Auckland Women's Health Council

Submission of the Auckland Women's Health Council on the consultation on the HPV Pathway

Q4 What is your feedback on the proposed revised HPV primary screening clinical pathway?

4.1 Recommendation: Cervical screening should be free for all women in NZ as recommended in the Report of the Parliamentary Review Committee 2019. This includes follow up cytology (smear taking) that occurs following a positive HPV result. General Practices must not be allowed to introduce doctor or nurse consultation fees on top of the HPV testing whether it is done by a clinician or as a self-test in a clinical or home setting. Nor should nurse or doctor consultation time be charged for follow taking of cervical smears for LBC.

Rationale: The recommendation of the Report of the Parliamentary Review Committee 2019: "the cost of screening has been consistently identified as a major barrier, and all eligible women should receive fully funded cervical screening, to align cervical screening with all other New Zealand cancer screening programmes. Initially, priority for fully funded screening should be given to priority group women with a strategic objective of including all eligible women"

Now is the time to create that strategic objective. From the Report:

> Key informants consistently referred to the barrier created by charges for a cervical smear test. '... if someone goes into the GP and asks for a smear, often the GP or the [nurse] practitioner will charge them a fee for ... that [actual] consultation. So regardless of whether the smear is free, they're still getting charged that consultation fee.'
>
> Pre-existing debt at the general practice was also referred to. 'So, if I have some debt at the GP that I can't afford to pay because I can't afford to put food on my table, then I'm not going to turn up to the GP to get a smear done because I know that they're going to hit me with the bill. So, for me, the no-brainer is make cervical free, and then your barriers would decrease overnight.'

It is an anomaly that breast and bowel screening are already universally free but women have the extra barrier of cost for cervical screening.

The AWHC previously recommended the NSU look at how it could manage routine invitation and recall and mailout of results to women as well as their primary care provider. In this new pathway, follow up could be done by nurses within primary care, in collaboration with an enhanced outreach service where extra support including help with transport to services, could be offered.

4.2 Recommendation: The HPV primary screening pathway should include home-based self-sampling as well as the option for self-sampling in a clinical setting as the most effective way of increasing participation, particularly for women most at risk of cervical cancer. Evidence shows greatest improvement in participation rates where women are offered self-testing at home. See Q5.

4.3 Recommendation: Significant Nurse Colposcopy training must be planned and implemented.

There will be a large increase on demand for repeat cytology and colposcopy. Investment in nurse-led services is necessary to ensure acceptability and accessibility for all those women who will be offered ongoing and repeat cytology tests. Smear-taking nurses can be trained and are the natural resource for investment to ensure an increased workforce with colposcopy skills.

4.4 Recommendation: Women, particularly young women, who are positive for HPV 16/18 following self-testing, need to be informed of the risks as well as the benefits of going direct to colposcopy and able to choose what is best for them.

Options could be:

a) referral directly to colposcopy if they are high risk or worried, or

b) a smear taken by a smear taking nurse or doctor for LBC as a preliminary step. Cytology results will follow the usual cautious pathway back to normal screening or referral to colposcopy.

Q5 What is your feedback on self-testing vs clinician-taken HPV tests?

5.1 Recommendation: Self-testing **in the home** should be offered to women routinely. This question assumes a clinical setting for the HPV test. Evidence supports the option of home-testing as the most effective way to increase participation in cervical screening.

Self-testing is now recognised as being just as effective as clinician-taken HPV tests – It should be available at a time and place that is most comfortable and convenient to the woman. Where barriers to access include arrangements for childcare, travel costs, time off work, and accessibility for disabled, this is likely to be her home.

Findings published in the Lancet in 2019 show "HPV testing done with a clinically validated PCR-based assay had similar accuracy on self-collected and clinician-collected samples in terms of the detection of CIN2+ or CIN3+ lesions. These findings suggest that HPV self-sampling could be used as a primary screening method in routine screening." Reference https://pubmed.ncbi.nlm.nih.gov/30658933/

Self-testing in the clinic or at home should be offered by the woman's usual smear taker, and through the NSU by mailout of self-testing kits where, for example, women are 15 months overdue and have not responded to usual follow up communications. This could generate wasted resources and be costly but should be tested as a pilot study to determine and discuss the associated benefits of increased participation and equity of access with associated improved outcomes.

The first Guiding Principle in your Public Consultation Document is to **"deliver a best-practice national cervical screening programme by international comparison".** We submit that International and research in New Zealand provides an argument for HPV self-sampling kits offered routinely as part of the usual reminder

process and by direct mailout to women who are overdue for screening and not responding to reminders. Two studies provide useful indications of the effectiveness of this approach.

- From Denmark: "Preventing cervical cancer using HPV self-sampling: direct mailing of test-kits increases screening participation more than timely opt-in procedures - a randomized controlled trial." https://bmccancer.biomedcentral.com/articles/10.1186/s12885-018-4165-4
    - 38% participation for mailed out kits.
    - 30.9% participation for a reminder with an offer of a self-sampling kit to be ordered by email, text
    - 25% participation for the usual reminder approach

- From NZ and using mail-outs on request: "Acceptability of human papillomavirus (HPV) self-sampling among never- and under-screened Indigenous and other minority women: a randomised three-arm community trial in Aotearoa New Zealand"
    - Māori women randomised to the home-based self-sampling group were almost ten times more likely to participate than usual-care women
    - Pacific women were six times more likely
    - Asian women around five times more likely

    This study is the first in Aotearoa New Zealand that specifically tested a mail-out approach for self-sampling for cervical-cancer screening and an intensive nurse-support model to achieve high rates of follow-up. An invitation to take a self-sample at a clinic was less effective, suggesting that at least some of the barriers to clinic attendance are the same whether for self-sampling or a healthcare-professional-taken sample. Known opportunity costs and barriers to clinic attendance for cervical screening may explain why a higher proportion of home-based women participated. They may also explain why the home-based group participated earlier than the clinic-based and usual-care groups.

5.3 Recommendation: Outreach services need to be extended to cope with increased demand for support.

Rationale: Follow up is vital for women choosing to test at home and whose test is HPV positive. These may be women who experience greater barriers to access and will require extended outreach services to provide adequate support to attend clinics for cytology. General Practices are also likely to refer more women to for outreach support where there is an increased burden on their nursing staff.

The new pathway needs to be amended to reduce barriers to clinic attendance through inclusion of home self-testing, and expanded Outreach Cervical Screening Services. Their role is vital in providing information directly to women where they are not likely to be engaged with their primary care service.

Where self-sampling has been done at home, and a positive HPV test indicates the need for cytology follow up, it is important that the woman's primary health provider, or the outreach service follows up to ensure the next step in the pathway is communicated and the woman is supported to attend the clinic for cytology.

From the Acceptability Study referenced above: "Most HPV-positive women (18/24; 75%) needed a short interval of phone support to achieve clinically appropriate follow-up; however, 5/24 women (20%) needed additional support (e.g., a home visit for a follow-up cytology test) and 4% (1/24) of women needed very intensive support (e.g., multiple phone-calls and visits to discuss options plus transport and support to attend colposcopy)." and "The mean nurse time required to achieve follow-up was 2.5 hours."

Q6 Do you foresee any problems with self-testing in a clinical setting, as part of the transition of the programme? What do you perceive as benefits?

There is a problem because self-testing in a clinical setting is described in the consultation document as the only option for women. The HPV primary screening pathway should include home-based self-sampling as well as the option for self-sampling in a clinical setting as the most effective way of increasing participation, particularly for women most at risk of cervical cancer. Evidence shows greatest improvement in participation rates where women are offered self-testing at home. See Q5.

Again, from the Acceptability Study:

"An invitation to take a self-sample at a clinic was less effective, suggesting that at least some of the barriers to clinic attendance are the same whether for self-sampling or a healthcare-professional-taken sample. Known opportunity costs and barriers to clinic attendance for cervical screening may explain why a higher proportion of home-based women participated. They may also explain why the home-based group participated earlier than the clinic-based and usual-care groups."

Benefits for women who choose self-testing in a home or clinical setting will be timeliness, privacy and comfort. Women who have been sexually abused may find this particularly helpful.

Q7 Do you foresee any likely impact on access and equity?

The most important strategies for eliminating inequalities in screening are to publicly fund cervical screening and thus bring it into line with other screening programmes in New Zealand, and to extend the pathway to include home-based self-testing.

If the government is serious about improving equity and access to cervical screening for women who are at high risk, then it will ensure that all women are offered a free screening service including self-testing at home as well as in a clinical setting.

Other inequities in cervical screening:

Women with physical and sensory impairments have to overcome a number of obstacles to screening. These include:

- Access to disabled parking close to those doctors who have their practices in shopping or shared parking areas
- Getting into those clinics which don't have ramps for wheelchairs
- Some clinics don't have accessible toilets, or beds that go up and down.

7.1 Recommendation: The pathway should include mail-out kits for home self-testing (see recommendations made in Q4)

7.2 Recommendation: Women who need cervical screening most tend to need the more support to access the services. The workforce development investment should include colposcopy training for smear-taking nurses in order to deliver the necessary timely, effective and accessible colposcopy service.

7.3 Recommendation: Opportunistic screening should be extended. Women who attend a GP appointment for another reason and are at least six months overdue should also be offered a free self-testing kit for use either in the clinic or at home.