the Ministry's reach. However, to make it clear to the young women that they are the intended audience, it is important that they can see themselves represented in images. This meant that images needed to include young women of the same ethnicity as them. While some young women only wanted to see their ethnic group, others wanted to see broader representation with a mixture of ethnicities. Moreover, most young Māori and Pacific women wanted a whānau/family approach, including men, to be used.



In addition to this, focus group findings indicated that there needs to be differing types and amounts of information that is provided across a variety of communication channels. A key theme was that for the Ministry and others to reach these young women, they need to meet them where the young women are. Popular options for receiving information included social media, campaigns and adverts, which could be shown on television, YouTube and Facebook. The young women wanted the information to be succinct, but it also needed to resonate with them. A number of young Asian women expressed that they experienced language as a barrier and that written material needed to be provided in their first language.

There was a range of information that needed to be covered in promotional material, including a step-by-step explanation of the entire process, what their options were, the risks involved and the benefits of being screened. However, careful consideration needs to be given to the extent risks and benefits are explained and when information about the processes around abnormal test results needs to be provided.

Similarly, the women had a variety of preferences when seeking information to answer questions. Some of these differences existed across the different ethnic groups, for example Maori, Pacific, Indian, Chinese and Korean. Preferred options for getting questions answered included searching google, frequently asked questions, online chat for young Asian women especially Chinese and Korean, weblink at the end of written material, someone at their GP surgery that was free to talk to and someone from within their own community. While almost all the young women wouldn't use a freephone, young Māori and Pacific women felt the service needed to be retained for the older generation.

An implication of these findings for the Ministry and others engaged in providing information about cervical screening and cervical health is that promotional material needs to both reflect the young women and meet the women where they are. This means for communication to be effective a multi-approach, 'no wrong door' approach needs to be adopted.

## REFERENCES

- Alber, J. M., Cohen, C., Nguyen, G. T., Ghazvini, S. F., & Tolentino, B. T. (2018). Exploring Communication Strategies for Promoting Hepatitis B Prevention among Young Asian American Adults. *Journal of Health Communication*.  
<https://doi.org/10.1080/10810730.2018.1534904>
- Bartholomew, N. (2011). An exploratory study of Muslim women's attitudes towards and experiences of cervical screening.
- Bethune, G. R., & Lewis, H. J. (2009). Let's talk about smear tests: social marketing for the National Cervical Screening Programme. *Public Health*, 123 Suppl 1, e17-22.
- Brusse, C., Gardner, K., McAullay, D., & Dowden, M. (2014). Social media and mobile apps for health promotion in Australian Indigenous populations: scoping review. *Journal of Medical Internet Research*, 16(12), e280–e280. <https://doi.org/10.2196/jmir.3614>
- Chan, D. N. S., & So, W. K. W. (2017). A Systematic Review of the Factors Influencing Ethnic Minority Women's Cervical Cancer Screening Behavior: From Intrapersonal to Policy Level. *Cancer Nursing*, 40(6), E1–E30.
- Chang, H. K., Myong, J. P., Byun, S. W., Lee, S. J., Lee, Y. S., Lee, H. N., ... Park, T. C. (2017). Factors associated with participation in cervical cancer screening among young Koreans: a nationwide cross-sectional study. *BMJ Open*, 7(4), e013868.
- Chou, W. Y., Preston, A., Lyons, C., & Wen, K. Y. (2013). Web 2.0 for health promotion: reviewing the current evidence. *Am J Public Health*, 103(1), e9-18.
- Churchward, M. E. (2015). *The Maternity Experience of New Zealand Samoan First-time Mothers*. Victoria University of Wellington, Wellington, N.Z. Retrieved from <http://researcharchive.vuw.ac.nz/handle/10063/7728>
- Cook, C., Clark, T., & Brunton, M. (2014). Optimising cultural safety and comfort during gynaecological examinations: Accounts of indigenous Māori women. *Nursing Praxis in New Zealand*, 30(3), 19–30.
- Cram, F. (2014). *Improving Māori Access to Cancer Health Care: Literature Review*. Ministry of Health. Retrieved from <http://www.katoa.net.nz/maori-access-to-health-services>
- Frost, M., Cares, A., Gelman, K., & Beam, R. (2016). Accessing sexual and reproductive health care and information: Perspectives and recommendations from young Asian American women. *Sexual & Reproductive Healthcare : Official Journal of the Swedish Association of Midwives*, 10, 9–13.
- Ghotbi, N., & Anai, A. (2012). Assessment of the knowledge and attitude of female students towards cervical cancer prevention at an international university in Japan. *Asian Pacific Journal of Cancer Prevention: Apjcp*, 13(3), 897–900.
- Gor, B. J., Chilton, J. A., Camingue, P. T., & Hajek, R. A. (2011). Young Asian Americans' knowledge and perceptions of cervical cancer and the human papillomavirus. *Journal of Immigrant & Minority Health*, 13(1), 81–86.
- Kaneko, N. (2018). Factors associated with cervical cancer screening among young unmarried Japanese women: Results from an internet-based survey. *BMC Women's Health*, 18(1).  
<https://doi.org/10.1186/s12905-018-0623-z>

- Lee, H. Y., Koopmeiners, J. S., Rhee, T. G., Raveis, V. H., & Ahluwalia, J. S. (2014). Mobile phone text messaging intervention for cervical cancer screening: changes in knowledge and behavior pre-post intervention. *Journal of Medical Internet Research*, 16(8), e196.
- Lee, H. Y., & Lee, M. H. (2017). Barriers to Cervical Cancer Screening and Prevention in Young Korean Immigrant Women: Implications for Intervention Development. *Journal of Transcultural Nursing*, 28(4), 353–362.
- Maar, M., Wakewich, P., Wood, B., Severini, A., Little, J., Burchell, A. N., ... Zehbe, I. (2016). Strategies for Increasing Cervical Cancer Screening Amongst First Nations Communities in Northwest Ontario, Canada. *Health Care Women Int*, 37(4), 478–495.  
<https://doi.org/10.1080/07399332.2014.959168>
- Ministry of Health. (2016). National Cervical Screening Programme: Changing the primary laboratory test: Public consultation submission summary. Ministry of Health. Retrieved from <https://www.nsu.govt.nz/health-professionals/national-cervical-screening-programme/hpv-primary-screening>
- Ministry of Health. (2019). National Cervical Screening Programme Coverage Report. Retrieved 25 March 2019, from <https://minhealthnz.shinyapps.io/nsu-ncsp-coverage/>
- Mishra, S. I., Luce, P. H., & Baquet, C. R. (2009). Increasing Pap Smear Utilization among Samoan Women: Results from a Community Based Participatory Randomized Trial. *Journal of Health Care for the Poor and Underserved*, 20(2A), 85–101.  
<https://doi.org/10.1353/hpu.0.0160>
- National Cervical Screening Programme. (2017). Equity and primary HPV testing. Unpublished.
- Oshima, S., & Maezawa, M. (2013). Perception of cervical cancer screening among Japanese university students who have never had a Pap smear: A qualitative study. *Asian Pacific Journal of Cancer Prevention*, 14(7), 4313–4318.  
<https://doi.org/10.7314/APJCP.2013.14.7.4313>
- PHO Performance Programme. (2013). How to increase the uptake of cervical screening: A profile of success. *Best Practice Journal*, (55), 42–49.
- Phoenix Research. (2009). Community perceptions survey: Public opinions about cancer, early detection and screening. Cancer Society of New Zealand.
- Phoenix Research. (2015). Understanding key inequity segments, motivations and barriers to participation in screening programmes. National Screening Unit.
- Sasagi, F. (2011). An investigation of the health information needs and behaviors of the Samoan community in Porirua, New Zealand. Victoria University of Wellington, Wellington, N.Z. Retrieved from <http://researcharchive.vuw.ac.nz/xmlui/bitstream/handle/10063/2354/paper.pdf?sequence=1>
- Schmidt-Grimminger, D., Frerichs, L., Black Bird, A. E., Workman, K., Dobberpuhl, M., & Watanabe-Galloway, S. (2013). HPV knowledge, attitudes, and beliefs among Northern Plains American Indian adolescents, parents, young adults, and health professionals. *Journal of Cancer Education*, 28(2), 357–366.

- Shea, J., Klainin-Yobas, P., & Mackey, S. (2013). Young Singaporean women's knowledge of cervical cancer and pap smear screening: a descriptive study. *Journal of Clinical Nursing*, 22(23-24), 3310-3319.
- Smear Your Mea. (2018). About. Retrieved from <https://smearyourmea.nz/>
- Women's Health Research Centre. (2016). He Tapu Te Whare Tangata: Research to inform cervical screening strategies for Māori women: Literature review. Unpublished.
- Women's Health Research Centre. (2018). He Tapu Te Whare Tangata: Research to inform cervical screening strategies for Māori women. University of Otago.
- Yeager, V. A., & Menachemi, N. (2011). Text Messaging in Health Care: A Systematic Review of Impact Studies. In J. D. Blair & M. D. Fottler (Eds.), *Advances in Health Care Management* (Vol. 11, pp. 235-261). Emerald Group Publishing Limited.  
[https://doi.org/10.1108/S1474-8231\(2011\)0000011013](https://doi.org/10.1108/S1474-8231(2011)0000011013)
- Yoo, G. J., Le, M. N., Vong, S., Lagman, R., & Lam, A. G. (2011). Cervical cancer screening: attitudes and behaviors of young Asian American women. *Journal of Cancer Education*, 26(4), 740-746.

## APPENDIX 1: TERMS OF REFERENCE FOR THE RAPID REVIEW OF COMMUNICATING CERVICAL SCREENING TO YOUNG WOMEN

### Ministry of Health library literature search

To conduct the search, *Allen + Clarke* developed an initial list of search terms in consultation with the Ministry's library services personnel. After discussion and confirmation with the Ministry, these terms were provided to its library services to conduct the searches. It involved searching both peer reviewed journal article databases and grey literature websites.

The following peer reviewed journal article databases were searched:

- Cochrane Library;
- Embase (including the OVID suite of databases such as Medline);
- CINAHL;
- ProQuest;
- ScienceDirect; and
- Scopus.

Grey literature search included the following websites:

- The Hub (Superu);
- The Ministry of Health (New Zealand);
- New Zealand District Health Boards websites;
- The Department of Health (Australia) National Cervical Screening Program;
- Australian State and Territory health department cervical screening websites;
- Government of Canada Cervical Cancer;
- National Health Service Cervical Screening (United Kingdom);
- An Roinn Sláinte Department of Health Cervical Check (Ireland); and
- National Institute for Public Health and the Environment Cervical Cancer Screening Programme (Netherlands).

### Source and review of literature and documents

The total number of sources included in this evidence review was 44. Thirty were peer reviewed journal articles and 14 were grey literature documents. Table 1 below provides an outline of the process of sourcing literature.

The literature search was conducted by the Ministry's library services between the 12<sup>th</sup> and 14<sup>th</sup> of November 2018. The Ministry's librarian removed duplicates and false drops from the searches and provided *Allen + Clarke* with the resulting RIS (Research Information Systems) file, as well as a list of the abstracts and links to grey literature found online. Citations were managed with Zotero.

The grey literature search covered resources that were not included in academic published literature. These resources included reports, theses and open-source articles.

Inclusion criteria were:

- peer reviewed journals;
- publication date range 2008 – 2018 (more emphasis on 2014 – 2018), including those in the process of being published;
- relevance to research questions;
- methodological rigour;
- English language; and
- applicability to the New Zealand context.

For grey literature, priority was given to:

- sources of information produced by recognised and reputable organisations;
- English language publications; and
- relevance to research questions, including ensuring adequate coverage of research relating to Māori and Pacific women.

**Table 1: Literature sourcing process**

Search step	First sweep	Shortlist bibliography	Inclusions after full-text review	Validity check	Final inclusions
<b>Total number of documents included for review</b>	<b>59</b>	<b>40</b>	<b>35</b>	<b>9</b>	<b>44</b>
Ministry of Health reports, literature reviews and documents (provided by NSU)	7	7	7		7
Sourced by <i>Allen + Clarke</i>	3	3	1		1
Peer reviewed journal articles from the Ministry's library	43	26	24		24
Grey literature from the Ministry's library	6	4	3		3
Additional peer reviewed journal articles for inclusion				6	6
Additional grey literature for inclusion				3	3

### Validation

A validation exercise to check that all the key literature and documents had been captured was undertaken. The bibliographies from three literature or systematic reviews from the shortlisted documents (Women's Health Research Centre, 2016; Brusse, Gardner, McAullay, & Dowden, 2014; Cram, 2014;) were identified to validate the findings from the Ministry's library database search. To validate, bibliographies were checked, and additional potentially relevant literature was



highlighted. This list was checked with the NSU, which resulted in *Allen + Clarke* independently sourcing five peer reviewed journal articles.

We also completed an additional search for kaupapa Māori literature, which included one peer reviewed journal article (Cook, Clark, & Brunton, 2014) and one website source (Smear Your Mea, 2018). Additional literature on Pacific women's health was also identified as a gap, so a further request was made to the Ministry's librarian for retrieval of additional material, which resulted two grey literature sources (theses) on Pacific women's health (Churchward, 2015; Sasagi, 2011).

## APPENDIX 2: CERVICAL SCREENING FOCUS GROUP GUIDE

Each focus group followed the same format. The guide is set out below.

### CERVICAL GROUP FOCUS GROUP GUIDE

#### Introduction (15 minutes)

1.	Welcome (and formalities appropriate to each group e.g. in Pacific FG this will include a prayer) 5 mins	Welcome: <ul style="list-style-type: none"> <li>• Thank everyone for coming along</li> <li>• Depending on culture – invite karakia, prayer (or move on)</li> <li>• Include whakatauki (Māori focus groups)</li> </ul>
2.	Introduce self/IPRO	My name is .... I work for <i>Allen &amp; Clarke</i> . We have been contracted by the Ministry of Health to find out what types of information and ways of communicating with you would help you make an informed decision about having a cervical smear.  But before we talk about that, I'd like to share a bit about myself and I'd like to know more about you. So if you feel comfortable it would be really nice if you could tell me a bit about yourself, your name, where you're from, a bit about your whānau/family. I'll start off ...
3.	Research Purpose:	The overall purpose of this research to help the Ministry of Health work out the best approach(es) to encourage young women, such as yourselves, to have regular cervical screening.  Cover informed consent information sheet.
4.	Focus Group Purpose:	We want to understand your views about what prevents young women having a cervical smear test? Also, what would be the most effective ways to communicate with ___ young women about screening. We're also keen to know about the kind of messages and information you think young ___ women would want to receive when thinking about screening, and if a young women was unsure about having a smear test what would convince her to do so?
5.	Read through:	Information Sheet – make sure they understand what they're agreeing to participate in  Consent Form

6.	Housekeeping matters	Building emergency procedures
	Time:	2 hours

### Icebreaker (10 mins)

What do you know about cervical screening and what happens? (Facilitator may start, depending)

Follow up questions:

- If in programme – how did you find out? (Through their GP/Nurse? Did they receive an invitation? – it would be good to find out generally how many of the women have received an invitation)

### What challenges do young women face when deciding to engage with organised cervical screening? (20 minutes)

<p>Post it exercise (small group)</p> <p><i>We've heard that there can be a range of reasons why some young women find it difficult to have regular smear tests, like:</i></p> <p><b>Personal reasons</b></p> <ul style="list-style-type: none"> <li>• <i>feeling shy or fear</i></li> <li>• <i>negative experiences, such as pain or discomfort</i></li> <li>• <i>fear of the results</i></li> <li>• <i>not really understanding why it's important</i></li> <li>• <i>language – not knowing that you could have a translator, finding reading the material difficult</i></li> <li>• <i>it's not a topic that's ok to talk about (the link with being sexually active)</i></li> <li>• <i>cost, times the clinic is open, family/work commitments, transport</i></li> <li>• <i>Not having a good experience when you visit health services such as a doctor or nurse</i></li> <li>• <i>Lack of information</i></li> <li>• <i>Believing that having the HPV vaccination protects you so you don't need to have a smear test.</i></li> </ul> <p><i>Does this relate to you? What do you think are some of the biggest challenges for young women like yourself?</i></p> <p><i>Please put on post-its each idea you have.</i></p>	<p>Equipment required:</p> <p>Pens</p> <p>Post its</p> <p>Poster paper</p>
--	--

Ask participants to then organise them in order of biggest challenges first, smaller challenges last. Have a round table discussion about what they think are the biggest challenges overall.

Check with them – are there any surprises?

(Team collect poster paper)

**What ways of communicating would be most effective in getting information about cervical screening programmes to them? (20 mins)**

Resource review exercise (small group)

*Prompt: please look at the resource in front of you, in groups please jot down the following*

- *What's good about it (i.e. this resource)?*
- *What's not so good?*
- *What do you think would be the best ways to communicate this kind of information?*
- *Do you see yourself and others like you in it?*

*Each group to provide 1 min feedback*

*Further prompts:*

- *How much information do you want to hear?*
- *What are some of the do's and don'ts (e.g. We've heard that words such as 'screening' and 'abnormal cells' can be off putting? That some women prefer smear tests to be linked to health and wellbeing as opposed to being sexually active and preventing cancer). Is sexual activity still a taboo topic?*
- *What do you think would engage people? Turn them off?*

Equipment required:

Selection from Ministry of Health of posters, fliers (generic, also particular ethnic groups)

Sharpies

Poster paper

**Break (10 mins)**

**We would like to know more about how you like to get information? And how you like to access information to answer your questions? (20 mins)**

**Getting information (group discussion)**

**Prompt:** *We've heard that people like to get information in different ways. For example:*

- *Text messages*
- *Email*
- *Through social media – such as Facebook ('smear your mea' and other campaigns)*
- *Letter in the mail*
- *Big campaigns on TV*
- *A trusted health professional, such as a doctor or nurse*
- *From family and friends*

*How do you prefer to get information – any others other than those listed? What would be your top 3 choices? Which ones would you be most likely to respond to?*

**Prompt:** *How do you like to get your questions answered? For example:*

- *Websites – searching the internet (google or other search engines)*
- *Online chat*
- *Discussion forums*
- *Blogs*
- *A trusted health professional, such as a doctor or nurse*
- *From family and friends*
- *On the phone – i.e. the Ministry's 0800 number that could be used – would you use it?*

*What would you prefer? What's your top 3 choices? Which options would make the biggest difference?*

*You might have seen some young Māori women and other young women in the media, such as Stuff does that influence you? What affect does it have on the choices you make about having a smear test?*

*Is it important that the information is coming from someone like yourself? Do you need to know?*

**What would make the difference for them that would mean they would join such a programme? (20 mins)**

<p>Magic wand exercise (group discussion)</p> <p><i>Prompt: You have a magic wand – it can give you everything you need to have your smear test regularly. What would the magic wand give you? What would it give the other young women in your life?</i></p> <p><i>What could the Ministry do differently to get young women such as yourselves to choose to participate?</i></p> <ul style="list-style-type: none"><li>• <i>What will bring other young women in?</i></li><li>• <i>What would get them to stay?</i></li></ul> <p><i>WRAP UP: Can you tell me three things that you've learnt or will take away from this morning/afternoon/tonight?</i></p> <p><i>Would it make a difference if you knew other young women developed the messages/communication tools? If so, why?</i></p> <p><i>Would it make a difference if you knew they were from the same background as you? (e.g. ethnic background)</i></p>	
---	--

**Thank you, farewell, provision of koha (in a culturally appropriate manner) (5 minutes)**