## Essay

# Breast cancer survivor-led patient advocacy: the ICanServe experience from the Philippines

### Introduction

Breast cancer is the most common cancer and the leading cause of cancer death for women in the Philippines, a large lower middle-income income country of 115 million people.[1,2] Although 5-year survival rates in high-income countries exceed 90%, the 5-year survival rate is only 44% in the Philippines.[3]

Despite the passing of the National Integrated Cancer Control Act (NICCA) in 2019, the country lacks a fully fledged breast cancer control programme.[4] Approximately two-thirds (63%) of cases[5] present with advanced disease, related in part to low screening access.[6] Although the Philippine Health Insurance Corporation (Philhealth), the state-run insurance company, provides some financial support, additional assistance is available through programmes such as the Department of Health-led Cancer Assistance Fund, Cancer and Supportive Palliative Medicines Access Program, Medical Assistance for Indigent and Financially Incapacitated Patients Program, Department of Social Welfare and Development, Malasakit Center, and Philippine Charity Sweepstakes Office. However, the costs not covered by these sources continue to impose a substantial financial burden, leaving many patients to cover both the direct and indirect expenses of care.[7]

Considering the substantial challenges with cancer awareness and health-care financing, cancer survivor-led patient advocacy and education have been crucial.[8] We present the experience of the ICanServe Foundation in the Philippines, which might inform efforts in other similarly resourced settings. The ICanServe Foundation is a non-profit organisation based in Manila, Philippines. Founded in 1999 by breast cancer survivors, ICanServe co-creates comprehensive community-based breast cancer control programmes, in partnership with local governments. ICanServe is a founding member of the Cancer Coalition that led the lobby for the passage of the NICCA in 2019. ICanServe creates health literacy campaigns for the general public, supports capacity building opportunities for the breast cancer community, and is involved in cancer control policy internationally. ICanServe also established Patient Power Philippines, an informal alliance of breast cancer patient groups in the Philippines.

### Ating Dibdibin: a programme for Filipinos with breast cancer

Founded and led primarily by survivors of breast cancer, ICanServe established a programme called Ating Dibdibin (Take Your Breast Care to Heart). Long before the enactment of the NICCA and release of WHO's Global Breast Cancer Initiative (GBCI), the programme has been in place since 2008 to promote prevention, early diagnosis, and timely access to treatment; to provide supportive and survivorship care; and to implement patient navigation to improve adherence. In the setting of the decentralised Philippine health-care system, ICanServe partners with local governments for funding and implementation.

The programme begins with finding an interested local government partner, usually a city, followed by a needs assessment. The partnership requires the passing of a local ordinance to institutionalise, fund, and sustain Ating Dibdibin. Funding is sourced publicly and privately. ICanServe and the local government map out the process or the journey of a patient through the cancer continuum of care and define a clear patient pathway and referral system for patients, contextualised to each city's capacity.

The general framework includes ICanServe-led education for the City Healthy Office team (physicians, nurses, midwives, and community health workers), focusing on clinical breast examinations, patient navigation, and the Ating Dibdibin digital infrastructure. After training, ICanServe provides free clinical breast examinations and educational forums in every barangay or locality within the city, gradually transitioning leadership to the local government. One of the most important parts of the forum includes testimonies from survivors of breast cancer, with the goal of helping to demystify and destigmatise breast cancer and promote patient empowerment. ICanServe also trains survivors in

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public speaking and messaging. In addition, the programme encourages the formation of a support group for patients with breast cancer. The support group can also be a source of task shifting. Some support group members have become patient navigators, supporting the programme's sustainability.

After establishing city-wide programming, ICanServe remains involved with local governments and facilitates refresher courses, city-wide forums, free clinics, free breast clinic programmes, capacity-building workshops, and access to international conferences, forums, and online learning platforms.

## Ating Dibdibin: community outcomes

Ating Dibdibin has been adopted by seven cities (Marikina City, Panabo City, Tagum City, San Juan City, Muntinlupa City, Taguig City, and Baguio City). In the city of Taguig, in which the Ating Dibdibin programme started in 2011, almost 200 000 women have attended lectures or forums, and more than 125 000 have been screened via clinical breast examination. Additionally, almost 6000 patients have had relevant findings on clinical breast examination and have subsequently undergone diagnostic procedures; of these, almost 700 have completed treatment. The programme has resulted in more women performing clinical breast self-examinations and undergoing mammographic screening. More breast cancers are being diagnosed at an earlier stage. Out-of-pocket expenses are reduced to nearly zero for patients enrolled in the programme. Time to treatment has also been substantially reduced.

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## Recommendations on implementing a cancer control programme

### Empower the target group and understand their needs

As a survivor-led organisation, ICanServe understands the challenges and needs of Filipino patients with breast cancer. Financial toxicity at each level of the cancer continuum is a substantial barrier. ICanServe addresses financial toxicity by empowering both patients and local governments to access already available funding sources such as the Gender and Development Fund, which mandates a 10% allocation from government budgets for programmes such as Ating Dibdibin. Additionally, the programme explores options within the city budget and special funds dedicated to people with disabilities and older people, which might also have designated health-care allocations.

Apart from financial toxicity, the programme also addresses the underlying anxieties patients face. Knowing that patient-identified barriers go beyond financial constraints forms the basis of the programme's focus on patient navigation, support groups, city-wide forums, and skills training workshops. Through these platforms, patients can see a path forward to access high-quality and affordable care. In addition to providing services, ICanServe values community engagement and empowers patients to become advocates for themselves and others.

### Train, empower, and fund patient navigators

Patient navigators have a crucial role in ensuring patients can access the care they need without delay. Patients often feel lost and overwhelmed when they are first diagnosed. Many patients choose to forgo treatment fearing that they will not be able to finish the full course due to the overwhelming costs and the belief that breast cancer is a death sentence. Helping them navigate the system through a clear, step-by-step process is crucial in ensuring they receive timely and appropriate care. Patient navigators have helped to increase patient compliance, leading to better patient outcomes, and, by encouraging early diagnosis, the navigators have made the management of breast cancer less costly.

Although patient navigators have an important role in improving patient outcomes, ensuring their long-term engagement requires sustainable funding. A key challenge is that many patient navigators are barangay health workers or front-line health workers who already shoulder a heavy burden of responsibilities. In many cities, these barangay health workers essentially act as volunteers, receiving salaries of ₱800–1000 per month.[9] This salary

makes it difficult for them to fully dedicate themselves to cancer control programmes.

In an Ating Dibdibin partner city, such as Taguig, barangay health workers cover approximately 5000 households or 6200 women each.[10] However, they are considered full-time employees with allocated salaries of around ₱13 800 per month from local governments, comprising 34% of the city's budget for the programme. This stipend allows them to dedicate more time and effort to their roles as patient navigators, ultimately leading to better patient outcomes and improved programme efficiency.

### Strengthen health information systems

ICanServe recognises the importance of data-driven programmes and launched a web-based application designed specifically for health-care teams called Circle of Life. Similar to an electronic medical records system, the application collects and stores data from patients related to the Ating Dibdibin programme. Ating Dibdibin records the health-care provider's consultation notes, all procedures and laboratory analyses performed, sources of financial assistance, and the amount of time spent in each phase of the care continuum. The platform facilitates programme monitoring and evaluation and allows local governments to make data-driven decisions on resource allocation, create solutions to pain points and causes of delay, and strengthen their requests for funding.

### Engage government leaders to prioritise cancer

The programme's success and sustainability hinge on its partnership with committed government leaders, engaging the political determinants of health.[11] Although ICanServe has seen success in cities such as Taguig, replicating this impact has not been without challenges. In some instances, securing partnerships with local leaders has proven difficult, particularly when health issues were not prioritised. Political will remains a key driver of success.

With the Universal Health Care Act (UHC) of 2019 also in motion, integrating cancer control and early detection is crucial.[4] The Government and advocates must ensure cancer is not left out, especially at the primary health-care level, the cornerstone of the UHC. Patient-led efforts can facilitate equitable implementation of the UHC.

## Conclusion

Ating Dibdibin can be a springboard to establish a breast cancer control programme that can branch out to other types of cancer. Other local government partners have used the same programme principles of the Ating Dibdibin programme for cervical cancer control.

ICanServe's Ating Dibdibin programme offers valuable insights for countries facing similar challenges in breast cancer control, showing that patient-led efforts are not only viable but successful in low-income and middle-income settings. The programme's success hinges on the commitment of patient advocate leaders to inspire and engage government leaders who can understand the value of health initiatives and health investments.

Ating Dibdibin also highlights the critical role of patient navigators in ensuring timely and appropriate access to care and in enhancing a local government health system so it fulfils the GBCI targets, facilitating earlier diagnosis and lower morbidity and mortality.

The experience shows that cancer survivors and advocates can be more than just a source of social and emotional support; they can be architects of change, empowering patients to navigate the health-care system, advocate for better access, and, ultimately, ensure no woman faces breast cancer alone.

We declare no competing interests.

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1 Bray F, Laversanne M, Sung H, et al. Global cancer statistics 2022: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. *CA Cancer J Clin* 2024; **74:** 229–63.

2 Co LMB, Dee EC, Eala MAB, Ang SD, Ang CDU. Access to surgical treatment for breast cancer in the Philippines. *Ann Surg Oncol* 2022; published online Aug 1. https://doi.org/10.1245/s10434-022-12311-8.

3 Montemayor T. 65% of breast cancer cases in PH diagnosed in advanced stage. Philippine News Agency, Oct 6, 2023. https://www.pna.gov.ph/articles/1211314 (accessed Sept 24, 2024).

4 Dee EC, Ang CDU, Ting FIL, Tangco ED, Eala MAB. Improving cancer care in the Philippines: the need for deliberate and careful implementation of the National Integrated Cancer Control Act. *Lancet Reg Health West Pac* 2022; **28:** 100615.

5 Tiangco B, Daguit SEJ, Astrologo NC, Flores L, Parma RN, Celi LA. Challenges in the maintenance of an open hospital-based cancer registry system in a low-to-middle-income country (LMIC): 2017–2022 experience. PLOS Digit Health 2024; **3:** e0000328.

6 Ho FDV, Arevalo MVPN, de Claro PTS, et al. Breast and cervical cancer screening in the Philippines: challenges and steps forward. *Prev Med Rep* 2022; **29:** 101936.

7 Eala MAB, Dee EC, Ginsburg O, Chua MLK, Bhoo-Pathy N. Financial toxicities of cancer in low- and middle-income countries: perspectives from Southeast Asia. *Cancer* 2022; **128:** 3013–15.

8 Feliciano EJG, Ho FDV, Yee K, et al. Cancer disparities in Southeast Asia: intersectionality and a call to action. *Lancet Reg Health West Pac* 2023; **41:** 100971.

9 Hartigan-Go K, Valenzuela S, Prieto M. [OPINION] Barangay health workers need more than recognition. Rappler, May 3, 2023. https://www.rappler.com/voices/ispeak/opinion-barangay-health-workers-need-more-than-recognition/ (accessed Sept 24, 2024).

10 PhilAtlas. Taguig. PhilAtlas. https://www.philatlas.com/luzon/ncr/taguig.html (accessed Sept 24, 2024).

11 Dee EC, Eala MAB, Robredo JPG, et al. Leveraging national and global political determinants of health to promote equity in cancer care. *J Natl Cancer Inst* 2023; **115**: 1157–63.