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THE NATIONAL BREAST CANCER COALITION

AN EVALUATION OF WORK OVER THE BREAST CANCER DEADLINE 2020 PERIOD (2011-2019)

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Impact of NBCC and the Breast Cancer Deadline 2020

Through the Breast Cancer Deadline 2020 and the Artemis Project, the National Breast Cancer Coalition (NBCC) has advanced breast cancer research and development to stop metastasis and develop a preventative vaccine. Most notably, NBCC help catalyze the development of a preventative breast cancer vaccine.

NBCC played a unique role in these advancements and in the breast cancer research and development (R&D) ecosystem due to **NBCC's mission-driven approach** and ability to develop research collaborations and seed new research. During the Deadline period, NBCC:

- Convened 147 motivated researchers and advocates to develop new collaborations and pathways for R&D through the Artemis Project.
- Assisted with the development of a preventative breast cancer vaccine and an application for vaccine clinical trials in 2019 while simultaneously organizing the research community around other promising pathways for prevention.
- Involved advocates in meaningful ways in creating new pathways for R&D.
- Produced clear-eyed assessments of the breast cancer R&D ecosystem. In particular, NBCC's understanding of the institutional structure and incentives of various R&D actors has allowed NBCC to identify gaps in the R&D system pertaining to stopping metastasis and developing a preventative vaccine—gaps NBCC has helped fill.
- Provided a leading voice in the advocacy and policy communities for a mission-driven approach to R&D critical to ending breast cancer.

NBCC's advocacy, policy, and R&D accomplishments over the Deadline period achieved the following strategic goals from NBCC's *Blueprint for the Breast Cancer Deadline 2020*:

- Facilitated collaboration across research disciplines.
- Leveraged existing financial resources.
- Changed the conversation about breast cancer from awareness and screening to prevention and saving lives.
- Mobilized the breast cancer advocacy community towards ending breast cancer.

These impacts and actions build on NBCC's history of accomplishments:

- Led the successful $300 Million More campaign and the creation of the Department of Defense's Breast Cancer Research Program.
- Through Project LEAD, trained approximately 2,500 advocates to participate in research funding decisions, clinical trials, and legislative advocacy.
- Conveyed a unique and powerful voice in shaping clinical trials, care, federal policy, and R&D through the involvement of advocates.

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Summary

This evaluation centers on the impact of the National Breast Cancer Coalition's (NBCC) research and advocacy programs and efforts, with an emphasis on NBCC's work after NBCC announced the Breast Cancer Deadline 2020 in 2010. I used documents, meeting minutes and agendas, press releases, scholarly literature, and interviews with NBCC leadership and affiliated researchers to examine the impact NBCC has made in lives and in the larger breast cancer research and advocacy ecosystem.

NBCC takes a radically mission-oriented approach to its work in the research community, as embodied in NBCC's Breast Cancer Deadline 2020, the goal of which was to know how to prevent breast cancer and stop it from metastasizing. NBCC's systemic understanding of research and development—including the connections among policy, scientific research, patient outcomes, and institutional structures—makes NBCC and its impact unique within the field of breast cancer research and advocacy. This systemic view pervades NBCC's work over the deadline period, including the deadline itself, strategic research initiatives, NBCC's policy advocacy, and NBCC's advocacy training programs. NBCC has leveraged that perspective through programs to train advocates, steer research enterprises, and develop collaborations and research opportunities with break through potential for patient outcomes.

NBCC's Artemis Project brought together leading researchers and trained advocates to advance promising pathways for a vaccine to prevent breast cancer and ways to stop metastasis. The Artemis Project was able to catalyze vaccine research—a clinical trial for a vaccine that emerged from the Artemis Project meetings is planned for 2020—due to NBCC's ability to seed collaborations and breakthrough research towards the Breast Cancer Deadline 2020 goals. NBCC's policy advocacy work has advanced their mission-driven emphasis and sought to increase access to care, though some NBCC legislation has yet to advance beyond Congressional committees. NBCC has trained hundreds of advocates to steer and support research, policy advocacy, and community building. In 2018 alone, NBCC-trained advocates contributed to 44 different committees and advisory boards for breast cancer research and care, including committees at the National Cancer Institute, the National Institute for Environmental Health Science, and the Department of Defense Breast Cancer Research Program.

NBCC's work over the Deadline period has realigned the breast cancer research and development ecosystem and created new communities of researchers and advocates towards the goal of ending breast cancer. NBCC's system-oriented approach allows it to play a qualitatively different role in the innovation ecosystem than other research institutions or advocacy organizations. NBCC provides a mission-driven voice to research and advocacy and has accelerated R&D and the breast cancer community towards the goal of ending breast cancer.

Evaluation Scope and Outline

This evaluation addresses the following questions: In what ways are NBCC's actions and programs unprecedented across the Deadline period? How has NBCC impacted research and patient advocacy? What difference has NBCC made in systems and lives? It is broken out into three sections. The first section outlines the larger breast cancer research ecosystem in which NBCC operates. Section two outlines NBCC's research, policy, and advocacy work.. Finally, section four presents a summary of NBCC's impacts for patients and systems.

1. The Breast Cancer Research Ecosystem

This evaluation centers on the National Breast Cancer Coalition's (NBCC) work with an emphasis on their programs and efforts after their Breast Cancer Deadline was established in 2010. NBCC's work, however, exists in a larger ecosystem of research, innovation, and practice around breast cancer, which I describe here. This is not meant to be an exhaustive description of the innovation system around breast cancer care and treatment—for example, it does not describe the federal government's role in approving treatments for breast cancer. Rather, this description puts NBCC's work into context to better demonstrate NBCC's impact on this ecosystem. Three main sectors compose the breast cancer innovation ecosystem in the United States: Federal agencies, nonprofit and philanthropic organizations, and private industry.

The innovation ecosystem for breast cancer is diffuse and distributed, with many actors working in the field but with little coordination among actors due to the outsized role of linear model approaches and existing institutional incentives.

Within the U.S. Federal government, the National Institutes of Health (NIH) and Department of Defense (DOD) administer substantial breast cancer research portfolios. The National Cancer Institute (NCI) and National Institute of Environmental Health Sciences (NIEHS) compose the majority of NIH's investments in breast cancer research[1]. The Breast Cancer Research Program represents the majority of the DOD's investment ($130 million in FY19) in research on breast cancer[2]. Importantly, the BCRP was congressionally mandated following advocacy efforts headed by NBCC in the 1990's.

NIH's approach to research funding is best described as investigator-driven. For external research (i.e., research conducted outside of NIH itself; also called extramural research) NIH hosts competitive grant programs evaluated on scientific merit through a peer-review system. A secondary review of research proposals is conducted by center or institute panels that include

[1] NCI's fiscal year 2017 budget was $5.9 billion, while NIEHS was $770 million. Only a portion of these budgets went to breast cancer research. https://www.niehs.nih.gov/about/congress/justification/2018/2018scj/sumtables/sum-budgetrequest/index.cfm

[2] https://cdmrp.army.mil/bcrp/default

scientists and other stakeholders, such as representatives from patient advocacy organizations. These panels review proposals based on societal considerations about impact and NIH planning goals. NIH distributes around 80% of its research funds through open solicitations for research within broad programs (known as Parent Announcements). NIH also funds research through more directed requests for proposals targeted towards narrow topics (known as Program Announcements or Requests for Applications). This reliance on investigator driven ideas for research emphasizes scientific merit and relies on research directions as expressed by investigators in written proposals and review of proposals by other scientists. Historically, this approach to research funding preserves the independence of scientists to pursue research they find most interesting and promising[3]. Internal research at NIH—also known as intramural research—is likewise driven by investigator priorities.

This model of research investment emphasizes independent scientific advancement as critical to developing treatments. A corollary of this approach is that more and better scientific research will open opportunities to apply that knowledge in service of outcomes. This model of research policy is known as the linear model of innovation whereby basic research is seen as the basis for technological or practical applications and subsequent societal outcomes. The linear model holds that scientists are best able to evaluate promising avenues for research through which applications like treatments and technologies will be discovered. Further, the unpredictable outcomes of research mean that the best science is the best precursor to social ends and that science should be undertaken independent of considerations of its application[4]. The linear model of innovation has guided decades of science policy in the United States following federal investment in science during and shortly after World War II[5]. NIH's mission builds on this model through its emphasis on basic research as the foundation for better health outcomes for the nation.

Scholars of innovation, however, have noted the weakness of the linear model of innovation. The notion that the path from research to societal outcomes is unpredictable masks accountability for those outcomes when public money is put towards them. More damning, however, is a history of more directed research and development of technologies and scientific applications. The discovery and development of the transistor by Bell Labs, for example, was guided by Bell Labs' commercial interests to improve telephone relays but was shaped to a large degree by the mission

[3] Scientific independence was a key factor in creating the legislative framework for NIH and other federal research entities in the 1950s; see McGeary, M., & Cook-Deegan, R. (2014). Biomedical Research Policy and Innovation (1940s-Present). In T. R. Oliver (Ed.), *Guide to U.S. Health and Health Care Policy* (pp. 181–195). CQ Press.

[4] Michael Polanyi's 1962 defense of the linear model, entitled *the Republic of Science*, provides a good overview of the linear model of innovation and associated approaches to research governance. Polanyi, M. (1962). The Republic of Science: It's Political and Economic Theory. *Minerva*, *1*(1), 54–73.

[5] Vannevar Bush, who shaped post-WWII scientific agencies in the U.S., somewhat formalized the linear model in U.S. scientific agencies. For further discussion of the linear model's history in American Science Policy, see Lane, N. (2011). Science Policy Tools: Time for an Update. *Issues in Science and Technology*, (Fall). Retrieved from http://www.issues.org/28.1/lane.html

of the U.S. Army Signal Corps[6]. Indeed, mission-driven research undergirds the approach of some R&D agencies within the federal government, such as the US Department of Defense's Defense Advanced Research Projects Agency (DARPA)[7]. Noting these mission-driven examples, scholars of science and technology policy have emphasized the utility of using goals and missions to organize scientific investment[8]. In medicine and health care, Nelson et al. pointed to three mechanisms through which medical know-how progresses: Advances in scientific understanding of disease, the development of new technologies that enable progress in treatment and diagnosis (e.g., x-rays), and clinical practice[9].

Historically, federal investment in biomedical research has been channeled through NIH's linear-model approach to innovation. Notably, NBCC spearheaded a congressional push to create the Breast Cancer Research Program (BCRP) within DOD in 1991, one example of federal mission-driven biomedical R&D[10]. BCRP targets research with clinical importance with an emphasis on prevention and improving treatment outcomes[11]. With its $130 million budget, the BCRP is substantially smaller than NCI—of NCI's $5.9 billion budget in FY19, around $545 million was invested in breast cancer research[12]. This evaluation details NBCC's involvement in the BCRP through patient advocates in section 2.4.

Many nonprofit and philanthropic organizations also fund and promote breast cancer research. The Susan G. Komen Foundation and the Breast Cancer Research Fund invest millions of dollars in breast cancer research and advance advocacy agendas. These organizations largely emulate the NIH in their approach to decision-making about *what* research to fund: Scientific advisory panels largely composed of researchers evaluate proposals to these groups' competitive research grant programs.

Within industry, comprehensive data about R&D for breast cancer treatment and research are unavailable. However, McGeary and Cook-Deegan, referencing data provided by a major pharmaceutical trade group, reported that R&D investment by industry has largely tracked with federal investment in health-related R&D[13]. But increases in industry R&D expenditures have not always led to tools for treatment or patient outcomes. Declan Butler, a reporter with the journal

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[6] Misa, T., J. (1985). Military needs, commercial realities, and the development of the transistor, 1948-1958. In *Military Enterprise and Technological Change: Perspectives on the American Experience* (pp. 253–287). Cambridge, MA: MIT Press.

[7] The mission-driven success of DARPA has spurred similar organizations in other federal agencies, such as the Advanced Research Projects Agency-Energy (ARPA-E) in the U.S. Department of Energy.

[8] See for example, Sarewitz (2016). Additionally, other problems have plagued science after decades of relying on the linear model of innovation, from a lack of outcomes to poor incentive structures within the scientific and research industry. Sarewitz, D. (2016). Saving Science. *The New Atlantis*, (Spring/Summer), 5–40.

[9] Nelson, R. R., Buterbaugh, K., Perl, M., & Gelijns, A. (2011). How medical know-how progresses. *Research Policy*, *40*(10), 1339–1344. https://doi.org/10.1016/j.respol.2011.06.014

[10] http://www.breastcancerdeadline2020.org/get-involved/public-policy/

[11] https://cdmrp.army.mil/bcrp/

[12] https://www.cancer.gov/about-nci/budget/fact-book/data/program-structure, https://www.cancer.gov/about-nci/budget/fact-book/data/research-funding

[13] McGeary & Cook-Deegan (2014).

Nature, referred to this disconnect as the 'valley of death'[14]. While private industry conducts research alongside university and medical research centers, conducts clinical trials, and partners with nonprofit and philanthropic organizations, it relies substantially on research and literature stemming from the larger R&D ecosystem.

R&D Ecosystem Summary

The innovation ecosystem for breast cancer is diffuse and distributed, with many actors working in the field but with little coordination among actors due to the outsized role of linear model approaches and existing institutional incentives. The federal government contributes substantial funds to research—more than any other individual actor—but the federal government does not play a coordinating role in that research. Major R&D efforts within the federal government rely substantially on investigator-driven approaches to the setting of research priorities. Notable exceptions within this innovation ecosystem include the DOD's BCRP, which attempts to identify and fund promising research through its mission-driven structure. This leaves a sizable gap within the system as research funding and research resources are deployed in ways not always designed to lead to outcomes for those with breast cancer or who may one day develop breast cancer.

2. NBCC's Work and the Breast Cancer Research Ecosystem

To understand the difference NBCC has made in systems and lives, I examined documents, press releases, meeting notes, and other materials made available from NBCC, including results from NBCC-led surveys sent to NBCC-affiliated advocates. I conducted interviews with scientists and researchers who participated in NBCC-led meetings and interviews with NBCC staff and leadership. I also examined publicly available documents from other breast cancer organizations to better differentiate NBCC's role in the breast cancer research, advocacy, and treatment systems. The next sections detail NBCC's approach to research, policy, and advocacy.

NBCC's strategic and mission-driven approach to breast cancer R&D and advocacy has helped fill gaps in the breast cancer research ecosystem.

NBCC's approach to R&D, advocacy, and policy making around breast cancer differs from other organizations in several important ways. First, that NBCC *even made a deadline* for ending breast cancer (the focal point of this evaluation) is unique and demonstrates a different, more strategic and mission-driven focus to breast cancer research and care. Second, NBCC led workshops attended by breast cancer advocates, researchers, and other stakeholders to shape promising pathways towards being able to end cancer by the 2020 deadline. In prioritizing certain pathways and leveraging funding to develop those pathways, NBCC takes a markedly different approach to R&D than federally-supported programs and other non-profit organizations—an approach that accounts for

[14] Butler, D. (2008). Translational research: Crossing the valley of death. *Nature*, *453*(7197), 840–842. https://doi.org/10.1038/453840a

gaps in the breast cancer treatment innovation and research ecosystem. Finally, NBCC's approach to advocacy contributes to the R&D system in unique ways.

2.1 The Breast Cancer Deadline 2020

In 2010, NBCC publicly announced the Breast Cancer Deadline 2020 as a call to action for the breast cancer community to "know how to end breast cancer by 2020"[15]. Initially, NBCC set out to develop plans for a preventative vaccine, though NBCC's strategic plans stemming from the deadline expanded to include metastasis. In subsequent documents, NBCC announced the deadline as a way to galvanize action among the innovation ecosystem for breast cancer research, prevention, and treatment, to coordinate research around these goals, and to renew a sense of urgency around breast cancer[16]. In 2012, NBCC released a plan blueprint to achieve the deadline[17]. The components from this document are summarized in Table 1.

Table 1. Major strategic goals from "*A Blueprint for the Breast Cancer Deadline 2020*"

1. Facilitate collaboration in all areas and minimize unnecessary competition. 2. Leverage existing financial resources to harness the knowledge and experience of years of research to catalyze innovation. 3. Develop a global strategy to ensure that individuals with, and at risk of, breast cancer have access to information, quality care and scientific advances. 4. Change the conversation [from awareness and screening to prevention and saving lives] 5. Mobilize the breast cancer advocacy community
Note: Each of these major goals included several specific strategies for achievement. The blueprint is available here: http://www.breastcancerdeadline2020.org/assets/pdfs/breast-cancer-deadline-2020.pdf

The deadline itself embodied strategic goals 4 and 5 listed in Table 1. As both a plan and a piece of research policy assessment, the plan addresses several facets of the breast cancer R&D ecosystem that few other actors acknowledge so plainly. First, the plan acknowledged that the, "lack of progress [in preventing breast cancer deaths] is not due to insufficient research funds," and that *understanding* of breast cancer does not automatically equate to better health outcomes. This acknowledgement points to NBCC's clear-eyed mission of ending breast cancer and to NBCC's systemic understanding of the innovation system for breast cancer prevention, treatment, care, and research. Questioning the link between research, understanding, and outcomes can garner critique from some in the scientific community. However, scholarship examining the role of science in solving societal challenges and examining different pathways through which innovation occurs supports NBCC's focus on what *outcomes for breast cancer patients* extend

[15] http://www.breastcancerdeadline2020.org/about-nbcc/newsroom/2010-press-releases/the-national-breast-cancer.html
[16] http://www.breastcancerdeadline2020.org/assets/pdfs/breast-cancer-deadline-2020.pdf
[17] http://www.breastcancerdeadline2020.org/about-nbcc/newsroom/2012-press-releases/NBCCUnveilsBlueprint.html

from understanding and research[18]. In other innovation contexts as divergent as nutrition sciences and climate change, more research does not automatically translate to better outcomes or progress in meeting challenges. Decades of research about salt consumption, for example, have done little to settle controversy over the health impacts of salt[19]. This is not to say that NBCC is ignoring marginal improvements in health outcomes for breast cancer patients, but rather that NBCC sees these improvements as insufficient and that more of the same type of research investment and more understanding have *not* translated to improved outcomes for many people who currently or may one day have breast cancer. NBCC's unique perspective highlights a blind spot within the field, suggesting that NBCC's differentiated approach helps diversify potential pathways to better outcomes for those with breast cancer. And even if one rejects NBCC's ambitious, deadline-driven approach to organizing research, the complexity of breast cancer prevention, treatment, and associated health outcomes requires a systems perspective and a diversity of approaches to better identify, pursue, and refine pathways to better patient outcomes. That NBCC is taking a different approach to organizing research and care towards ending breast cancer contributes to new pathways for prevention and treatment.

2.2 The Artemis Project

Towards facilitating collaboration and leveraging existing R&D resources (goals 1 and 2 from NBCC's Blueprint; see Table 1), NBCC convened regular meetings of researchers and advocates to identify pathways towards a preventative vaccine and stopping metastasis. The Artemis Project is and continues to be the primary mechanism through which NBCC coordinates R&D in light of their 2020 deadline. The Artemis Project is, "…an advocate led, innovative, mission-driven approach of strategic summits, catalytic workshops, research action plans and collaborative efforts of various stakeholders"[20]. Additionally, the Artemis Project sought to "[create] the infrastructure for collaboration around the development of [a preventative] vaccine," as outlined in a 2011 project plan[21]. The

The Artemis Project brought together advocates and researchers to catalyze R&D breakthroughs. Through nine years of Artemis Project meetings, NBCC created momentum in the breast cancer community to test a preventative vaccine in clinical trials.

[18] See Nelson et al. (2011) and Sarewitz (2016). Epstein's account of the involvement of AIDS activists in research also point other models of innovation focused on outcomes for research users. Epstein, S. (1995). The construction of lay expertise: AIDS activism and the forging of credibility in the reform of clinical trials. *Science of The Total Environment*, *240*(4), 408–437.

[19] Bayer, R., Johns, D., & Galea, S. (2012). Salt and Public Health: Contested Science and the Challenge of Evidence-Based Decision Making. *Health Affairs*, *31*(12), 2738–2746. https://doi.org/10.1377/hlthaff.2012.0554

[20] http://www.breastcancerdeadline2020.org/about-the-deadline/artemis-project.html

[21] SAIC for NBCC. (2011). *The Artemis Project Plan to Develop a Breast Cancer Preventative Vaccine: Identification of Targets & Immune System Variations*. Retrieved from http://www.breastcancerdeadline2020.org/assets/pdfs/artemis-project-plan-saic.pdf

description and evaluation of the Artemis Project presented below is based on NBCC documents, meeting agendas, invitee lists, notes from Artemis Project Meetings, interviews with NBCC staff and leadership, and interviews with three investigators who participated in Artemis Project Meetings.

At the core of the Artemis Project are catalytic workshops involving advocates, researchers, and other stakeholders. Broadly, Artemis Project meetings involved sharing the current state of research, assessing potential pathways for primary prevention and stopping metastasis, and the creation of plans for advancing research along those pathways. From 2011-2019, a total of 147 people, including patient advocates, researchers and investigators, and stakeholders from other institutions (e.g., federal agencies) participated in Artemis Project Meetings.

The first Artemis Project meetings were focused on exploring the potential for a preventative vaccine for breast cancer. These meetings focused on evaluating if technology and knowledge at the time indicated such a pursuit would be worthwhile. In the words of NBCC president Frances Visco, attendees at the earliest Artemis Meetings in 2011, "respected our work but thought we were crazy"[22]. Over subsequent meetings, scientists and advocates explored pathways for a preventative vaccine and ways to stop metastasis by identifying knowledge gaps, discussing approaches to clinical trials and related regulatory challenges, and sharing progress and updates from work stemming from prior Artemis meetings.

NBCC's emphasis on developing a preventative vaccine and stopping metastasis stemmed from their experience working with others in the breast cancer R&D ecosystem. NBCC identified these areas as 'gaps' within this system due to other priorities more engrained into research at the time, such as a strong emphasis on early detection of breast cancer[23]. While the DOD's BCRP also funds breakthrough research with the potential to shift R&D and treatment paradigms, NBCC saw preventative vaccines and stopping metastasis as research areas few researchers and agencies were discussing but with potential to radically change patient outcomes.

The approach of the Artemis Project, according to NBCC, was not based on the approach of another organization or entity. Rather, NBCC felt that years of calls for collaboration, interdisciplinarity, and the breaking down the silos separating researchers within the breast cancer research community had gone unheeded. NBCC noted driven, passionate researchers and other stakeholders from their decades of participation in the breast cancer R&D ecosystem, but also

[22] Interview with Frances Visco of NBCC. (2019, November 20).

[23] A focus on early detection through regular mammograms may, in part, be due to advances medical imaging technologies, an example of medical treatment advancing through technological changes rather than knowledge stemming from clinical practice and or basic science about disease. See Nelson et al. (2011). NBCC has, at times, been critical of changes to early detection and mammography screening recommendations stemming from public health agencies and care groups, noting that early detection does not equate to changes in mortality. An emphasis on early detection and associated treatment represents one paradigm that NBCC consistently noted as an inadequate focus of the R&D ecosystem. For a good discussion of the uncertainty surrounding breast cancer screening, see Welch, H. G., & Passow, H. J. (2014). Quantifying the Benefits and Harms of Screening Mammography. *JAMA Internal Medicine*, *174*(3), 448. https://doi.org/10.1001/jamainternmed.2013.13635

noted a lack of opportunities for such researchers to collaborate. Further, institutional incentives—in particular the ways researchers are rewarded for their work—did not always align to produce collaborative, interdisciplinary, and break-through efforts. NBCC saw the Artemis Project as one way to provide driven members of the R&D ecosystem with the opportunity to pursue bold research towards strategic ends with potentially system-changing results.

Artemis Project Participant Selection

For the first Artemis Project meetings, NBCC identified researchers working on either breast cancer-related vaccines or metastasis, along with researchers in related fields (e.g., medical anthropologists, evolutionary biologists, etc.). NBCC chose researchers who were willing to challenge the status quo of research and treatment, who had demonstrated research interest in topics related to Artemis Project goals, and who were dedicated to the cause. Initial participants were identified through NBCC's past work with the DOD BCRP and through connections made through conferences, meetings, and other professional interactions over the prior decades. From there, recruitment for participants 'snowballed' to include other researchers sharing diverse disciplinary backgrounds but passionate and dedicated to the goal of ending breast cancer through breakthrough research. Early on, NBCC made clear that Artemis Project meetings and research outputs were not about traditional research metrics such as scholarly publications or institutional prestige. Rather, the meetings were a space for researchers and advocates to work together to progress research towards a preventative vaccine and stopping metastasis.

Involvement of Advocates

Artemis Project meetings included trained advocates from NBCC to help shape the questions, research, and clinical trials discussed (see the next section for details about NBCC advocacy trainings). For NBCC, advocates provide a critical perspective to the R&D ecosystem. In an editorial to *the Cancer Letter*[24], NBCC's Visco noted that **the incentives for researchers, pharmaceutical companies, and funding agencies fail to align with needs of breast cancer patients nor innovation in breast cancer research.** Researchers are rewarded for publications, patents, and grants awarded, the private sector prioritizes profits, and funding agencies are steered by researchers' priorities and the commitments of institutions involved. Patient advocates care about patient outcomes, bringing clear-eyed direction to discussions about R&D and treatment pathways. The Artemis Project sought to guide collaborative R&D efforts by involving advocates well-versed in science and policy related to breast cancer R&D and treatment. Beyond contributing at meetings, advocates contributed to the Artemis Project by conducting academic

> ***"[Advocates] have no agenda other than to end breast cancer."***
>
> **Frances Visco in *the Cancer Letter* [24]**

[24] Visco, F. (2018). Conflicts have killed trust in the system. Advocates must rebuild it. *The Cancer Letter*, *44*(46), 10–12.

literature searches to inform potential vaccines and helping identify resources outside of NBCC that could further research and testing[25].

Outcomes of the Artemis Project

The Artemis Project promoted novel collaborations and research about tumor dormancy and vaccine targets and pushed the breast cancer community to test a vaccine in clinical trials. Early on, Artemis Project meetings led NBCC and the National Philanthropic Trust (NPT) to fund seed projects for identifying immunological targets for a vaccine[26] and infectious agents in breast cancer tumor cells[27]. In 2013, NBCC and NPT funded a seed grant focused on understanding the biology of ductal carcinoma in situ (DCIS) in order to identify other potential targets for vaccines[28]. Seed grants focused on understanding metastasis also emerged from collaborations at the Artemis Project, including one study funded to understand why some tumor cells lay dormant[29]. In 2018, Dr. Alana Welm and Dr. Cyrus Ghajar submitted a research proposal to Cancer Research UK to study how microenvironments impact tumor cell dormancy based on the Artemis Project meetings[30], highlighting the ability of these catalytic meetings to generate new ideas, proposals, and collaborations that further research and practice towards a preventative vaccine and means to stop metastasis. Researchers also highlighted this catalytic impact in interviews conducted for this evaluation (see below). As the Artemis Project progressed, investigators who received seed grants continued to participate in annual meetings to share their progress and inform next steps.

Through 2017 and 2018, the Artemis Project led to meetings among researchers, NBCC, and the Federal Drug Administration (FDA) to inform clinical trials on six antigens for a preventative vaccine[31]. In 2019, Artemis Project-affiliated researchers were preparing a formal application to FDA for the clinical trial[32]. While progress was being made on the first vaccine trials, the participants in the 2018 Artemis Project meeting started creating a framework for selecting other antigens for a potential vaccine[33]. **Through nine years of Artemis Project meetings, NBCC**

[25] Visco, F. (2015, May). *Keynote Address: At the Midpoint of Breast Cancer Deadline 2020*. Speech presented at the 2015 Advocate Leadership Summit, Washington, D.C. Retrieved from http://act.breastcancerdeadline2020.org/site/DocServer/President_s_Address_2015_Summit.pdf?docID=4941

[26] NBCC. (2012, October 9). National Breast Cancer Coalition Awards Seed Grant for Preventive Breast Cancer Vaccine. http://www.breastcancerdeadline2020.org/about-nbcc/newsroom/2012-press-releases/NBCCAwardsSeedGrant.html

[27] NBCC. (2013, February 6). National Breast Cancer Coalition Awards Additional Seed Grant for Preventive Breast Cancer Vaccine. http://www.breastcancerdeadline2020.org/about-nbcc/newsroom/2013-press-releases/NBCCAwardsSecondSeedGrant.html

[28] NBCC. (2013, November 6). National Breast Cancer Coalition Awards Grant to Look for Vaccine Targets in DCIS Samples. http://www.breastcancerdeadline2020.org/about-nbcc/newsroom/2013-press-releases/ArtemisSeedGrantforDCIS.html

[29] See the 2016 Artemis Project report: http://www.breastcancerdeadline2020.org/assets/pdfs/artemis/artemis-project-2016.pdf

[30] See the 2018 Artemis Project report: http://www.breastcancerdeadline2020.org/assets/pdfs/artemis/artemis-project-2018-final-1.pdf

[31] Ibid.

[32] See the 2019 Artemis Project report: http://www.breastcancerdeadline2020.org/assets/pdfs/artemis/2019-artemis-report-final.PDF

[33] See the 2018 and 2019 Artemis Project reports linked above.

has created momentum in the breast cancer community to test a vaccine in clinical trials while simultaneously organizing the research community around other promising pathways. This underscores NBCC's profound impact on the breast cancer community and the progress made towards a preventative vaccine. NBCC's ability to catalyze research and action around a preventative vaccine through the Artemis Projects demonstrates NBCC's unique contributions to patients and science through a deadline and mission-driven approach to research and advocacy. Capping these nine years, the 2019 Artemis Project meeting included open conversations exploring a diversity of other potential pathways for primary prevention, further demonstrating NBCC's commitment to mission over specific pathways, patents, research priorities, or institutional commitments[34].

Impacts on Artemis Scientists

Beyond the specific efforts and research advances highlighted above, the Artemis project contributed to changes in the research approaches of participating scientists. **Scientists have reported to NBCC leadership that the Artemis Project allowed them to pursue bold ideas and made lasting impacts on the way they approach their research.** All scientists interviewed for this evaluation pointed to the deeply collaborative nature of the Artemis Project meetings. While collaboration is often discussed as a goal of research funding strategies from other organizations in the breast cancer R&D ecosystem, participants in the Artemis Project noted a substantial difference between the Artemis Project meetings and efforts to foster collaboration by other organizations. Participants interviewed for this evaluation spoke of the highly integrative nature of the discussions at Artemis Project meetings. They noted that the meetings encouraged them to work through challenges outside of their own discipline to identify knowledge gaps that could contribute to stopping metastasis or the creation of a preventative vaccine, discussions that were unique to the Artemis Project meetings.

Together, these factors led to self-reported changes in the approach of researchers to their work. Dr. Keith Knutson worked on preventing tumor re-occurrence through vaccines when he joined the Artemis Project meetings in 2011. In an interview for this evaluation, Dr. Knutson noted how the Artemis Project greatly influenced his thinking about the feasibility of a primary prevention vaccine, which subsequently expanded his own approach to research as he took on a leading role in developing the clinical trials outlined above[35]. Dr. Alana Welm noted that the Artemis Project meetings encourage researchers to think about challenging problems related to metastasis and primary prevention. She noted, "I wouldn't have had the courage to focus on [dormancy in metastasis]," but the meetings led her to pursue this research with collaborators[36]. Dr. Cyrus Ghajar noted that the Artemis Project meetings, "free[d] conversations from thinking about grants… and focus on what's the best possible way to answer the question"[37]. For example, Dr. Ghajar recalled an Artemis Project meeting in which he joined a discussion about metastasis

[34] See pages 10-11 of the 2019 Artemis Project report.
[35] Interview with Dr. Keith Knutson of the Mayo Clinic. (2019, November 12).
[36] Interview with Dr. Alana Welm of the Huntsman Cancer Institute at the University of Utah. (2019, November 12).
[37] Interview with Dr. Cyrus Ghajar of the Fred Hutchinson Cancer Research Center. (2019, November 13).

and immunology, which was somewhat outside of his expertise: "[This discussion] turned into collaborations that answered questions about T-cells and led to some treatment pathways." More recently, Dr. Ghajar launched a project with other Artemis Project collaborators to further this work and test the ability of certain T cells to target metastatic tumors in human tumor tissue.

Ongoing and multi-pronged impacts

NBCC furthers the impact of the Artemis Project through continued engagement with researchers after annual Artemis Project meetings. Subgroups for the preventative vaccine and metastasis research helped sustain collaborations and leverage research funding from a variety of sources. Subgroups continue to meet remotely as frequently as every three weeks to evaluate progress and plan efforts. Through annual meetings, the creation of subgroups of researchers and collaborators, and regular meetings of those subgroups, NBCC helps to coordinate research, align goals and incentives, and encourage collaboration. Other organizations fund a great deal of research (e.g., federal agencies, the Susan G. Komen Foundation) and other organizations convene groups of researchers to share knowledge (e.g., major scientific conferences). NBCC, however, blends these different roles through the Artemis Project in service of the Breast Cancer Deadline 2020.

The approach of the Artemis Project differs from that pursued by other institutions in the breast cancer research ecosystem, such as other non-profits and federal research institutions, in its refusal to be limited by the linear model of innovation. Rather than emphasizing scientific novelty, publications, or other metrics associated with research excellence, the Artemis Project meetings connected leading researchers, advocates, and other stakeholders to pursue research and trials that may have been neglected or have otherwise stagnated. NBCC provided the mission, meetings, and trained advocates to spur change within the research ecosystem and ultimately guided the development of a preventative vaccine and advanced new treatment pathways for stopping metastasis.

2.3 Policy Advocacy

Throughout the Deadline period, NBCC conducted advocacy efforts with federal lawmakers to further the goals of the Breast Cancer Deadline 2020. Advocacy efforts helped advance all five of the strategic goals laid out in NBCC's Blueprint to End Breast Cancer (Table 1). These efforts built on decades of NBCC policy advocacy successes.

NBCC's History of Policy Advocacy

Across several decades, NBCC has shaped policy and successfully lobbied for changes to improve treatments, increase access to quality care, and further breast cancer research despite challenges associated with Washington's changing political climate. NBCC's recent advocacy work builds on their long history of successful legislative accomplishments. In the 1990's, NBCC led an effort to create the Breast Cancer Research Program at the Department of Defense to further potential breakthroughs in research and treatment while involving patient advocates in

decisions about research[38]. This effort was part of the $300 Million More campaign, an NBCC-led campaign that secured over $300 million for breast cancer research through the congressional appropriations process. As mentioned above, these legislative accomplishments underscore NBCC's strategic approach to breast cancer research and treatment: NBCC recognized that 1) federal investment would be required to address the hardest questions facing the breast cancer community and 2) high risk, high reward research embodied in the BCRP was critical to advancing research and treatment for patient outcomes.

Breast Cancer Deadline 2020 Policy Advocacy

NBCC's recent legislative advocacy efforts emphasized patient access to care and R&D goals related to the Deadline. The Accelerating the End of Breast Cancer Act, first introduced in 2012 and subsequently reintroduced in later congresses, would have promoted initiatives to develop measures to prevent breast cancer and metastasis that were, "not prioritized in the public sector and unlikely to be achieved by the private sector due to technical and financial uncertainty"[39]. As described above, the Deadline 2020 blueprint highlighted NBCC's keen mapping of the breast cancer research ecosystem. Likewise, the Accelerating the End of Breast Cancer Act shows NBCC's systemic approach to managing research, uncertainty, and the differentiated roles of private and public investment in breast cancer research. **The Accelerating the End of Breast Cancer Act would have created a federal commission charged with developing a strategic plan for ending breast cancer with these factors in mind—in short, empowering the values and intellectual strengths of the Artemis Project with federal support.** The act received bipartisan support in both the Senate and House of Representatives, including 53 Senate co-sponsors and 274 co-sponsors in the House, but failed to advance out of committee.

NBCC sought to replicate the intellectual strengths and outcomes of the Artemis Project through the Accelerating the End of Breast Cancer Act.

Several pieces of legislation that NBCC continues to support or shape seek to expand access to quality care. The Metastatic Breast Cancer Access to Care Act introduced in 2019 would eliminate waiting periods for patients with metastatic breast cancer who are on Medicare or Social Security Disability Insurance[40]. NBCC also pushed back on legislation that might have curtailed access to

[38] Institute of Medicine (US) Committee to Review the Department of Defense's Breast Cancer Research. (1997). U.S. Army Breast Cancer Research Program. In *A Review of the Department of Defense's Program for Breast Cancer Research*. Retrieved from https://www.ncbi.nlm.nih.gov/books/NBK233669/

[39] See the summary for the 2015 version of the bill from the Senate: https://www.congress.gov/bill/114th-congress/senate-bill/746. Bill summary from the House of Representatives: https://www.congress.gov/bill/114th-congress/house-bill/1197. See NBCC's press release about the act here: http://www.breastcancerdeadline2020.org/about-nbcc/newsroom/2016-press-releases/national-breast-cancer-4.html

[40] Bill summary from the Senate: https://www.congress.gov/bill/116th-congress/senate-bill/1374. Bill summary from the House or Representatives: https://www.congress.gov/bill/116th-congress/house-bill/2178. See NBCC's press release about the act here:

affordable health care, including the Better Care Reconciliation Act[41] and the American Health Care Act[42]. These efforts demonstrate NBCC's commitment to outcomes for breast cancer patients: Access and affordability moderate the impacts of advances in breast cancer treatment, care, and prevention.

NBCC contributes to broader public discourse about breast cancer prevention, mammography screenings, care, and research. Over the last two decades, researchers, clinicians, and advocates have debated the merits of regular mammograms for early detection of breast cancer. NBCC contributed to this public discourse both through press releases and articles in periodicals[43]. NBCC advocated for the use epidemiological studies of the benefits of annual mammograms in creating screening recommendations, noting that screenings can lead to false positives and over-treatment at rates higher than deaths avoided due to early detection[44]. NBCC's stance built on findings from public health literature and a belief that patients should have access to more information about the harms and benefits of regular mammography screenings[45]. NBCC's statements reinforced the need for individuals to evaluate the risks and benefits of screening in making decisions about their care while also noting that a focus on early detection of breast cancer does not equate to preventing the deaths of tens of thousands of women and men each year in the U.S. alone.

Beyond the priorities and accomplishments listed above, NBCC has advocated for the responsible and fair use of investigational treatments, federal support for treatment for those diagnosed with breast cancer, and the involvement of patient advocates in research and clinical trials. **Throughout the Deadline 2020 period, NBCC's advocacy efforts have preserved access to care and promoted research efforts that prioritize patient outcomes. These efforts speak to NBCC's systemic approach to research and care for current and future patients.**

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http://www.breastcancerdeadline2020.org/about-nbcc/newsroom/2018-press-releases/national-breast-cancer-1-1.html

[41] See a bill summary here: https://www.budget.senate.gov/imo/media/doc/ERN17500.pdf. NBCC's statement on the Better Care Reconciliation Act of 2017 is available here: http://www.breastcancerdeadline2020.org/about-nbcc/newsroom/-2017-press-releases/national-breast-cancer-2.html

[42] See a bill summary here: https://www.congress.gov/bill/115th-congress/house-bill/1628. NBCC's statement on the American Health Care Act is available here: http://www.breastcancerdeadline2020.org/about-nbcc/newsroom/-2017-press-releases/national-breast-cancer.html

[43] See, for example, NBCC's President Frances Visco's contribution in the Huffington Post: https://www.huffpost.com/entry/new-studies-for-an-old-story-mammography-screening-isnt-saving-lives_b_8033770

[44] Welch, H. G., & Passow, H. J. (2014). Quantifying the Benefits and Harms of Screening Mammography. *JAMA Internal Medicine*, *174*(3), 448. https://doi.org/10.1001/jamainternmed.2013.13635

[45] See, for example, NBCC's 2015 statement on the United States Preventive Services Task Force's screening recommendations (http://www.breastcancerdeadline2020.org/about-nbcc/newsroom/2015-press-releases/nbcc-statement-on-u.html) or NBCC's letter to the Federal Drug Administration regarding the Mammography Quality Standards Act (http://www.breastcancerdeadline2020.org/assets/pdfs/fda-letter-june-2019.pdf). Notably, both statements emphasized current understanding of the benefits and harms of screenings and cited numerous studies on the subject.

Undergirding these efforts, NBCC has trained hundreds of advocates to participate in legislative advocacy, clinical trials and clinical trial design, and research funding decisions.

2.4 Advocacy Training and Advocate Impact

NBCC's impact on research, policy, and patients stems directly from the involvement of trained advocates. Over the Deadline 2020 period, NBCC's Project LEAD—their long-standing advocate training program—and Advocate Leadership Summit programs have diversified to match the goals of the Breast Cancer Deadline 2020. Project LEAD extends across all five strategic goals of the Deadline 2020 Blueprint (see table 1) by empowering advocates to make change towards those goals through participation in research, policy advocacy, and outreach. As noted in prior sections of this evaluation, NBCC brings systematic understanding of the breast cancer R&D ecosystem to its work with policy makers and researchers. Project LEAD builds on that understanding by equipping hundreds of advocates to contribute to research, policy, and advocacy.

Project LEAD

Established in 1995, Project LEAD trains advocates in science and research through a week-long training program and an online and in-person continuing education program to accelerate learning. Advocates must be involved in the breast cancer advocacy community to apply to the program and NBCC covers the costs of participation for NBCC members. Trained advocates serve on research panels, local or regional research committees, and inform research through participation in the design of clinical trials and other efforts. Project LEAD graduates have steered major clinical trial efforts through their participation, such as the TAILORx trials conducted to evaluate the effectiveness of chemotherapy when used with other treatments[46] and clinical trials for treatments of hereditary breast cancer[47]. In 2018 alone, NBCC-trained advocates contributed to 44 different committees and advisory boards for breast cancer research and care[48]. These included committees at the National Cancer Institute, the National Institute for Environmental Health Science, and DOD's Breast Cancer Research Program. NBCC estimates that more than 2,500 people have participated in Project LEAD since its creation in 1995[49].

Piloted in 2016 and 2017 and continued through 2019, NBCC's Advanced Project LEAD program trains a small cohort of advocates for more intensive leadership roles in shaping breast cancer

[46] See here for a summary of the TAILORx project: https://www.cancer.gov/news-events/press-releases/2018/tailorx-breast-cancer-chemotherapy. The study showed, "no benefit from chemotherapy for 70 percent of women with the most common type of breast cancer," an important finding given the side-effects of chemotherapy. See here for NBCC's statement on the involvement of NBCC-trained advocates in the project: http://www.breastcancerdeadline2020.org/about-nbcc/newsroom/2018-press-releases/national-breast-cancer-1.html.

[47] See NBCC's statement on their partnership with BioMarin Pharmaceutical Inc.'s clinical trials: http://www.breastcancerdeadline2020.org/about-nbcc/newsroom/2013-press-releases/NBCCandBioMarinCollaborate.html

[48] A list of all committees on which an NBCC-trained advocate served in 2018 is available from NBCC: http://www.breastcancerdeadline2020.org/assets/pdfs/nationalcommittees.pdf

[49] Personal communication with Michelle Tregear of NBCC. January 31, 2019.

research, particularly through their participation in Artemis Project meetings. Participants in the Advanced Project LEAD training devise, hone, and write a research proposal or policy paper on a critical breast cancer issue with the assistance of NBCC and researchers. The process of writing a research proposal or policy paper immerses participants in the ever-changing landscape of breast cancer research to help develop their critical thinking and research abilities. Graduates of the Advanced Project LEAD program have participated in Artemis Project meetings, conducted literature reviews, and presented at scientific conferences[50]. Researchers who attended Artemis Project meetings and who were interviewed for this evaluation spoke highly of the advocates from the Advanced Project LEAD program. Researchers noted advocates' keen understanding of the science and their ability to keep discussions focused on strategic goals[51].

The Advocate Leadership Summit

NBCC's annual Advocate Leadership Summit brings NBCC-trained advocates to Washington, D.C. to learn about emerging issues in research, research governance, and policy. The Summit concludes with visits to congressional offices. Past topics shared at the Advocate Leadership Summit include Artemis Project-affiliated research findings, practical skills related to navigating science and breast cancer news in the media, and a variety of sessions on research governance[52]. Advocates were encouraged to consider issues of conflicts of interest in research, the ways advocates can shape and steer research and clinical trials, and policy proposals critical to breast cancer R&D and affordability and access to treatments. Past Summits have included workshops about leading grassroots breast cancer advocacy efforts.

Project LEAD and the Advocate Leadership Summit empowered thousands to change legislation and the R&D ecosystem.

The results of a NBCC-conducted survey of Project LEAD advocates in 2018 and 2019 demonstrate the broad impact of NBCC's training program. Of 338 advocates who answered a question about advocacy activities they have participated in, almost 60% reported advocating at a local or state breast cancer organization (Table 2). Around 40% participated in the scientific peer review process, applied to review for the DOD BCRP, served as an advocate for an organization focused on addressing health care disparities around breast cancer, or served on a research advisory panel. Twenty percent have served as an advocate in clinical trials. Individual advocates noted further activities, such as testifying at their state legislature, supporting

[50] This summary of the Advanced Project LEAD program is based on interviews with Frances Visco and Michelle Tregear of NBCC and on the following documents: NBCC's 2016 Annual Report (http://www.breastcancerdeadline2020.org/about-nbcc/annual-reports--finances/2016-annual-report.pdf); NBCC Fund's 2017 Financial Statements (http://www.breastcancerdeadline2020.org/about-nbcc/annual-reports--finances/2017-nbcc-fund-financial.pdf); and several Call to Action announcements available from NBCC's Newsroom (http://www.breastcancerdeadline2020.org/about-nbcc/newsroom.html).

[51] Interview with Dr. Keith Knutson of the Mayo Clinic. (2019, November 12). Interview with Dr. Alana Welm of the Huntsman Cancer Institute at the University of Utah. (2019, November 12). Interview with Dr. Cyrus Ghajar of the Fred Hutchinson Cancer Research Center. (2019, November 13).

[52] As of writing, the 2019 Advocate Leadership Summit Agenda was available here: http://act.breastcancerdeadline2020.org/site/PageServer?pagename=Summit_ProgramDay1

researchers in grant applications, and started their own breast cancer organizations. While a handful of advocates used the survey to express their frustrations with advocacy or NBCC's emphasis on preventative vaccines[53], a wide majority reported participating in advocacy or research activities or wanting to do so. Further, 74% of respondents have continued participating in Project LEAD events and activities after their first event or training (Figure 1).

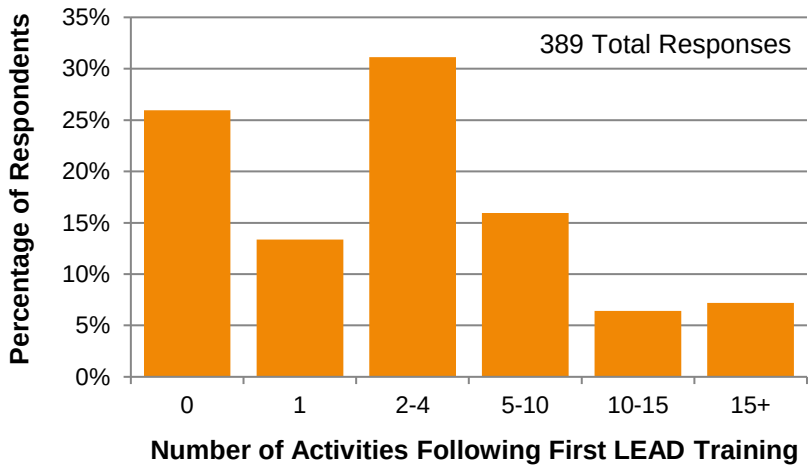
Table 2. Advocate responses to the following prompt: "Since participating in Project LEAD, have you done any of the following activities (select all that apply)"

	Percentage	Respondents
Served as an advocate for a local or state-based breast cancer organization.	**59%**	200
Participated in a scientific peer review process.	**46%**	155
Applied to or served as a reviewer for the Department of Defense (DOD) Congressionally Directed Medical Research Program (CDMRP).	**44%**	148
Served as an advocate for a program/organization focused on addressing health care disparities around breast cancer.	**43%**	144
Other (please specify)	**42%**	143
Served on some other research advisory panel/committee.	**39%**	132
Thought more about being involved in a scientific peer review process but have not yet taken steps to do so.	**27%**	91
Served as an advocate research member on a clinical trial.	**24%**	80
Served as an advocate on expert panels for clinical practice guideline development.	**13%**	44
Applied to or served on an Institutional Review Board (IRB).	**13%**	43
Applied to or served as a Merit or Peer Reviewer for the Patient-Centered Outcomes Research Institute (PCORI).	**12%**	41
Applied to or served on the National Cancer Institute (NCI) Research Advocates Council	**8%**	26
Applied to or served on a PCORI Advisory Panel.	**6%**	21
Applied to or served on an NCI working group or steering committee	**6%**	20
Applied to or served as a PCORI Ambassador.	**3%**	9
Answered	**86%**	338
Skipped	**14%**	56

[53] For example, one advocate lamented Project LEAD's lack of discussion of lifestyle changes (e.g., diet and exercise).

Project LEAD and NBCC's Advocate Leadership Summit have empowered leaders from a diversity of organizations from across the country and world to participate in research and policy making. Members of the Breast Cancer Care and Research Fund for example, discussed their positive experience attending the 2018 Advocate Leadership Summit in a blog post[54]. Survey's collected by NBCC included responses from advocates in organizations from Canada, Texas, California, and numerous other states and countries. NBCC's ability to reach and unite a diversity of organizations, leaders, and advocates through advocacy training furthers NBCC's impact and demonstrates the unique role in the breast cancer community.

Figure 1. Advocate responses to the following prompt: "Approximately how many LEAD workshops, institutes, conferences, and/or webinars have you attended since your first LEAD event?"



3. NBCC's Impact

NBCC's Breast Cancer Deadline 2020, the Artemis Project, and NBCC's approach to advocacy run counter to other approaches to R&D for breast cancer prevention and treatment. NBCC's work challenges the notion that the fruits of investment in research are unpredictable and thus more investment in research is the only sound science policy decision. In countering this narrative, NBCC's Artemis Project focuses energy, attention, and research resources in ways that further promising pathways towards preventing breast cancer and stopping metastasis—research and development that otherwise might not happen. As outlined throughout this assessment, this approach mirrors other models of innovation from both scholarly literature and from research and innovation practice. Mission-driven research administration, such as that practiced by the U.S. Defense Advanced Research Projects Agency (DARPA), have proven invaluable to the development of breakthrough technologies with substantial societal outcomes. NBCC's Artemis Project and promising research from the Artemis Project has advanced R&D due to NBCC's explicit mission-oriented drive and ability to convene motivated researchers.

NBCC plays a unique and critical role in the innovation ecosystem. NBCC provides a mission-driven voice that has catalyzed R&D and the breast cancer community towards the goal of ending breast cancer.

[54] http://breastcancercare.org/2018/05/a-view-from-the-summit/

The involvement of advocates in the Artemis Project, and NBCC's continual emphasis on the role of advocates, mirrors a history of advocate involvement in scientific research of public importance, from the administration of clinical trials for the treatment of AIDS to the monitoring of poor air quality[55]. NBCC sees advocates as critical to scientific endeavors, a perspective backed up by research about user-oriented science well documented in the science policy literature[56]. NBCC further leverages the role of advocates through their mission-oriented approach to R&D. Further, NBCC's prioritization of the perspective of advocates helps align incentives within the R&D ecosystem towards patient outcomes. As NBCC's Visco stated in a recent editorial, advocates are bound to the interests of those with breast cancer or who may one day develop breast cancer[57]. Advocates are not seeking to make money, to secure more research grants, or to get published. NBCC recognizes that institutional incentives for developing a preventative breast cancer vaccine have historically been lacking and has taken the helm to align research with outcomes across other organizations' research portfolios.

NBCC's Breast Cancer Deadline 2020 set the ambitious goal of establishing the know-how to prevent breast cancer from developing and stopping it from metastasizing to other parts of the body. NBCC's work over the Deadline Period led to unique research and development advances, brought together stakeholders in unique and mission-oriented ways to further research, and involved advocates in meaningful and robust ways in shaping that research. Research, collaborations, and clinical trials that emerged from NBCC's Artemis Project have contributed to breakthrough progress towards the Deadline 2020 goals. Further, NBCC's work has realigned the R&D ecosystem and created new communities of researchers and advocates to achieve the goal. NBCC's role in the innovation ecosystem is qualitatively different than other research institutions or advocacy organizations. NBCC provides a mission-driven voice for research and advocacy, and has catalyzed R&D and the breast cancer community towards the goal of ending breast cancer.

[55] See Epstein (1995) as referenced in footnote 18. See Ottinger (2016) for an overview of the role of advocates in developing air quality monitoring protocols. Ottinger, G. (2016). Citizen Engineers at the Fenceline, In *Issues in Science and Technology* (Winter) (pp. 72–78).

[56] For more on the role of users and advocates in shaping science, technology, and related policy, see Oudshoorn and Pinch (2003). Oudshoorn, N., & Pinch, T. J. (Eds.). (2003). *How users matter: The co-construction of users and technology* (1st ed.). Cambridge, Mass. London: MIT Press.

[57] See Visco (2018) as referenced in footnote 24.