IMPROVING BOWEL CANCER OUTCOMES FOR MULTICULTURAL WOMEN

IN PARTNERSHIP WITH THE CANCER INSTITUTE OF NSW

PROJECT OVERVIEW

Women's Health NSW (WHNSW) was funded by the Cancer Institute of NSW (CINSW) and partnered with six of our Women's Health Centres (WHCs) across NSW to participate in this project. The WHCs were selected in consultation with CINSW based on their rich multicultural population, both well established and more recent arrivals.

The Project team consisted of workers from Women's Health NSW and the six Women's Health Centers. We worked in partnership with local multicultural leaders, groups and organisations.

Our project aimed to walk alongside migrant women as we had discussions about bowel cancer and colonoscopies helping to destigmatise and normalise a challenging topic. We identified barriers, trialed possible solutions and established referral pathways with local healthcare providers, GPs, pharmacies and community organisations to assist multicultural women to independently access bowel cancer screening.

Aim: To improve bowel cancer outcomes for multicultural women

Objectives:

- To work in partnership with six Women's Health Centres in NSW that include both metropolitan and rural locations across the following Local Health Districts: Western NSW (Bathurst) Illawarra-Shoalhaven (Nowra), Southwestern Sydney (Liverpool and Fairfield), Western Sydney (Blacktown and Penrith) and Murrumbidgee (Albury)
- To explore, analyse and report on the current challenges faced by women and their families from multicultural communities in accessing colonoscopy services and completing diagnostic tests in the catchment area identified above.
- Identify recommendations and, where possible, implement strategies to address these challenges to promote timely diagnoses and treatment to improve health outcomes.

We were mindful of cultural differences and sensitivities whilst creating awareness of Bowel Cancer (and other cancers). It was therefore essential that we worked with community leaders and organisations. Our goal was to empower women with the knowledge and resources to enable them to independently access culturally sensitive, trauma informed, preventative health services, Health Checks and screening in their local area. This involved increasing awareness of the benefits of screening, increase knowledge about the importance of screening and reduce the associated anxiety. Additionally, Women's Health NSW had a secondary aim for the sector which was to increase the capacity of WHC's to engage with multicultural communities and deliver targeted programs to meet the needs of women who may or may not be accessing their services.

The project had three phases. The first was project establishment including preliminary scoping of the issue, identifying the populations we would work with, understanding their lived experience of bowel cancer screening and building the capacity of the WHC's to deliver the project.
WHNSW worked with the six Women's Health Centres to:

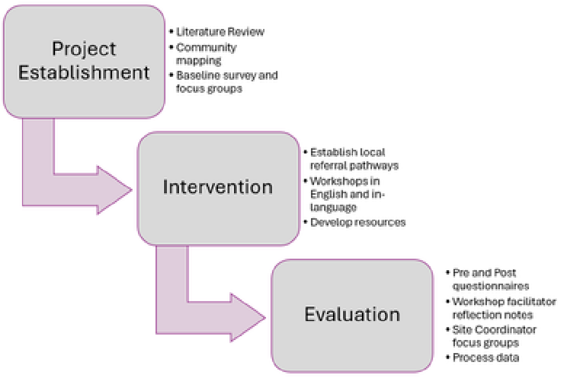
- Identify local multicultural community groups and any language and interpreter needs, to facilitate health and focus groups;
- Work to reach particularly underserved areas with limited access to healthcare services.
- Increase knowledge of staff at the Women's Health Centres to understand the journey from screening to colonoscopy in their local area;

- Source or develop resources for staff training, community engagement and materials in language, health and focus groups, health professional information, and evaluation materials;
- Increase intercommunication and collaboration with local community leaders, religious institutions and cultural organisations to enhance knowledge on bowel screening and follow up pathways resulting from a positive bowel cancer screening test to access and complete colonoscopy;
- Increase intercommunication and collaboration with local health professionals involved, including local Pharmacists, GPs and Nurses, to support the needs of multicultural women effectively and, support pathways from positive bowel screening test to understanding colonoscopy;
- Analyse barriers and challenges to accessing colonoscopy and develop recommendations;
- Identify appropriate strategies that can mitigate barriers to access service delivery in their local areas and create sustainable systems for ongoing feedback.

The second phase was the intervention which involved each WHC adopting their own approaches responding to the local community needs and preferences and involved the following:

- Establishing working relationships and collaborations with multicultural women, leaders and organisations
- The development of local referral pathways to facilitate access to bowel cancer screening including GPs and pharmacies and follow up in the event of positive results requiring further investigation including colonoscopies and care.
- Each WHC was set the goal of delivering one workshop in English and two in-language workshops minimum. At least one delivered to a new community group where there had not been engagement. Workshops drew on the Cancer Institute of NSW's educational flip chart resources.
- The development of resources identified as being beneficial e.g. doctor’s referral letter template and "questions to ask" checklist. Out of scope was translation of resources, however we identified the need and provided details to CINSW to consider.
- Optional follow up support of workshop participants by WHC case workers

The third phase was the evaluation which was conducted over the life of the project.



METHODOLOGY

We adopted a mixed methodology involving a literature review, baseline focus groups and surveys, pre and post questionnaires and process evaluation. The tabletop scan of literature on colorectal and bowel cancer screening and education programs with migrant groups published within the past 15 years in Australia, the UK and USA was conducted. This was in addition to reviewing the Cancer Institute of NSW website and resources to learn what was currently being done to support multicultural communities.

In the establishment phase we engaged with a range of cultural groups and languages across all sites leveraging off existing WHC groups and clients to establish baseline knowledge, skills and confidence. We analysed 80 surveys and insights from eight informal pilot focus groups were conducted. 37 participants facilitated in three English focus groups and five in-language focus groups; Indian (2), Bangladeshi (1), Rohingya (1), Farsi (1) and Indonesian (1).

Recognising the importance of tailored localised approaches, the six WHC's reviewed ABS and local government information, and liaised with multicultural organisations to identify the cultural, faith and language diversity across the region. They gathered information on where women meet, connected with their cultural and religious leaders, socialised and access health information. In addition, our WHC's identified underserviced communities where engagement was needed, and so, reached out to local Religious and Community leaders and Migrant Resource Centres to tap into identified populations. They also mapped local health services and referral pathways for bowel screening and colonoscopies that assist multicultural women including hospitals, pharmacies, GPs and community health centers.

At the conclusion of the project, we conducted a focus group with the six Site Coordinators, following up individually where more detail was wanted. The focus group covered discussion on the motivation for participating in the project, learnings, their experience of the process and future recommendations for the Cancer Institute of NSW and the Women's Health sector.

OUTCOMES

Over the implementation phase of the project, we engaged an additional 213 women representing 33 language groups across Albury (Murrumbidgee LHD), Blacktown (Western Sydney LHD), Central West (Western NSW LHD), Liverpool/Fairfield (South-Western Sydney LHD), Penrith (Western Sydney LHD) and Shoalhaven (Illawarra LHD). A total of 18 workshops were delivered, 8 in English and 10 in language. The program produced positive changes in general health literacy, knowledge, skills and confidence in women to complete bowel cancer screening and colonoscopy.

- We saw a significant increase in women self-reporting that they strongly agreed that they knew the health screening they should do for their age moving from 66 to 95 and a decrease in neutral from 40 to 4 (n=127).
- In relation to bowel cancer, we saw a significant increase in women self-reporting they know what a bowel screen test is increasing strongly agree responses from 54 to 114 and a decrease of neutral from 37 to 3, disagree from 14 to one and strongly disagree from 18 to none (pre n=162 and post n=148). Women also reported increased knowledge of colonoscopy with strongly agree increasing from 59 to 100 and agree from 27 to 45, and decreases in neutral from 36 to 11, disagree from 11 to 2 and strongly disagree from 14 to none (pre n=147 post n=148)
- Participants reported increased confidence to do health screens from 77 to 100 strongly agreeing and neutral decreasing from 60 to 3 (pre n= 183 and post n=132). Regarding confidence in doing a bowel cancer screen at the end of the workshop 103 of 133 respondents (77.5%) reported they strongly agreed with a further 26 (19.5%) agreeing (n=147).'

Women's Health NSW was pleased that the project achieved the secondary aim of increasing the Women's Health sector's capacity to work with multicultural women and deliver preventative health promotion activities. The six participating sites have seen an increase in multicultural women accessing their services during and following the project. The WHC's also report a strong desire to continue this work and increased confidence in delivering programs and facilitating workshops with multicultural women including in-language.

LEARNINGS

Over two years we gained an increased understanding of the needs and barriers faced by multicultural women in NSW resulting in lower participation rates. Research into the lived experiences and needs of multicultural groups in accessing colorectal cancer and bowel screening in Australia, the UK and US have shown differences in knowledge and perception of health behaviours. Studies show lower awareness of bowel cancer prevalence, risks, screening and benefits of colonoscopy within multicultural communities. In Australia those who speak a language other than English at home have around 15-20% lower participation rates in bowel cancer screening compared to those whose main language is English (24.8-34.4% versus 45.4%-49.2%). [1] It is also found that people who speak another language at home are also less likely to have diagnostic follow up after a positive at home testing kit.

We learnt in both the needs analysis and intervention workshops low numbers of multicultural women had received the bowel screening kit in the mail. In the needs analysis this was 22% and the workshop 43% of participants. A high proportion of women disclosed throwing the kit away or putting it in a drawer. The reasons were multifaceted. Many who received the kit in the mail did not know what it was or what to do with it. This was more common amongst women with lower literacy and use of English, with women reporting reliance on family members for translation and assistance navigating health services. For those who did receive and open the kit a significant number reported they believed it was not necessary as they did not have active symptoms.

Additionally, there was low confidence and anxiety about completing the screening. Of highest concern was the possibility of learning of a result that required further investigation, potentially requiring treatment for bowel cancer. We heard women say that if they knew the result then they would have to do something about it and that was daunting. Some women equated a bowel cancer diagnosis with death and reported knowing they had it would not change the outcome. The other reason given for anxiety completing the test was concern they would not do the test correctly either through not understanding the instructions or general overwhelm and low confidence. Most alarmingly in one workshop with African women we heard they did not believe women were at risk of bowel cancer. When explored why this was it was because education campaigns they had seen mostly depicted men. Our involvement in this project reinforced the importance of working in a trauma informed and culturally safe way. This was achieved by working closely in partnership with multicultural leaders, groups and organisations to tailor workshop content, messages and approaches to the needs of each community.

We experienced a strong desire from multicultural organisations to be supported to do this work with the workshops highlighting low health literacy and engagement with preventative health screenings particularly amongst recently arrived women and asylum seekers.

We cannot underestimate the cultural underpinnings of beliefs and misconceptions related to bowel cancer. We heard in workshops discussions that people from subcontinent India for example felt they were not at risk due to their healthy diet. Some cultural groups were more reticent to discuss bodily functions and private matters as seen in a Turkish group who expressed traditional cultural views. The African group explained the taboo around anything to do with anus and rectum with perceived homosexuality and therefore stigma. Women of Muslim faith were hesitant to access health screening that would require undressing or discussing private matters with male healthcare professionals.

While for Vietnamese women who were more established in Australia, they did not express concerns and indeed demonstrated high health literacy and uptake of bowel screening and colonoscopy. It is therefore important that each cultural and language group is offered support and resources tailored to their lived experience and needs.

We need to consider these barriers in the context of a health system that does not reflect the multilingual and multi-ethnic society of Australia. We heard from women of their wariness of western health care and poor experiences. Health institutions are yet to take the steps to move beyond the culturally dominant model of care which is catered to white English-speaking people. This model causes marginalisation of ethnic and cultural minority populations and reinforces assumptions and practices that leads to health inequities. [2] The likelihood of doing bowel cancer screening however increased if recommended by a trusted health professional. The cost of screening kits, colonoscopy preparation kits, travel, missing work and whether someone had Medicare was consistently raised as a barrier. With fewer bulk billing GPs, particularly in regional areas, women reported only go to the doctor when sick and so are falling between the gaps.

We therefore believe the way forward to increasing preventative health screening amongst multicultural women, including but not limited to bowel cancer, is through fostering conversations in places women feel safe and comfortable. The partnering of Women's Health Centres and multicultural organisations maximised the skills and expertise of both providing a culturally safe and credible source of health information. While the project was two years, we learnt that more time is needed for community organisations to build relationships. We found that an additional six months should be factored in to allow enough time to deliver the interventions and for follow up, otherwise the project is rushed and won't achieve desired the outcomes. Through this project we enlisted, to great benefit, bi-lingual workers, interpreters, demonstrations and visuals and the sharing of lived experience. This is an important consideration in planning and resource allocation.

RECOMMENDATIONS

We identified several recommendations for the future, the key ones being:

- Expand the in-language online and print resources to be more accessible to new and emerging multicultural groups. Feedback from our program is that the 'Do the Test' website should be available in the following additional languages: Turkish, Thai, Farsi/Dari, Punjabi, Hindi, Nepalese, Filipino/Tagalong and Swahili.
- Facilitate in-language online registration for the National Bowel Screening Program kit.
- Include in-language messaging on the bowel cancer screening kit envelope and instructions in the screening kits or information on where to access.
- Increase the diversity and prominence of multicultural stories and messages in mainstream media campaigns and channels where migrant communities consume e.g. SBS and community radio.
- Women's Health Centres continue to foster relationships with multicultural leaders, groups and organisations including proactively looking for opportunities to partner.
- Pursue longer term investment in health promotion for multicultural women providing in-language education particularly for cancers that affect women e.g. cervical and breast.
- More capacity building work done by the Cancer Institute with pharmacists and GPs to support screening access.

ACKNOWLEDGEMENTS

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We thank our Women's Health Sector partners:

- Blacktown Women's and Girls Health Centre
- Central West Women's Health Centre
- Liverpool and Fairfield Women's Health Centres
- Penrith Women's Health Centre
- Shoalhaven Women's Health Centre
- Women's Centre for Health and Wellbeing Albury-Wodonga

We thank community Leaders, groups and organisations who partnered and provided expertise.

We wish to express our gratitude to the multicultural women across NSW who participated and shared their lived experience.

Citations:

1. Scanlon, B., Brough, M., Wyld, D., & Durham, J. (2021). Equity across the cancer care continuum for culturally and linguistically diverse migrants living in Australia: a scoping review. Globalization and Health, 17(1), 87.
2. Lee, S. M., Versace, V. L., & Obamiro, K. (2022). Public awareness of Bowel Cancer Risk factors, symptoms and screening in Tasmania, Australia: a cross-sectional study. International Journal of Environmental Research and Public Health, 19(3), 1497.