

# 2019 NPCR MASSACHUSETTS SUCCESS STORY

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*Recruitment Success: Partnering with Dana-Farber Cancer Institute to Increase Enrollment in Breast Cancer Survivorship Study*

## NATIONAL PROGRAM OF CANCER REGISTRIES SUCCESS STORY

**SUMMARY:** Dana-Farber Cancer Institute (DFCI) is conducting a study, Pathways to Wellness, whose primary objective is to evaluate the efficacy of two different types of group interventions (mindfulness meditation and survivorship education), specifically designed to meet the needs of younger female breast cancer survivors (diagnosed  $\leq 50$ ), in reducing depressive symptoms compared to a usual care control group. The study is conducted in collaboration with the University of California, Los Angeles (UCLA) Jonsson Comprehensive Cancer Center and the Johns Hopkins Kimmel Cancer Center, and it is funded by UCLA and the National Institutes of Health. The Massachusetts Cancer Registry (MCR) assisted in study recruitment by mailing 4,000 letters to young breast cancer survivors with information regarding the study.

**CHALLENGE:** There were several challenges:

1. Recruitment - The DFCI Pathways to Wellness researchers had challenges with recruitment in previous study cohorts since they had access to a limited patient pool. Previous cohorts were under-enrolled by almost half (15-20 participants vs the expected 30) and participants were mostly white and of a high socio-economic status.
2. Criteria for mailing - Initially, DFCI researchers requested that the MCR mail a recruitment packet to all early stage breast cancer cases diagnosed in women 50 years of age or younger during the period 2014-2017. To make the mailing more manageable, we had to narrow down the geographic criteria to target those who would be more likely to participate.
3. Mailing logistics and supplies - This effort required coordination of many resources, such as securing supplies, postage, staff to prepare the mailing, and room space; determining whose contact info to include for potential participants who had questions; and obtaining confidentiality pledges from those working on the mailing.
4. DCIS and LCIS - We discovered that we should have considered whether to include DCIS and LCIS cases. Some women with these diagnoses are told they do not have cancer even though they are reportable to the MCR. We became aware of this issue only after recruitment letters were sent and a handful of women called to say they had never been diagnosed with breast cancer.

**SOLUTION:**

1. Recruitment - The MCR partnered with Dana-Farber Cancer Institute to expand recruitment efforts by mailing letters to potentially eligible patients.
2. Criteria for mailing - Study participation requires a weekly class attendance for 6 weeks at DFCI in Boston, so criteria for the mailing were narrowed to residents in counties within a certain proximity to Boston as they would be more likely to attend.
3. Mailing logistics and supplies - Responsibilities for staffing and supplies were divided equitably between the MCR and DFCI: MCR provided and paid for envelopes with a pre-printed return address as well as address labels with recipients' names, and they also reserved conference rooms. DFCI staff made copies of the introductory letter from MCR and the flyer, and they provided stamps and staff to conduct the mailing at MDPH offices. We decided that the MCR would just be the conduit for reaching the women, and all subsequent communication from potential participants would be directed to the Pathways to Wellness staff, not the MCR director.
4. DCIS and LCIS - In the future, we will deal with DCIS and LCIS cases by either sending a separate letter that refers to a breast 'condition' rather than breast cancer, or, depending on the study, excluding these cases entirely.

**RESULTS:** The MCR mailing helped the current Pathways to Wellness study cohort double enrollment compared to previous cohorts. In the past, enrollment was steady at 15-20 participants per cohort, while this one enrolled 33 participants. Twenty of the 33 were recruited as a result of the MCR mailing. About 150 people total contacted the Pathways to Wellness researchers with interest in or questions about the study after receiving the MCR mailing, and many of those were subsequently screened but were either not available during the intervention class period, not interested, or ineligible (PHQ depression screener too low, presence of local recurrence, disqualifying comorbidities, etc.).

The mailing significantly increased the number of participants enrolled who did not receive their breast cancer treatment at DFCI. In previous cohorts, only one or two participants (10%) were coming from outside institutions, but in the current cohort there are 12 non-DFCI participants (35% of the cohort). The study has become more accessible to and inclusive of the broader eastern Massachusetts patient population, and the true number of non-DFCI patients is probably higher since some participants may have come to DFCI for a second opinion (and thus be technically classified as DFCI patients) but then received their treatment elsewhere. Even some participants who were treated at DFCI reported that they were recruited through the MCR letter, so the mailing either reached them when previous internal mailings had not, or it was a more effectively presented message coming from the MCR than from DFCI.

The DFCI staff received far more inquiries from people of diverse racial and socio-economic groups than in previous cohorts, and participants in the current cohort represent a wide swath of race/ethnicity, national origin, BMI, and socio-economic status. The study data have become more representative and results may be more generalizable. This fact alone, given historical and continuing disparities in research data, justifies continued utilization of the MCR as a tool for study recruitment.

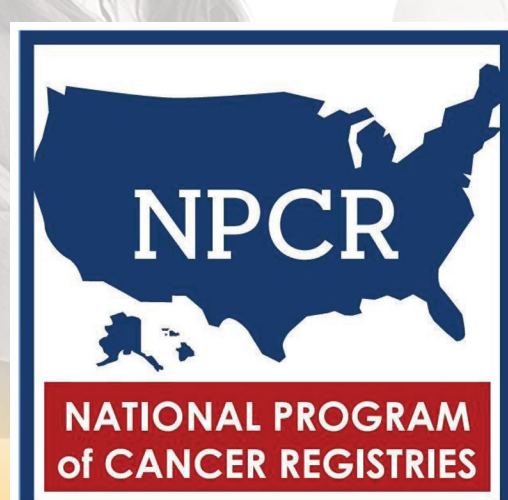
Three people called the DFCI staff to express confusion or anger about receiving a letter, and many more had questions about how their health information was shared without their knowledge. The cover letter provided an explanation as to why they were receiving the mailing, but this either went unread or was not clear to everyone who received it. The existence and purpose of the MCR was completely unknown and respondents were not aware that their treating institutions are required to report cancer diagnoses to the state. Several asked to be removed from the registry entirely, or at least not contacted again. This seems to be an unavoidable side effect to contacting a large number of people, but some confusion may be alleviated in future mailings if the explanation of the MCR's purpose is expanded and made even more explicit.

**SUSTAINING SUCCESS:** This collaboration provided an opportunity to use MCR data in a different way than usual. It was extremely gratifying to MCR staff to hear of the success of this effort in increasing enrollment numbers and reaching women who otherwise would not have been aware of this study. Most important, study participation could have a direct positive impact on a patient's quality of life after diagnosis. This pilot run for using the MCR to aid in recruitment was an all-around positive experience so the MCR has agreed to help another researcher with a similar effort. The success of this effort encourages us to continue to be open to new uses of MCR data.

**CONTACT INFORMATION:**

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<https://www.mass.gov/massachusetts-cancer-registry>



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