CASE STUDY

Metastatic Breast Cancer Alliance Bolsters Patient Engagement and Data Insights with Greenphire's Patient-Powered Research Registry

> "Having a tool that regularly provides helpful and relevant information, along with sharing trials that patients may be eligible for, is critically important."
>
> Laurie Campbell
> Executive Director
> MBC Alliance

The Challenge:

The Metastatic Breast Cancer Alliance ("the Alliance") is a collective of cancer nonprofits, pharmaceutical and biotech industry members, and individual patient advocates that serves as a national leader in collaborative action to transform and improve the lives of people living with metastatic breast cancer (MBC).

Metastatic breast cancer is a disease that currently receives less attention and research than primary breast cancer. Because of this, the Alliance endeavors to find ways to gain deeper insight into the patient experience and ensure that they are aware of and connected to research opportunities. The Alliance wants to better understand the MBC patient journey, including the initial diagnosis, disease and treatment histories, and overall quality of life. The organization also seeks to maintain connection and engagement with the patient community it serves.

The Alliance's desire for richer information and heightened engagement led them to create MBC Connect™, a patient experience registry that provides bi-directional benefit to both their research efforts, and their patient population.

The Solution: The Patient-Powered Research Registry

Unfortunately, patient registries and engagement methods are often focused only on gathering data, and lack the ability to offer meaningful information and support back to the participants. After evaluating several vendors and alternative approaches, the Alliance selected Greenphire's Patient-Powered Research Registry as the platform for creating MBC Connect™ Patient Experience registry. They chose our platform based on technical expertise, solution flexibility, dynamic content creation, and the ability to derive unique analytics.

Greenphire's Patient-Powered Research Registry allows foundations and advocacy organizations like the MBC Alliance to offer a bi-directional, supportive patient experience. The patient-focused mobile application includes robust assets that enable the Alliance to create interactive and informative content, resulting in enhanced participant engagement and richer and more robust ongoing engagement.

> “I used to look for trials on clinicaltrials.gov, which is a huge, complicated site. You really have to pore over search results and determine, is this a trial for my certain condition? That was very challenging and time consuming. MBC Connect automates that process.”

Shirley Mertz
Patient Advocate

Some of the key solution features and associated benefits realized by the Alliance incude:

Feature	Function	Result
Surveys	Collects participant-reported information via five surveys focused on demographics, disease history, quality of life, genetics, and clinical trials.	The surveys housed on the platform have generated a completion rate of > 70% across all five surveys. With minimal drop off, the Alliance has access to a full set of meaningful patient-reported data.
Treatment Tracker	Allows patients to track their medication, radiation, surgery, clinical trials, and other treatments, offering a convenient record of their treatment history.	More than 600 participants have shared information on over 3,700 treatment lines, providing researchers with unique insights into the patient treatment patterns from across the US.
Layered Consent Form	Offers a mobile-friendly eConsent form that is compliant with FDA Part 11 and easy to access and complete, using the layered approach developed by Apple® for the ResearchKit® framework.	Over 1,100 research participants have completed the Alliance’s eConsent form via mobile or web, taking advantage of this easy-to-understand form and streamlined process for patients.
Insights Feature	Allows the Alliance to share resources, event information, and timely and supportive updates with participants.	Patients appreciate and benefit from receiving information such as registry findings, education on MBC, and event listings and details. The Alliance released two important insights during the early period of COVID-19, providing participants with much-needed information.
Trial Matching	Allows participants who have provided sufficient information via surveys to be automatically matched to relevant clinical studies, based on their data in the registry.	The passive matching approach used by the registry means that participants are regularly kept aware of potential trials. At any given time, around 25% of the participant population is engaged with trial matching in some form.
Access Across Platforms	Participants can use and view the web-based registry across iOS, Android and web.	Participants appreciate using an intuitive and ”burden-free” experience on their preferred device or browser.

Looking to the Future

The Alliance continues to partner with Greenphire because of their experience and focus on innovation, participant engagement expertise, and regulatory compliance. Together, we will continue to gather and leverage the valuable data shared by participants to help the Alliance improve our understanding of the patient experience, and better support the patient journey.

By offering insight and support to patients while simultaneously creating a database of rich patient information, the Alliance is using the Patient-Powered Research Registry to drive research for better care, better treatments, and ultimately a cure for Metastatic Breast Cancer.

Greenphire is a Thoma Bravo-backed software company specializing in providing comprehensive solutions for streamlining clinical trials. With a focus on optimizing patient and site experiences, Greenphire offers innovative software for travel and logistics support, automated patient and site payment solutions, and trial budgeting software and analytics.

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