Working together to give women choice: community-based HPV self-sampling for Aboriginal women

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Rationale

Cervical cancer is largely a preventable cancer, *if* women regularly participate in screening programs.[1] There is currently little information on how many Aboriginal and Torres Strait Islander women participate in cervical screening as recording of Aboriginal and Torres Strait Islander status on pathology forms (and thus cervical screening samples) has not been consistent across States and Territories of Australia, and thus it has not previously been possible to quantify national cervical screening rates. It has been estimated though, that the screening rate of Aboriginal and Torres Strait Islander women is more than 20% lower than that of women who do not identify as Aboriginal and Torres Strait Islander.[2] Given that cervical cancer is more likely to occur in never-screened and under-screened women[3-5], of which many Aboriginal and Torres Strait Islander women are, it is crucial to increase the participation of Aboriginal and Torres Strait Islander women in cervical screening programs.

Attempts to increase participation in cervical cancer screening under the Pap test amongst never-screened and under-screened women met with varying levels of success.[6-8] It has been suggested that alternative models of care, incorporating a social innovation aspect, are needed to more effectively engage with those women who are not currently engaged with a health system/service.[9]

The renewed National Cervical Screening Program (NCSP) implemented in December 2017 provides an opportunity to explore modes of increasing the participation of never-screened and under-screened women, including Aboriginal and Torres Strait Islander women who fall into this category. In place of the former Pap test, the renewed NCSP incorporates clinician-led HPV testing with clinician-supervised, patient self-sampling for HPV testing in specific circumstances. This new method of testing has the potential to improve screening rates, however the current NCSP pathway relies on existing patient engagement with a clinician and/or health service. Innovative models of care are needed to engage with hard to reach women in communities where there are a significant proportion of never screened and under-screened women.

Aim

The aims of this study were: to assess the effectiveness of a community-based HPV self-sampling program for Aboriginal women in rural and remote NSW; develop a best-practice service model; and provided recommendations on how to best access this under-screened and hard-to-reach population to increase cervical screening rates.

Methods

Marathon Health (a regional, rural and remote Primary Health Care Organisation) implemented the pilot program, working with numerous stakeholders to co-design the program and ensure those 'best-placed' to provide clinical advice and deliver components of the program were involved. The pilot program was trialled in eight communities in Western NSW. Core components of the model included:

- Partnership between Marathon Health (particularly the Primary Health Care Nurses (PHCNs)) and the Local Aboriginal Lands Councils (LALCs) in each community, with the LALC being the contact point in each community (in many cases they are the only representative body for Aboriginal people in communities).

- Identifying a female, Aboriginal Community Engagement Worker (CEW) in each community to deliver the Program. All CEWs were required to complete a Cert III Community Services Unit to enhance their knowledge and skill set, and to also ensure they had a thorough understanding of the program and research involved.

- A PHCN allocated to each community, with regular and ongoing communication and coordination between the CEW and designated PHCN.

With the assistance of an Aboriginal Community Engagement Worker (CEW), women completed an eligibility survey, the self-sample kit (pathology by the Victorian Cytology Service) and a follow-up evaluation survey. Primary Health Care Nurses engaged with women around their results and appropriate follow-up care. Focus groups were held with Marathon Health staff and separately with CEWs to explore the barriers and enablers to the pilot program and identify the key components of a best-practice service model.

Results/discussion

The program effectively recruited 215 women, of which 79.5% were classed as under screened (>than 4 years since previous PAP), never screened, or they were unsure of last screen (suggesting it had been some time). Of the remaining women 15.8% had been screened between 2 and 4 years ago (overdue for screening) and there was missing data for the remaining 4.7%.The positive return rates for HPV were 4% (9) for HPV 16/18 and 14% (30) for HPV other; 56% of women who tested positive attended their follow-up appointment and a further 18% had booked appointments by the end of the pilot.

The pilot program was highly feasible and showed a high level of acceptability amongst Aboriginal women, highlighted by the following individual case studies:

Case study 1 'It was easier than the old way, I'm happy with everything'—A 55-year old Aboriginal woman who was unsure of when she last had a cervical screen. She tested positive for high risk HPV, type 16. Her GP proactively worked with the CEW and PHCN to ensure pathways of care were

complete. Three appointments were booked with her GP before she ultimately attended and she only attended because the PHCN and CEW accompanied her. She was referred for colposcopy with community transport arranged by the PHCN/CEW. The colposcopy led to vaginal USS and day surgery for cervical biopsy and assessment. The CEW and PHCN visited the woman several times and spent time providing reassurance, supporting her with navigating the treatment pathways and medical terminology. This case study suggests that under-screened women will still follow necessary pathways of care after self-sampling and receiving a positive result, if ongoing support is provided.

Case study 2 'Women put that stuff off. If they can do it in their own home; they are more likely to do it.'—A 41-year old Aboriginal woman who was very pleased to have the option to take the test in her own home. She tested positive for HPV 'other' type, that is, not HPV 16 or 18. She visited her GP (female, locum GP) for a cervical screen. As she hadn't seen a GP for a long time, she also had a breast check and advice, overdue pathology and other general health checks. She was very satisfied and suggested women have the right to make choices about where they take the test. This case study suggests women are still able to engage and seek support from their own GP, maybe even more so than they would have had they not completed the self-screen (a common concern of GPs/clinicians and primary health services).

Case study 3 'Would never have done a PAP, would not have gone to doctors. Happy I did the kit. Easy, private'—A 35-year old Aboriginal woman who had never had a cervical screen. She tested positive for HPV 16 type. She was supported to her colposcopy by the PHCN for her first appointment but the gynaecologist was running very late and the woman could not wait, despite having travelled more than two hours to see her. Two further attempts at appointments were unsuccessful due to menstrual bleeding/other issues. Although she had still not had her colposcopy 8 months after the positive result, she had become regularly engaged with her GP despite previously being a rare attendee. She is currently also engaged with a counsellor and the visiting Women's Health Nurse to support her with her long standing anxiety. This it seems had greatly affected her reluctance in receiving further treatment/colposcopy or any other health care advice in the past.

These case studies highlight the importance of the PHCN and CEW working together with the client, their GP and other health professionals to help to ensure necessary pathways of care are complete. This collaborative approach increases the women's confidence with accessing services that they may otherwise have been hesitant to access on their own and increases their overall health literacy.

As highlighted by Marathon Health staff and the CEWs in focus group discussions, key elements to the success of the model include: clarity of roles and responsibilities of individuals/organisations involved, flexibility within the service model to be responsive to community need; community support, endorsed by the LALC; professional, personalised care by the PHCNs and CEWs, and the consistency they provided from kit distribution to supporting pathways of care. Current eligibility criteria for self-sampling are quite prescriptive and a previously never- or under-screened woman needs to have lapsed back into the under-screened category in order to become eligible again. It was thus a key recommendation of the both focus groups that once a woman becomes eligible for self-sampling she should always remain eligible if she declines practitioner-led cervical screening. Future research and evaluation is needed to explore translation of the best practice service model developed in this study into other regional, rural and remote locations.

This pilot provided an opportunity to work 'better together', to walk on Aboriginal land, alongside Aboriginal women, achieve research 'with them' rather than 'on them', while supporting empowerment and women-centred decision making in Aboriginal 'Women's Business'.

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Presenter

Jo Marjoram is a registered midwife, registered nurse and women's health nurse who lives and works in regional NSW, residing on the outskirts of Orange. Having worked in the primary health care setting during the more recent years of her career, she strives to achieve improved health outcomes in regional and rural areas of NSW. Using holistic, coordinated care provision and her passion for improving Aboriginal health and wellbeing, Jo seeks to support communities and organisations in changes in the health pathways that improve health for existing and future generations of Australians. Jo recently completed her role as research lead for a pilot study of HPV self-sampling of Aboriginal women from rural western NSW communities, working in collaboration with Western Sydney University and VCS pathology. This project has been presented at the WHRN research conference in Orange (awarded 'Best conference speaker'), the 6th Rural and Remote Scientific Symposium in Canberra and the 14th National Rural Health Conference in 2017. Jo feels privileged to present the final findings of the project at the 15th National Health Conference in Hobart in 2019, and is excited to share the results of such a valuable project with health professionals and researchers.