



The Refugee Cancer Screening Partnership Project

A summary of findings

This Project was proudly funded by the NSW Government through the Refugee Health Flexible Fund 2021-22 to 2022-23.

Project Funding

This project is proudly funded by the NSW Ministry of Health, which has provided a grant to Cancer Institute NSW under the Refugee Health Flexible Fund 2021-22 to 2022-23. Key strategic partners included NSW Refugee Health Service and Settlement Council of Australia. Four agencies from the refugee sector implemented the project at a local level: Metro Assist, NSW Service for the Treatment and Rehabilitation of Torture and Trauma Survivors, Mosaic Multicultural Connections, and Illawarra Multicultural Services.

Acknowledgements

The team would like to acknowledge refugee and migrant communities, community leaders, and settlement service providers who generously participated in this study. We would also like to acknowledge bilingual health workers who assisted with running the interactive community forums and nominal group discussions. Our special thanks to steering committee members, working group members and the evaluation team members.

Research Lead

Lead Researcher Distinguished Professor Andre M.N. Renzaho

Project Team

Sheetal Challam and Nina Hartcher

Suggested citation:

Renzaho, AMN, Hartcher, N, Challam, S (2023). The Refugee Cancer Screening Partnership Project: A summary of findings. Sydney: Cancer Institute NSW

© Cancer Institute NSW 2023

This work's copyright remains with the Cancer Institute NSW. Its reproduction in whole or in part for study training purposes is allowed subject to the inclusions of an acknowledgement of the source. Reproduction of the work for purposes other than training purposes requires written permission from the copyright owners. The use of this work for commercialisation purposes (commercial usage or sale) is not permitted.

Disclaimer

Views expressed in the report represent the views expressed by consulted communities. Therefore, the expressed views are exclusively those of the authors who undertook data analyses. They do not necessarily reflect the official views of the organisations they are affiliated with, nor those of partner organisations.

Table of Contents

EXECUTIVE SUMMARY	1
Overview	1
Key findings	2
Demographic profile	2
Cancer awareness and behaviours.....	3
Cancer screening enablers among cancer screening adopters	4
Barriers to cancer screening among non-adopters	4
Ranked and prioritised interventions.....	5
Interventions recommended by participants.....	5
Recommendation 1: Increase cancer screening literacy and behaviour change	5
Recommendation 2. Policy and Practice changes	6
Recommendation 3: Strengthen community action.....	6
Recommendation 4: Monitoring, Evaluation, Accountability & Learning	7
Quotes.....	7
Breast cancer screening.....	7
Bowel cancer screening.....	7
Cervical Screening	8
References.....	9

EXECUTIVE SUMMARY

Overview

The New South Wales (NSW) Cancer Plan 2022-2027 acknowledges the disproportionate burden of cancer on specific communities and seeks to address inequities and variations in access to care and outcomes they experience. Culturally and linguistically diverse (CALD) communities have been identified as the key focus populations in the Plan. Priority 2 of the NSW Cancer Implementation Plan has a particular focus on prioritising early detection efforts in communities with the greatest need and the highest potential for improved outcomes. Cancer Institute NSW (the Institute) sought to facilitate the achievements of Priority 2 of the NSW Cancer Implementation Plan through the Refugee Cancer Screening Partnership Project, which has been led by the Institute in partnership with Settlement Council of Australia (SCoA), and NSW Refugee Health Service (NSW RHS). The project is funded by the NSW Ministry of Health, which has provided a grant to the Institute under the Refugee Flexible Funding Pool. Four agencies from the refugee sector were recruited to implement the research project at a local level. The agencies were Metro Assist, NSW Service for the Treatment and Rehabilitation of Torture and Trauma Survivors (STARTTS), Mosaic Multicultural Connections, and Illawarra Multicultural Services.

Refugees and migrants of African and Middle Eastern backgrounds have been found to screen for breast, prostate, colorectal, and cervical cancers less frequently than the host populations, and at lower rates than recommendations and guidelines^{i,ii}. People from a refugee background may have additional disabling factors such as forced displacement and exposure to violence and human rights abusesⁱⁱⁱ. One study showed that African women of refugee background had lower knowledge of screening than their migrant counterparts despite being settled in Australia for longer^{iv}. Increasing cancer screening uptake in African and Middle Eastern migrants and refugees necessitates an understanding of some of the barriers and the implementation of culturally appropriate co-designed community cancer initiatives to address identified barriers.

The aim of the project has been to explore cancer screening behaviours in Sub-Saharan and Middle Eastern refugee communities and identify culturally appropriate interventions to improve participation of target communities in national screening programs. The project's objectives were two-fold: 1) to explore Sub-Saharan African and Middle Eastern refugee and migrant communities' awareness of, participation in, and barriers to three population-based cancer screening programs—breast, bowel, and cervical screening, and 2) to co-design community-based interventions that would address identified disabling factors and maximise participation in and the uptake of three national cancer screening programs. The research used a participatory concurrent mixed-methods research design involving 17 community-led interactive community forums (ICFs) and 10 participant-driven nominal group techniques (NGTs) among people from Sub-Saharan and Middle Eastern refugee and migrant communities across NSW (Total N=161). Two consultations were not included in the analysis due to invalid data as the nominal group ranking was not ideal for those particular group settings and therefore further analysis could not be undertaken. As a result, analysis of 15 ICFs (N=130) and 10 NGTs (N=90) were included in the findings.

The project's implementation was overseen by a steering committee comprising project management team members, diverse representatives from partner organisations including settlement and health sectors, primary care sector, national screening programs, subject matter experts, a research expert, and other key community stakeholders. The steering committee met once every three months to provide high-level guidance and support for the project.

Key findings

Fifteen forums about breast (N=5), bowel (N=7), and cervical (N=4) screening were conducted with 130 participants. Consultations were conducted in English, Arabic, Swahili, Kinyarwanda, Kurdish Kurmanji, Amharic and Tigrinya. Consultations were held in Sydney, Newcastle, Wollongong, and Armidale.

Demographic profile

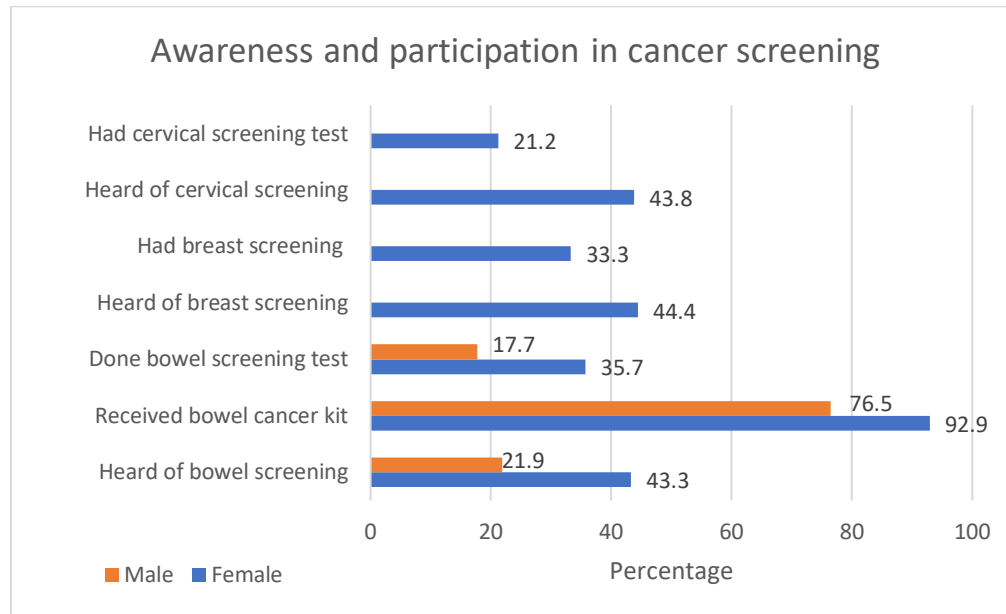
Participants' mean age ranged from 36.8 to 59.3 years, and length of stay in Australia ranged from 3.1 to 19.7 years. Participants came from a wide range of cultural and linguistic backgrounds. The focus of the study was people from a refugee background, regardless of visa status or year of arrival in Australia. Community members from 26 countries of birth and 14 language groups were engaged in the workshops. Participants' mean age and length of stay in Australia varied across groups, from 36.8 to 59.3 years and 3.1 to 19.7 years respectively. Participants came from a wide range of cultural and linguistic backgrounds and included refugees and migrants from Uganda (languages spoken at home were Luganda, Alur), Sierra Leone (Krio, Fulla, Madingo), Burundi (Kirundi, Kinyarwanda), Ethiopia (Amharic; Tigrinya), South Sudan (Dinka, Arabic and Madi), the Democratic Republic of Congo (Swahili, French), Zambia (Nyanga, Bemba), Zimbabwe (Shona), Nigeria (Kalabari), South Africa (Setswana), Iraq (Arabic, Chaldean), Syria (Arabic), Eritreans (Tigrinya), Iraq (Kurdish Kurmanji), and Liberia (Liberia, Pidgin).

Country of Birth	Number of participants	Language spoken at Home	Number of participants	Language spoken at Home	Number of participants
Iraq	65	Arabic	71	Ndebele	1
Democratic Republic of Congo	27	Krio	22	Nyanga	1
Sierra Leone	24	Ezidi	18	Pidgin	1
Syria	20	Swahili	21	Setswana	1
Eritrea	6	Dinka	5	Shona	1
South Sudan	6	Kinyarwanda	7	Temne	1
Ethiopia	3	Mende	3		
Zambia	2	Tigrinya	5		
Burundi	2	Chaldean	3		
Uganda	2	Amharic	2		
South Africa	1	Bemba	2		
Zimbabwe	1	English	2		

Nigeria	1	French	2
Liberia	1	Fulla	2
		Kirundi	2
		Mandingo	2
		Alur	1
		Kalabari	1
		Luganda	1

Cancer awareness and behaviours

Participants showed low awareness of the three national screening programs (which was lower among men than women) and very low uptake of cancer screening services (Figure 2). Awareness levels were highest for cervical screening (43.8% of 33 participants), followed by breast screening (40.9% of 36 participants) and bowel screening (32.7% of 62 participants). While awareness levels of bowel screening were low (32.7%), recognition of the bowel screening kit was higher (69.1%). Only 29.6% and 21.9% of consulted women had undertaken breast screening and cervical screening, respectively.



Cancer screening enablers among cancer screening adopters

Three central themes highlighted drivers of the uptake of breast cancer screening: the role of GPs in prompting participants, the fear of the unknown (early detection and treatment), and the family history of breast cancer. For bowel cancer, cancer screening enablers were health system interventions (especially reminder letters), fear of the unknown (preventive precautionary measures), free bowel cancer screening kits, and clear instructions on how to self-test. The main single factor influencing cervical screening uptake was general practitioners being mostly at the forefront of carrying out the test and promptly reminding participants to undertake the test for precautionary purposes. However, some participants became more aware of importance of cervical screening through community structures such as schools, TAFE, and workplaces.

Barriers to cancer screening among non-adopters

Three major themes characterised significant community-level barriers to breast cancer screening: the lack of knowledge and information, fear of knowing the outcome (and associated missed appointments and lack of agency), and system issues like travel to appointment and language and cultural needs not being met by health providers. Bowel cancer screening barriers included the lack of knowledge and information, socio-cultural beliefs and perceptions, the fear of knowing of the outcome, and health system challenges. Barriers to cervical screening were predominantly sociocultural and health system challenges (e.g., gender sensitive services, religious requirements, followed by fear of the outcomes, pain/discomfort, and the lack of knowledge).

Ranked and prioritised interventions

Interventions were ranked according to the number of votes, and within each intervention, subthemes were listed and voted on by the participants. For bowel cancer screening, a total of five NGTs were carried out and 24 possible interventions were identified and ranked, with the thematic analysis grouping them into four distinct but complementary interventions: 1) increasing bowel cancer screening literacy through behaviour change (3 pillars: enhancing and harnessing relationships within the communities, engaging community assets, and addressing personal level factors related to knowledge, attitudes, and skills), 2) policy changes and reform, 3) strengthening community action, and 4) monitoring, evaluation, accountability & learning. For breast cancer screening, a total of three NGTs were carried out and a total of 11 possible interventions were identified and ranked, with the thematic analysis grouping them into two distinct but complementary interventions: 1) increasing breast screening cancer literacy through behaviour change and 2) policy influences on behaviours. For cervical screening, a total of two NGTs were carried out a total of 8 possible interventions were identified and ranked, with the thematic analysis grouping them one distinct intervention: increasing cervical screening literacy through behaviour change.

Interventions recommended by participants

Participants had many recommendations for interventions to maximise participation in the three national cancer screening programs for their community. There were four main areas: increase cancer screening literacy, policy and practice changes, strengthen community action and monitor and evaluate. Interventions were ranked according to the number of votes, and within each intervention, subthemes were listed and voted on by the participants.

Recommendation 1: Increase cancer screening literacy and behaviour change

Prioritise and operationalise 14 interventions that value refugees and migrants' lived experiences as well as recognise and engage with community assets and community structures' core capabilities to increase cancer literacy, trigger behaviour change, and increase participation in the three population-based cancer screening programs (breast, bowel, and cervical screening). These interventions are:

1. Establishing community-owned cancer support groups
2. Identify and train cancer screening role models and community champions
3. Incentivise GP services as a focal point for routine cancer screening
4. Adopt family inclusive approaches that encourage partners' involvement in cancer screening awareness (to overcome religious and cultural barriers)
5. Empower social and refugee-led community organizations to spread the word about cancer screening
6. Maximize the role of social workers as cancer screening frontliners
7. Initiate community-based panel discussions and Q &A about cancer
8. Address intergeneration issues related to cancer screening education
9. Embedding cancer information and screening into predeparture cultural orientation, Humanitarian Settlement Program (HSP) and Settlement Engagement Transition Support (SETS) Programs as well as refugee health nurse home visits
10. Incorporate cancer screening education into community structures through school students (e.g., take home brochures), TAFE, and workplaces
11. Map, document, and disseminate cancer survivors' testimonies to dispel myths about bowel cancer
12. Translate cancer screening messaging into community languages and reduce cancer screening messaging and language complexity.

13. Information and education about cancer screening including evidence on early detection and treatment outcome through themed community events and cultural celebrations/festivals, sponsored community-based panel discussions and Q &A, TV programs in community languages, social media, customised workshops, and dissemination of translated materials
14. Nutrition and health education targeting lifestyle changes and healthy eating behaviours.

Recommendation 2. Policy and Practice changes

Incorporate refugees and migrants' input into current funding and service agreements with cancer prevention partner organisations and settlement service providers. Such input is required to customise policy and practice changes needed to effectively address some of the barriers to participation in cancer screening programs. Participants proposed six policy and practice changes:

1. Reduce the age for the national bowel screening program to 40 years
2. Make participation in the three population-based cancer screening programs compulsory
3. Reduce bowel cancer screening after 50 years to every year
4. Reward for participation in any of the three population-based cancer screening programs
5. Sponsor regular breast screens
6. Provide transport for those who are unable to travel to test facilities

Implicit in this policy and practice change intervention is the incremental shifts in existing cancer screening guidelines (policy change e.g., making the screening compulsory or rewarding those who get screened) and major policy changes (reform e.g., revisiting the eligibility criteria). It is worth acknowledging that policy changes and reform are not easy to achieve because of the different level of governance guiding cancer service delivery (commonwealth vs. state and territories policies) and each level of governance may want to protect the existing practice. While the National Preventive Health Strategy 2021-2030 seeks to align action through whole-of- government approaches, policy changes and reform to meet the needs of refugees and migrants may be difficult to implement. The complexity and challenges relate particularly to the lengthy and quite complex engagement process of establishing the benefits and incentives that a policy change and reform may bring.

Recommendation 3: Strengthen community action

Build community capacity and fund local cancer control initiatives to support community ownership and control as drivers of sustainability and intervention scale-up. Proposed interventions are:

1. Capacity building and funding of community structures
2. Engaging and strengthening community governance structures.

Enhancing and harnessing relationships within the communities through strengthened community action would allow the co-development and co-implementation of targeted community-based education and awareness programs. Co-developed programs would motivate community members to seek cancer screening programs and increase their participation. Participants suggested that such community-based education and awareness creation should target both the younger and older

generation. This is because, for most migrants, a young person cannot educate an older person due the collectivist and hierarchical models of interactions in target communities, compounded by age, gender, and religion. Overcome these barriers may necessitate building and harnessing adequate community governance structures through which to implement community-owned cancer screening programs.

Recommendation 4: Monitoring, Evaluation, Accountability & Learning

Facilitate and promote biennial knowledge, attitude, awareness, and practice surveys to evaluate emerging theory of changes and establish the effectiveness of the proposed interventions. This may require working with community structures to develop the survey tools and trained community bilingual workers to be involved in data collection and dissemination of emerging findings.

Quotes

Breast cancer screening

*“For me, I’ve been in Australia for a while. Back home, we never heard of breast cancer screening. After every 2 years [in Australia], you have to go and check to see if your breasts are healthy...**From time to time, after you pass 50 years, they send you a reminder letters for you to do breast screening, to go and check your breasts.** They say it’s really important because if there is some early tissue, its early detection is really important because they’ll be able to start treatment so that it will not spread. That is really important. That is what I’ve heard about breast screening and the importance of it for women”. (P1)*

“How often should we do a blood test [for breast cancer]? Every month?” (P2)

“...I received a letter asking me to come to do the test via post. And then they sent another letter that said thank you”. (P3)

“...But there are a lot of people in the community who do not know how [about cancers] and what to do about them. “They just live in the community here” (P4).

Bowel cancer screening

“Why do they do this if you are not sick?” (P1)

“First, I have a question, is this cancer contagious? (P2).

“My understanding is its more for men. For bowel cancer, I don’t know if it’s sent to women” (P3)

“Before the kit, they actually send you a letter. As soon as you turn 50 you get a letter, to let you know about the test, and what you should expect, and what to do when you get the test. Before the kit I received a letter” (P4).

“In Africa, when you test positive, there is something wrong in you. If the test is positive, it is hard to tell people, even your wife. If you tell your wife, you have something in your body, that you cannot be close to the people. One day, when you have a problem with her, she will start insulting you with that” (P5).

“In some tribal family cultures, there are personal cultural barriers, because it is not okay to show weakness. And some diseases cause stigma, shame... Some families hide their people with disease, hide kids with disability decades ago. Disease is a stigma, shame, and a sign of weakness” (P6).

“... African men, we are hunters, we are strong. Once you declare you have that [bowel cancer], you will lose your self-esteem and your image— you must be strong” (P7).

“...in Africa, there are certain things not talked about when women are there, or when young people are there. We have to be careful what we discuss. Hard to break those barriers” (P8).

Cervical Screening

“The cervix, cervical cancer is something that many people, women have. We’ve heard about it, we used to see a lot about it in magazines and on the news” (P1).

“Yes, I had an infection I went to the doctor he told me to do this test. I didn’t even know what this test was; I said no worries, except he said it is internal. I said, okay” (P2).

“Yes, they came to the TAFE and said whoever wanted to do it let them do it; they said it in the class and at the TAFE... When we came here my family doctor did it also TAFE periodically came and talked to us. We were a lot of people, when they talked to us at TAFE, and told us whoever wants to do it can go and do it, your doctor can do it for you and we can do it for you, whoever wants to go and do it can go and do it” (P3)

*“**For me, the issue was my GP was a male. I don’t want to change my GP just for cervical screening**, but I ask him if he can authorise any female staff, like a registered nurse or doctor, to do the test for me. And I discussed that with some of my friends because, in the Muslim community, we are not allowed to expose ourselves to men that are not our husbands. So, I realise that a lot of women in my community don’t do the test because their GPs are male. And some of them, I know, have no idea they have the right to say, ‘I need a female practitioner’. For most of them, when they first get here, a male GP is who they see. We are facing these barriers and is very strong in my community- most of our sisters haven’t done the Pap Smear test. And I ask why? And they say because of this reason” (P4).*

“I think it also has to do with the sensitivity around the area as well because we are coming from a culture where sexuality is something not discussed, so it’s something embarrassing. You wouldn’t want someone to see your private area, so even if you are aware of a female, it takes a lot of courage to go and undress yourself. And also, the person you could see could be someone not from your skin colour, so you might also be embarrassed about that. So, you don’t feel comfortable. So that could be a form of a barrier, even though they know there is harm in not doing it. They say, ‘I’d rather keep myself intact, not to expose’. And some people come from a trauma background as well, like sexual assault, so this could also bring memories. People will try to protect themselves by not exposing themselves to more harm” (P5)

“So, with cervical screening, with the word cancer, people are so scared of going there, of getting the negative result, because they say when you get cancer, it’s a death warrant. So, I’d rather not know than know... And the thing that makes you worried is that the procedure is a bit difficult, not that it is embarrassing” (P6).

References

- ⁱ Consedine NS, Tuck NL, Ragin CR, Spencer BA. Beyond the black box: a systematic review of breast, prostate, colorectal, and cervical screening among native and immigrant African-descent Caribbean populations. *Journal of immigrant and minority health*. 2015;17(3):905-924.
- ⁱⁱ Wild S, Fischbacher C, Brock A, Griffiths C, Bhopal R. Mortality from all cancers and lung, colorectal, breast and prostate cancer by country of birth in England and Wales, 2001–2003. *British Journal of Cancer*. 2006;94(7):1079-1085.
- ⁱⁱⁱ Survivors of Torture Inc (Foundation House) (2018) Australian Refugee Health Practice Guide, Refugee patients in primary care.
- ^{iv} Anaman, J. A., Correa-Velez, I., & King, J. (2018). Knowledge Adequacy on Cervical Cancer Among African Refugee and Non-Refugee Women in Brisbane, Australia. *Journal of cancer education : the official journal of the American Association for Cancer Education*, 33(3), 716–723. <https://doi.org/10.1007/s13187-016-1126-y>