

# UNITING FOR EQUITY IN CANCER CONTROL

Success Stories Across Diverse Communities



**CANCERFONDEN**  
Swedish Cancer Society



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## **UNITING FOR EQUITY IN CANCER CONTROL – Success Stories Across Diverse Communities**

Photos: p. 1 Sanna Percivall, p. 3 Edis Potori, p. 4-15 photos from each respective organisation, p. 18 photo from UICC

The report can be read and downloaded from [cancerfonden.se](http://cancerfonden.se)

# Foreword

Cancer affects everyone, but it affects everyone differently. Your geographical address, your physical or mental status, sexual orientation, gender, ethnicity, religion or other social determinants should not be a factor in your cancer care continuum from prevention, and early detection, to diagnosis, treatment and a life with, or after, diagnosis.

The global cancer burden is increasing, as are the disparities in cancer control both within and between nations. The inequities that accompany this rising burden are increasing rather than lessening. People who seek cancer care hit barriers at every turn. Factors such as income, education and geographical location, amongst others, negatively affect diagnosis, treatment and care. Disadvantaged groups are also more likely to have increased exposures to risk factors which increases the risk of a number of different types of cancer.

Disparities in cancer control risk being further emphasized by the rise in national protectionism we see around the world due to amongst other climate change and armed conflicts. This is unacceptable. We need to continue the fight against cancer and remember that the challenges with cancer are much like the ones we see with climate change - we cannot solve them alone. The challenges may seem insurmountable, but a lot is being done to overcome these inequities and these examples need to be highlighted and increase.

## Success stories

This report highlights various ways to address inequities in cancer control. Through case studies, we aim to inspire and provide tangible ways in which, for example, organisations can increase screening uptake within specific demographics or reach populations which historically have been hard to reach. With relatively small measures, we can try to address inequities within nations and strive to make a difference within the communities we serve.

Our contributors span the globe, as a way of showing that the inequities present within one nation often are recognizable in others. As such, the concrete tools utilized in the included initiatives can be transferred to other geographical settings.

I hope you will be encouraged by a campaign to increase screening uptake within the LGBTIQ+ community in the United Kingdom, or efforts trying to increase screening uptake amongst physically disabled women in Egypt. Or perhaps a new programme in psychiatric hospitals in Japan to increase screening uptake amongst patients with a schizophrenic diagnosis, or understanding the lived experiences of Indigenous cancer patients in Aotearoa New Zealand, or how to reach out to previously hard to reach communities in the USA.

I would like to thank our contributors for their dedication in eradicating inequities in cancer control and care, and I wish that you, as the reader, will be inspired by our efforts.

Together we can beat cancer.

Ulrika Årehed Kågström,  
Secretary-General of the Swedish Cancer Society  
and President-Elect of UICC



# Targeted Screening Initiatives

## The Swedish Cancer Society

The Swedish Cancer Society has, like the other organisations featured in this report, carried out various initiatives to try to combat inequities in cancer control and care in Sweden. Two such initiatives center around increasing uptake in cancer screening. These initiatives are aligned with our strategic goal for Sweden within early detection, which states that by 2030 a third of all cancer is detected at an earlier stage.

### Inequities in cancer screening

There are three national cancer screening programmes in Sweden; for breast cancer, cervical cancer and colorectal cancer. While participation in these programmes are relatively high compared to other European countries, there are unwarranted inequities between and within Sweden's regions, and between different groups in society. For instance, participation in breast cancer screening varies between 70-90 percent across regions, and similar disparities exist within municipalities of the regions.

In general, there is a lower participation rate amongst groups with lower socioeconomic status. Women with limited education and lower socioeconomic status are the least likely to participate in all cancer screening programs in Sweden, and this pattern is also seen for rates of catch-up vaccinations against human papillomavirus (HPV).

To prevent and detect more cancer cases at an earlier stage, it is crucial to increase participation in both screening and catch-up HPV vaccination. Therefore, the Swedish Cancer Society has met with political decision-makers in almost all 21 regions during 2023 to conduct a dialogue on how we can

### The Swedish Cancer Society

Founded in 1951 the Swedish Cancer Society is a Swedish non-profit organization with a vision of a society in which fewer people get cancer and more people are cured or are able to lead long lives, enjoying a good quality of life. Together, we are helping to give more people a better future through the funding of research, advocacy and information dissemination.



Find out more at [cancerfonden.se](https://cancerfonden.se)

work together to get more people to participate. The message is clear: targeted efforts and new ways of working are needed. We have also seen that the level of knowledge about cancer screening differs and that there is a demand among many regional politicians for more exchange of knowledge between the regions.

### Save lives – increase uptake

In order to combat the differences in screening and HPV-vaccination participation, the Swedish Cancer Society has produced a guide compiling evidence-based tools in an easy-to-understand format. This guide aims to support proactive efforts to encourage more people in Sweden to attend cancer screening and catch-up HPV vaccination. The target groups in the guide are women born abroad who reside in socioeconomically disadvantaged areas, people in rural areas, individuals with disabilities, people with mental health conditions, long-term non-attendees of cancer screening, everyone called to attend cancer screening and catch-up HPV vaccination (women born between 1994 and 1999).

We believe this guide can be a source of inspiration for other countries that want to increase participation in cancer screening, and those who wish

to reach specific population groups who previously may have been difficult to reach. The guide has been disseminated to relevant parties in all Swedish regions and was also discussed in a digital seminar held together with the Swedish Regional Cancer Centres (RCC).

The guide has furthermore been a point of discussion in meetings with national and local politicians, decision makers, patient organisations, civil society actors and researchers. An abridged version has also been produced to highlight the most important policy proposals to increase uptake. The guide has been translated into English with the intent of disseminating it internationally. The guide can be found at [cf.se/save-lives](https://cf.se/save-lives).

### Addressing language barriers for better healthcare

When it comes to cancer screening, we know that language can be a significant barrier that prevents many from seeking healthcare or attending their screening appointments. In order to combat this barrier, the Swedish Cancer Society has produced material that combines language education with information on the Swedish healthcare system's cancer risk reduction, and through this material we aim to contribute to meaningful change.



Our education material is used to reach people who are new in Sweden through their introductory language courses, Swedish for Immigrants. It includes information on the vital role of the national screening programmes.

The material is a targeted effort to reach students in Swedish for Immigrants (SFI) programmes. SFI is a language curriculum designed to provide immigrants the basics of our language, and knowledge about Swedish society. The information provided in the material covers various topics, including an overview of the Swedish healthcare system, guidance on how to seek care in

Sweden, current cancer statistics and the importance of participating in screening programmes. By addressing these critical areas, we hope to ensure participation uptake increases, ultimately making us one step closer to our goal of beating cancer.

The demand to our initiative has been high and was awarded with the Publishing Prize in 2023.

Experience shows that both language and cultural factors contribute to lower participation in cancer screening among recently arrived women in Sweden. Therefore, we aim to directly address these women, with the goal of increasing foreign-born women's participation in screening programmes.



### 3 MAIN TAKEAWAYS

- ▶ Targeted interventions are an effective way to reach previously hard-to-reach groups.
- ▶ Collaboration with political decision-makers and knowledge sharing to promote increased participation in cancer screening is a positive way to increase engagement.
- ▶ Language and cultural barriers significantly impact participation in cancer screening among immigrant women.



# Best for My Chest

## OUTpatients, UK

Prior to the pandemic, the UK's routine breast screening uptake was in gradual decline across England. London in particular had lower rates than the national average, placing the city below the acceptable rate of 70 percent. Attendance to routine breast screening was significantly affected by the COVID pandemic, with London's uptake rate falling to 50.4 percent, and it has failed to return to pre-pandemic levels.

In our experience as a specialist charity and from reviewing published literature, we noted that LGBTIQ+ people had a complex relationship with breast screening due to aspects related to identity, perceived risk, and systemic barriers to invitations for patients who are transgender. We also noted that breast cancer campaigns routinely failed to target the LGBTIQ+ community.

In response, we worked with the North East London Cancer Alliance

**OUTpatients**  
OUTpatients is the UK's LGBTIQ+ cancer charity. Proudly patient-led, they exist to shake up the system, advocate for equity, and stand up for every LGBTIQ+ individual navigating the cancer journey. They host peer support, educate healthcare professionals, and help to shape national policy that supports the LGBTIQ+ community.

Find out more at [OUTpatients.org.uk](https://outpatients.org.uk)



(NELCA) to explore if an LGBTIQ+ breast screening campaign would be welcomed by the community.

### Community co-production

Our campaign began with co-production sessions that welcomed LGBTIQ+ people eligible for routine breast screening either presently or in the future, and those with prior experience of breast imaging. Sessions were held in an LGBTIQ+ bookshop in East London after trading hours so that people could be in a familiar space with

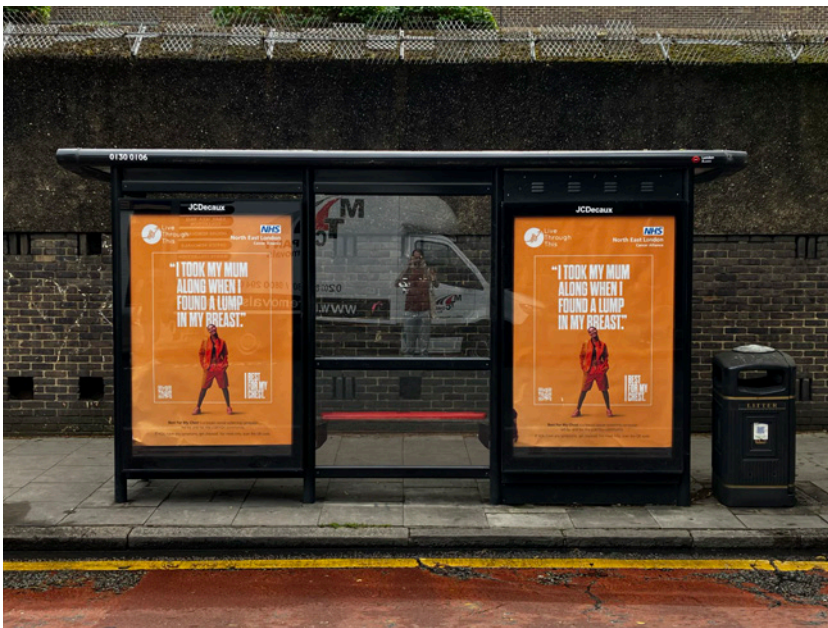
the privacy required for effective discussion. Attendees were placed into two groups 1) LGBTIQ+ people below screening age (N=6), and 2) LGBTIQ+ people above screening age (N= 4).

Sessions ran as guided discussions about patient experience and potential campaign styles. Both groups shared that the campaign should be clear in its healthcare focus and feature real people. These models needed to visually represent the LGBTIQ+ community to create greater personal relevance for the materials. The models also needed to have a voice so that they could gain the trust of the target audience and show that screening could be a positive experience.

The younger cohort demonstrated some incorrect assumptions about the screening process, with a few people thinking the exam happened in the GP's clinic. Even in patients with symptomatic experience of screening, understanding of the routine pathway, its eligibility criteria, and its invitation schedule was still poor.

The older cohort felt disconnected from and forgotten by the younger generations. However, when it was shared with them that the younger cohort had discussed the importance

Best for My Chest posters displayed on a London bus stop, 2023.



of seeing their “queer elders” in the campaign, they became much more engaged, seeing it as a duty to their community to be visible and share their experiences. Two attendees of this group went on to become models in the campaign.

The guided discussions were well received with one attendee sharing: “As a trans person, I felt heard in ways I had never felt heard before, in healthcare settings. And it was incredible to hear and compare my experiences with many people while working on something that would make the process of getting screened less daunting, easier, more accessible.”

### Delivering the campaign

The campaign went through an iterative process between OUTpatients, NELCA, and a creative agency. Two additional models were recruited to the campaign via snowball recruitment from co-creation attendees. An LGBTIQ+ photographer was used on set to make campaign models feel at ease. Video interview footage was collected in addition to stills. Content was edited and packaged for release during Breast Cancer Awareness Month.

Outputs took multiple forms. Targeted out of home placements focused on LGBTIQ+ venues in the East London area and high footfall local areas, such as Brick Lane. Posters and other paraphernalia were given to local LGBTIQ+ venues, and a



OUTpatients staff presenting the Best for my Chest campaign at UK Black Pride, 2023

launch event raised the campaign’s awareness to the local community. Models were invited to speak at the launch and reflect on their involvement in a panel discussion.

Online activity was both paid and organic reaching 790k+ impressions to 160k+ people, converting to 75k+ engagements with the content which included social media posts, videos, and a dedicated campaign webpage [BestForMyChest.com](http://BestForMyChest.com). Of the posts, the transgender model was the most popular resulting in the greatest level of organic social media engagement and praise for her inclusion. The campaign was

also taken to UK Black Pride to maximise impact within diverse and intersectional communities.

A year after its initial launch, an extension to the campaign was suggested by one of the campaign models for Black History Month and Breast Cancer Awareness Month in the form of a conversational video. This was supported, developed, and delivered online and features a 15-minute video that explores identity, relationship to the chest, perceptions of screening, and the unique experiences of Black LGBTIQ+ people.



## 3 MAIN TAKEAWAYS

- ▶ Co-production is a valuable technique to deliver person-centred campaigns
- ▶ Recruiting real people to campaigns improves audiences’ trust in the message
- ▶ Healthcare services working directly with charities creates a mutually beneficial impact

# Understanding the Lived Experiences of Indigenous Cancer Patients in Aotearoa New Zealand

## Te Aho o Te Kahu, New Zealand

Aotearoa New Zealand has approximately 5.2 million people, with Indigenous Māori making up an estimated 17 percent of the population. Like many other Indigenous peoples, Māori in Aotearoa experience significant inequities across the cancer continuum. Māori are 20 percent more likely to be diagnosed with cancer than non-Māori. Once diagnosed they are twice as likely to die from cancer.

Māori people are also less likely to access cancer screening, and less likely to access best practice treatment for their stage of disease. These disparities reflect systemic disparities in access to the social determinants of good health, including cancer prevention and best practice care.

### Te Aho o Te Kahu – Cancer Control Agency

In 2021, the national Cancer Control Agency undertook a major engagement process with Māori affected by cancer. It aimed to connect with as many Māori as possible, so their experiences and thoughts could be embedded in the Agency's work. It was also an opportunity for the newly formed Agency to establish relationships with Māori from iwi (tribal), cancer, health, and community organisations.

When the Agency was created in 2019, it was gifted the Māori name 'Te Aho o Te Kahu' meaning 'the central thread of the cloak'. This name symbolises the Agency's role to lead and unite the many organi-

Te Aho o Te Kahu – Cancer Control Agency reports directly to the Aotearoa New Zealand Minister of Health and provides strong central leadership and oversight of cancer control across the country with its vision of 'fewer cancers, better survival, and equity for all'. It was created in 2019 to recognise the impact cancer has on New Zealanders. The agency is supported by clinical and lived experience advisory groups, and works in partnership with Hei Āhuru Mōwai, the independent national Māori Cancer Leadership Network.



Find out more at [teaho.govt.nz](https://teaho.govt.nz)

sations involved in cancer control. The name was gifted by Hei Āhuru Mōwai Māori Cancer Leadership Aotearoa - an independent Māori organisation that partners with the Agency and was a key stakeholder in the national engagement process.

### Meeting the community

Te Aho o Te Kahu partnered with local iwi and health organisations to plan and hold 13 hui (meetings) across the country. These hui were open to all Māori affected by cancer. Collectively, more than 2,500 Māori took part, including current and former cancer patients, their whānau (families), clinicians, and local and national cancer care organisations.

We deliberately chose a Kaupapa Māori (Māori epistemological) approach to the hui series. This is an ethically and culturally appropriate tool for engaging with Māori communities in Aotearoa. Core components of this approach were:

1. Strong foundations of Māori knowledge systems, worldviews, perspectives, and practices. This included practices of tikanga tika (doing the right thing) and whakawhanaungatanga (building relationships).
2. Acknowledgement of the legitimacy of Māori experiences of cancer. A Kaupapa Māori approach removes the gaze from exploring Māori patient factors as reasons for inequities. Rather it underscores the structural and systemic barriers within Aotearoa's health system that contribute to current cancer inequities.
3. A sharp focus on producing results that are meaningful to Māori communities. In this way a Kaupapa Māori approach can transform, disrupt, and decolonise the health system and cancer services in Aotearoa New Zealand.



Examples of this approach in practice included:

- Devolving as much decision-making authority as possible, which enabled local organisations to demonstrate their rangatiratanga (leadership and autonomy).
- Opening and closing each hui using local tikanga (customary practices) and kawa (rituals).
- Providing safe spaces at hui for whakawhanaungatanga, wairuatanga (spiritual upliftment) and kōrerorero (discussions).
- Partnering with Māori public health and cancer leadership organisations to demonstrate kotahitanga (unity) around the kaupapa (issue/purpose).
- Demonstrating manaakitanga (respect and kindness) through the offering of kai (food), koha (gifts), waiata (traditional songs) and kapa haka (traditional performance/dance).

### Insights from the hui series

After the hui series, Māori staff within the Agency spent a year synthesising, analysing and discussing the vast amounts of information shared by hui participants. This culminated in the release of a report titled 'Rongohia Te Reo, Whatua He Oranga: The voices of whānau Māori affected by cancer'.

The Report details 30 high-level themes or 'whānau insights'; and their alignment to the New Zealand Cancer Action Plan 2019-2029. The hui participants shared positive and negative experiences of cancer care, and suggestions for changes at patient, service and whole of system levels. Some examples of the whānau insights include:

- Māori cancer leadership is needed at every level
- Whānau face multiple barriers to primary care
- Whānau regularly experience racism and discrimination

- The current cancer system isn't designed for Māori
- Kaupapa Māori prevention and health promotion should be increased
- The cultural capability of the non-Māori workforce needs to improve.

Two supplementary reports were published: one focused on the methodology of the hui series and the second highlighted examples where the cancer and health system was making changes that aligned to the whānau insights.

### Impact of the initiative

Releasing the Reports generated local and national media coverage, with many health and training organisations requesting meetings to discuss and understand the work. Since then, Te Aho o Te Kahu has been collaborating with health agencies to embed and respond to the voices of lived experience. Areas

**Whakawhanaungatanga (building relationships) is a core element of Māori culture. Māori customs were incorporated into every hui (meeting), including in the welcome ceremonies shown here.**



of focus include lung cancer screening; cancer navigation; cancer care pathways; national travel assistance policies; and developing anti-racism resources.

The Agency returned to the hui locations to share the findings with whānau Māori (families) and key stakeholders. This is an important part of Māori cultural practises and highlights the adage 'nothing about us without us.' This reinforced the significance of the voices heard and allowed the Agency to check with whānau to ensure their voices had been captured correctly. The work and methodology have also been highlighted in several international fora.

### Reflections and moving forward

The hui series is believed to be the largest engagement exercise ever undertaken with Māori affected by cancer in Aotearoa. The Kaupapa Māori approach gave whānau confidence to share their cancer

experiences, creating valuable insights for the entire cancer control sector. These insights have significantly contributed to the Agency's work programme, driving change in many areas of work.

There were some challenges and learnings from the project. Due to internal constraints, it took over a year to complete the data analysis and publish the reports, frustrating both the Agency and its stakeholders. In addition, the Agency could not deliver this work using a full Kaupapa Māori framework. This requires that data about Māori people is interpreted through a Māori lens, by researchers or writers of Māori descent and worldview.

It was not always possible to do this - for example, the Agency used the New Zealand Cancer Action Plan (a Western health model, rather than a Māori model) to frame the Reports. This choice was deliberate, so that the insights could drive

work under the Cancer Action Plan. But this example shows that while the Agency incorporated as many elements of Kaupapa Māori as possible, the process is not considered authentically Kaupapa Māori.

This hui process highlights how lived experiences of Indigenous peoples' can drive system change in health policy, service design and delivery. Such engagements must be delivered in respectful ways that honour Indigenous cultures and worldviews. In our country, Te Aho o Te Kahu will continue to advocate for culturally appropriate practices that acknowledge and reinforce the inherent strengths of whānau to achieve sustainable change for whānau Māori.

Te Aho o Te Kahu acknowledges all the whānau and community stakeholders who attended the 2021 hui series and generously gifted their time, experiences, and insights to improve the cancer system.



## 3 MAIN TAKEAWAYS

- ▶ Māori comprise 17 percent of the national population of Aotearoa New Zealand and face significant inequities at every step along the cancer continuum. Māori are 20 percent more likely than non-Māori to develop cancer; and once diagnosed, twice as likely to die from it.
- ▶ In 2021, Te Aho o Te Kahu met with more than 2,500 whānau Māori affected by cancer, via 13 hui (meetings) held across the motu (country). The aim was to hear the stories and experiences of whānau Māori in a manner that reflected their worldview, so their voices could shape the future direction of cancer care in Aotearoa.
- ▶ The resulting insights have significantly shaped the work programme of Te Aho o Te Kahu and highlight the importance and impact of Indigenous approaches.

# Ensuring Equitable Breast Cancer Control and Care for Individuals with Disabilities

## Baheya Foundation, Egypt

Baheya Foundation for Early Detection and Treatment of Breast Cancer, in Egypt, recognizes that all women, regardless of socioeconomic background, deserve access to life-saving cancer care. Their core mission of ensuring equitable access to early detection and comprehensive breast cancer treatment services, free of charge for all women in need, exemplifies their overarching commitment to inclusivity, which underpins their specific initiatives aimed at women with disabilities, who often face significant barriers to accessing healthcare.

### Successful initiative in promoting equity within Baheya demographic: Protocols for partnership

Building upon this foundation of inclusivity, Baheya has implemented several successful initiatives and developed a unique model aimed at promoting equitable access to early detection and treatment for women with disabilities within its demographic. This model hinges on signed protocols of cooperation with organizations representing specific disability groups to provide our free medical services to women with vision and hearing impairments, Paralympic Athletes, and mothers and caregivers of children with disabilities. These protocols outline a framework for collaboration, including:

- **Awareness Campaigns:** One of Baheya key initiatives is the provision of specially tailored awareness sessions conducted in sign language for women with hearing impairments, for example. These sessions are part of Baheya's commitment

Baheya Foundation is a leading non-profit organization in Egypt dedicated to the early detection and treatment of breast cancer, providing free, comprehensive breast cancer care to all women in Egypt. The foundation is committed through their extended mission to ensuring equitable access to all women, including those with disabilities through innovative partnerships and outreach programs. The foundation's overall approach to cancer care is rooted in the belief that every individual deserves access to the best treatments, emotional support, and a caring environment.



Find out more at [baheya.org](http://baheya.org)

to ensuring that their services are accessible to all women, regardless of their disability status.

- **Dedicated Screening Programs:**

Baheya has regular annually scheduled planned screening appointments to facilitate early detection and free treatment in case of diagnosis for women with disabilities. Baheya patient navigation volunteers' team, trained in sign language, is always ready to support these women.

- **Patient Navigation Support:**

- *Communication Support:* Specially trained volunteers, equipped with sign language skills, assist patients throughout their healthcare journey, ensuring clear communication and addressing any language barriers.

- *Physical Support:* Recognizing that mobility challenges can be a barrier to care, Baheya's Patient Navigation Program also addresses physical barriers. Physical navigators, trained volunteers, utilize supportive equipment (e.g., wheelchairs, stretchers) to transport patients

to different service points within the facility. These volunteers also escort and support weak or struggling patients as needed.

- **Media Advocacy:** Baheya has succeeded in raising awareness about their services to women with disabilities, promoting and encouraging the community for more inclusion. Baheya actively promotes its inclusive services through media coverage, encouraging wider community participation. This advocacy includes partnering with media celebrities with Down syndrome and visual impairments who serve as Baheya ambassadors.

These ambassadors encourage the community for the inclusion of individuals with disabilities and inspire other breast cancer fighters with disabilities to get screened. Baheya also celebrates Paralympics champions and their families, further highlighting its commitment to inclusivity. Furthermore, trainings held for staff (volunteers and employees) are attended by



celebrities, increasing advocacy efforts and reach.

### Tangible results and transferable practices

Baheya has successfully reached and served over 500 women with disabilities. Here are some key statistics:

- Partnerships with organizations for women with visual impairments, hearing impairments, Paralympic athletes, and mothers of children with disabilities.
- Over 500 women with disabilities screened through dedicated programs.
- Increased media coverage highlighting Baheya's commitment to inclusivity.
- Free, comprehensive breast cancer care provided to all women in Egypt.

The key to success lies in Baheya's collaborative approach and unwavering commitment to inclusivity. Partnering with disability-focused organizations fosters trust and facilitates targeted outreach. Additionally, tailoring services and training staff in sign language demonstrates a genuine commitment to inclusion. These practices are readily transferable and can inspire similar initiatives in other healthcare settings.

Baheya's work offers valuable lessons for organizations aiming to promote equity in cancer care:



Event hosted by Baheya Foundation to empower deaf and hard-of-hearing individuals, featuring sign language training, breast cancer screenings, and advocacy for disability inclusion.

- **Broader Commitment to Inclusion:** A fundamental commitment to inclusivity is essential for effective outreach to diverse populations, regardless of socioeconomic background or disability.
- **Collaboration is Key:** Partnering with disability organizations fosters trust and facilitates outreach.
- **Tailored Services:** Adapt awareness campaigns, screening programs, and support systems to address specific needs.
- **Invest in Training:** Equip staff with the necessary skills to effectively serve diverse populations.
- **Media Advocacy:** Utilize media to promote inclusive practices and encourage wider participation, including partnering with disability community representatives as ambassadors.

### A model for equitable care

Baheya Foundation serves as a leading example of how healthcare institutions can prioritize inclusivity. Through their innovative partnerships, targeted outreach programs, accessible facilities, and commitment to ongoing staff training, Baheya ensures that all women, regardless of disability, have access to high-quality breast cancer care. Baheya's dedication to inclusivity goes beyond disability, encompassing every woman in Egypt, ensuring socioeconomic background does not become a barrier to accessing life-saving cancer treatment. By following Baheya's model, other healthcare providers can create a more equitable healthcare landscape that benefits all individuals.



## 3 MAIN TAKEAWAYS

- ▶ **Unwavering Commitment:** Baheya Foundation is committed to providing equitable access to early detection and treatment services for breast cancer to all women, including those with disabilities. A foundational dedication to inclusivity is essential for equitable healthcare access.
- ▶ **Targeted Services:** Special awareness sessions conducted in sign language and regular scheduled planned screening appointments are part of Baheya's initiatives. Tailored awareness campaigns, screening programs, and support systems ensure accessibility.
- ▶ **Partnerships:** Collaboration with disability organizations is crucial for building trust and effective outreach.

# Community Engagement to Increase Health Equity

## American Cancer Society, USA

The American Cancer Society (ACS) continues to strengthen its organizational commitment and actions to advance health equity to improve the lives of patients and families impacted by cancer and eliminate disparities through its work at global, national, state, and local levels. To ACS, and its non-profit, nonpartisan advocacy affiliate, the ACS Cancer Action Network (ACS CAN), health equity means that everyone has a fair and just opportunity to prevent, detect, treat, and survive cancer.

The American Cancer Society is a leading cancer-fighting organization with a vision to end cancer as we know it, for everyone. We are improving the lives of people with cancer and their families as the only organization combating cancer through advocacy, research, and patient support, to ensure that everyone has an opportunity to prevent, detect, treat, and survive cancer. There are an estimated 2 million new cases of cancer and 600,000 deaths in the U.S. in 2024. Each year, ACS touches 152 million lives with \$450 million invested in research grants and work being done in 21,000+ communities across the nation and with partners in 85 countries around the world.



Find out more at [cancer.org](https://cancer.org)

### The health equity community projects

Medical mistrust is commonly defined as suspicion or lack of trust in medical organizations, providers, and/or systems. Research has shown that mistrust of medical professionals and medical systems results in worse health outcomes for patients. Emerging evidence suggests medical mistrust may influence colorectal cancer (CRC) screening disparities among certain groups including African American men and women.

In partnership with the Robert Wood Johnson Foundation, ACS awarded 11 community project sites to explore, identify, and implement community-driven solutions to support Federally Qualified Health Centers (FQHCs) in collaboration with their Patient Advisory Councils/ Governing Boards and a chosen Community-Based Organization (CBO) partner. FQHCs in the United States serve medically underserved areas and populations by providing primary care services regardless of a person's ability to pay. Over a period of 18 months, the sites worked

to address medical mistrust related to CRC screening by cross-learning with other sites using

Project ECHO, implementing community-driven solutions to elevate patient perspectives and strengthening partnerships across all sectors. Project ECHO (Extension for Community Healthcare Outcomes) is an innovative telementoring program designed to create virtual communities of learners by bringing together healthcare providers and subject matter experts using videoconference technology, brief lecture presentations, and case-based learning, fostering an 'all learn, all teach' approach. Additionally, FQHCs partnered with CBOs and measured patient's general feelings towards the healthcare system using the Group Based Medical Mistrust Scale (GBMMS) and used data to inform interventions to increase colorectal cancer screening rates.

### The health equity community projects in action

Launched in September 2022, the

second cohort of ACS Health Equity Community Projects invited the team at Community Health Centers of Greater Dayton (CHCGD), an FQHC in Dayton, OH, to participate in a medical mistrust learning collaborative. The goal of the project was to help the health system explore, identify, and implement community-driven solutions to address medical mistrust related to colorectal cancer screening and follow-up.

CHCGD was charged with finding a CBO partner to work with and chose Westcare Ohio, inc. East End Community Services, which serves the neighborhoods surrounding one of CHCGD's inner-city locations. Historically, ZIP codes in this area have been occupied by African Americans, Eastern European immigrants, and White people of Appalachian descent who had moved to this urban area for work opportunities.

This area's residents have been subject to redlining (a discriminatory practice consisting of the systematic



Leaders from some of the Community Projects.

denial of services such as mortgages, insurance loans, and other financial services to residents of certain areas, based on their race or ethnicity) and exclusionary zoning for decades and have experienced the social drivers of health at rates higher than their neighbors in nearby communities.

In 2023, CHCGD restructured their community advisory council and began meeting mid-2023 with the goals of increasing trust, community interconnectivity, and the FQHC's colorectal cancer screening rates. The council currently meets bi-monthly and sees representation from people in each of the communities mentioned above, gaining insight into how providers can build trust within the community.

Additional projects have cropped up from the learning collaborative that include creating inclusive and equitable health communications for the many people served by the health system with a focus on cancer screening, the importance of primary care, and the beginnings of some health justice conversations amongst community members.

### **Community partnership to address HPV vaccination in medically underserved Latino communities**

In 2023, two of ACS' South Region Associate Directors of Community Partnerships worked to forge a partnership with MD Anderson Cancer Center in Texas and the University of Texas at El Paso (UTEP) to provide training to improve outreach and

outcomes for individuals throughout the El Paso Texas area.

The training was provided to Community Health Workers (CHWs) who were funded to increase HPV vaccination and implementation rates in adolescents in the age demographic of 9-13. UTEP selected ACS to support this grant due to the long-standing partnership and trust established over the past 5 years. The impact made previously with other community partners and the resources ACS has brought to the community by implementing different evidence-based interventions and strategies has served as a value add to these partnerships.

ACS was the keynote trainer of this project. In October of 2023, ACS



trained over 50 CHWs and CHWs called promotores in the Hispanic/Latino community. Because of this training, the promotores will have the opportunity to educate parents on HPV vaccination and schedule appointments with FQHC partnerships to initiate and/or complete vaccination. This program seeks to connect medically underserved Latinos in El Paso and the surrounding counties.

El Paso has over 30 colonias with an estimated population of over 100,000 people. Colonias are defined by the Housing and Urban Development (HUD) and United States Department of Agriculture Rural Development as “rural communities within the US-Mexico border region that lack adequate water, sewer, or decent housing, or a combination of all three.” These

colonias are built on land that was never zoned for residential use and is economically disenfranchised. This is a gap that ACS has identified and is working to address.

ACS also partnered with three school districts in the El Paso area that cover these colonias to expand the outreach and education of HPV Vaccination. ACS is also currently working on training the nurses at all school districts around the area to work closely with the promotores.

The value and trust the promotores bring:

- Create a bridge between the community and the health providers.
- Provide health education and information in a culturally appropriate manner.

- Assist Latinos in accessing and maintaining health screenings like colorectal, cervical, and breast cancer.

The subject matter experts who conducted the training were able to fulfill a barrier by providing the training in Spanish. Since then, ACS has been approached by other organizations and the University of Texas at El Paso has expressed interest in having more training in 2024. These promotores have the potential to reach over 1,500 parents within the colonias, the 3 school districts and 3 FQHC clinics in El Paso. The interest has also expanded to other cancer prevention topics.



### 3 MAIN TAKEAWAYS

- ▶ Health Equity is not a program but rather an approach to improve health outcomes and reduce cancer disparities. Our mission is to engage people and communities who are marginalized or historically excluded to shape patient support policies, programs, and services while addressing barriers to quality preventive care, screening, cancer treatment, and survivorship.
- ▶ Cancer affects everyone, but not equitably. Multiple barriers impact equitable cancer prevention, detection, treatment, and outcomes. A person’s quality of life and cancer outcomes are, and should not be, determined by ZIP code, income level, access to health care, and access to healthy and affordable foods, among other differentiators.
- ▶ Inequity barriers are deeply rooted, long-standing conditions that will take an intentional effort to address for equitable cancer outcomes.

# Reducing Disparities in Colorectal Cancer Screening in Patients with Schizophrenia in Japan

Okayama and Shimane University, Japan

## Explaining the initiative

Disparities in cancer screening uptake among people with severe mental illnesses are a global challenge. The authors were the first in Japan who demonstrated in a cross-sectional survey that the cancer screening uptake rate among ambulatory patients with schizophrenia in psychiatric hospitals was about 50 percent of that of the general population. Patients with more severe psychopathology were less likely to receive cancer screening.

For such patients, cancer screenings provided by local governments are the primary cancer screening opportunity. Although local governments distribute leaflets recommending cancer screening to the residents, patients with schizophrenia often have difficulty understanding the content of the leaflets or are unaware of the leaflets. Further, most of the patients

with schizophrenia receive psychiatric treatments at a hospital that does not offer cancer screening, thus the patients need to go to another facility to receive cancer screening.

The authors considered that an individualized *Patient Education And Navigation Program* provided by psychiatric outpatient staff is a promising solution. In collaboration with psychiatrists, nurses, and social

workers of two psychiatric hospitals in Okayama City, the authors developed a recommendation program that was consistent with the stakeholders' context, which could be implemented by existing medical staff in daily clinical practice (Figure 1).

The primary focus was on colorectal cancer (CRC) screening, which has a strong evidence case and is recommended annually for both

This research was conducted in collaboration of Okayama University, National Cancer Center, local psychiatric hospitals, and the local government. Funding for the research was supported by a grant from the Ministry of Health Labor and Welfare Japan. Authors are Masaki Fujiwara (Department of Neuropsychiatry, Okayama University Hospital, Okayama, Japan), Masatoshi Inagaki (Department of Psychiatry, Shimane University School of Medicine, Shimane, Japan) and Daisuke Fujisawa (Department of Neuropsychiatry, Keio University School of Medicine, Tokyo, Japan).



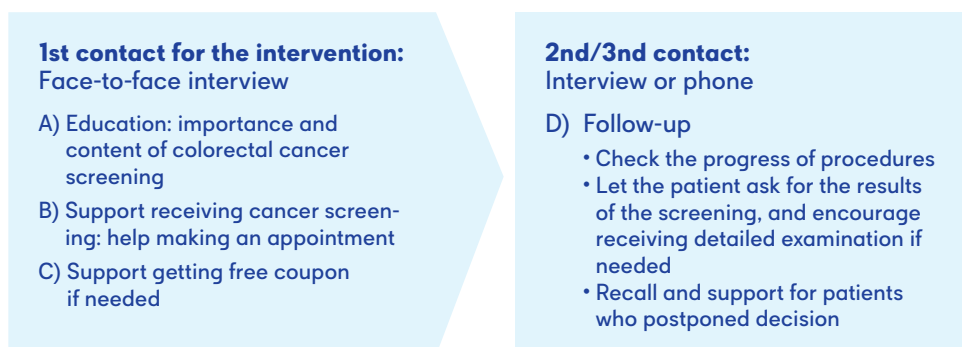
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Figure 1. The intervention including patient education and navigation.



Nurse/social workers will provide education and navigation as case manager.

men and women aged 40 years. In conjunction with CRC screening, other cancer screenings were recommended. No special training was required for the implementation of the intervention since this was within the scope of physical health counseling and support that can be provided in daily medical practice.

### Successful initiative in promoting equity

A randomized controlled trial was conducted to examine the efficacy of the developed intervention in outpatient settings of two psychiatric hospitals. A total of 170 patients with schizophrenia were randomized to the intervention and the usual care. The CRC screening uptake rate was 47.1 percent in the intervention group, which was significantly higher than the control (11.8 percent) (Figure 2). Further lung cancer screening rate was also significantly higher in the intervention group (35.3 percent) than in the control (16.5 percent) ( $P < 0.01$ ).

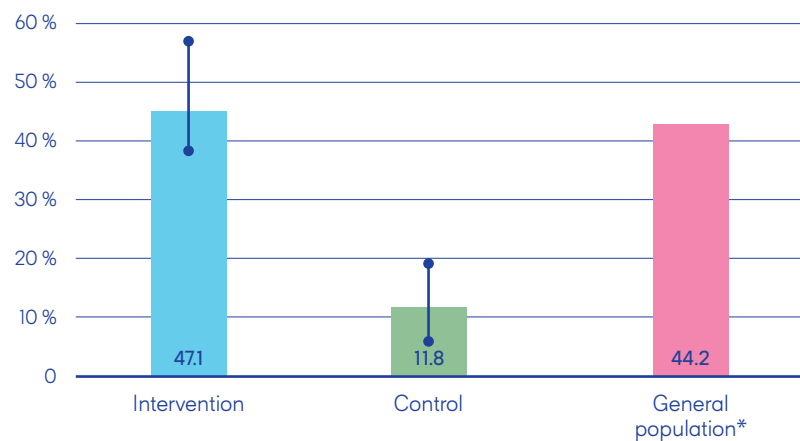
As the next step, a provider-level implementation protocol was developed to implement this intervention in daily practice. It comprised three key strategies, including 1) the establishment of an implementation team by the leadership of the facility director, 2) interactive support based on explicit guidance on who should do what, and 3) the development of accessible educational materials. The feasibility

of the protocol was confirmed in six psychiatric hospitals of different settings (two public and four private psychiatric hospitals in Okayama and Shimane prefectures). These facilities are standard psychiatric hospitals in Japan, but the number of psychiatrists for outpatient services (4-32) and the average number of outpatients per day (27-156) varied widely among the hospitals.

Currently, the authors are engaged in developing a multi-level strategy

to implement the intervention throughout the region, as originally planned. Apart from this, efforts are underway to address the disparities in cancer treatment for individuals with mental illness by examining the barriers present in our health-care system for cancer treatment following positive cancer screening results. These initiatives aim to improve the survival rates and quality of life of patients who have received positive cancer screening results.

**Figure 2. Colorectal cancer screening rates**



\* Comprehensive Survey of Living Conditions 2019



## 3 MAIN TAKEAWAYS

- ▶ An individualized *Patient Education And Navigation* intervention provided by outpatient psychiatric staff significantly increased cancer screening uptake among patients with schizophrenia.
- ▶ When developing a program, it is essential to clarify the mechanism of cancer screening disparities in line with the reality of the surrounding health system.
- ▶ It is crucial to plan for implementation from the outset and to work in collaboration with experts in implementation science. It is advisable to develop implementable interventions that leverage existing health care resources and align with the context of the stakeholders.





Members of UICC's Board of Directors at the World Cancer Leaders' Summit 2023 in Long Beach, CA. Bringing together leaders of cancer organisations from around the world.

## Closing remarks

In conclusion, the inequities in cancer care highlighted in this report are not isolated problems confined to specific countries or groups; they are common challenges that transcend borders. The disparities faced by marginalized populations in accessing and receiving equitable cancer care underscore the urgent need for collective action. By working together and sharing successful strategies, we can make significant strides in reducing these inequities.

This report is intended to provide inspiration with practical examples and innovative approaches to addressing cancer care disparities. The case studies demonstrate that with dedication and targeted initiatives, tangible progress can be achieved.

Equitable cancer control has always been a main priority for the Union of International Cancer Control (UICC) and Ulrika Årehed Kågström, Secretary-General of the Swedish Cancer Society, is proud to be part of this work as UICC's upcoming president. Her presidency will focus on reducing inequities in cancer care, advocating for vulnerable populations, and fostering international cooperation.

Here UICC is an important partner on the global advocacy agenda. Collaboration in advocating for better cancer care is crucial, and as we move forward, it is important to remember that no single organization or nation can solve these issues alone. Collaboration, knowledge exchange, and mutual support are essential in our fight against cancer.



The Swedish Cancer Society's vision is to defeat cancer. By funding the foremost research, spreading knowledge about cancer and impacting change through policy development, we work to ensure that fewer people are affected and more people survive cancer.

The Swedish Cancer Society is an independent, non-profit organisation without government support. Our work is entirely dependent on wills and gifts from individuals and companies.

We are one of the largest financiers of Swedish cancer research. Since 1951 we have distributed SEK 16 billion to leading research projects in Sweden. Cancer survival rates have more than doubled over the same period. Thanks to the progress of research, today two out of three people who are diagnosed with cancer survive.

We've come a long way, but we're not there yet.

**#togetheragainstcancer**

