

Metastatic Breast Cancer Communications Toolkit

PHASE 1 REPORT: DEVELOPING THE PROTOTYPE



Metastatic Breast Cancer

MBCalliance >

together we are stronger than the disease



normal cell



stage 0



stage I



“When an analogy can be used to explain breast cancer diagnosis and treatment, it is usually much easier for a patient to understand. This is a well-thought-out patient education tool that I know will be valued by future patients diagnosed with metastatic breast cancer.”

– Lillie Shockney, RN, BS, MAS
Administrative Director, Johns Hopkins Breast Center



“[My prognosis] didn’t seem so dire [when we used the toolkit cards]. It definitely explained the severity of it but it doesn’t make it seem like ‘you’re going to die!’”

– MBC Patient Workshop Participant



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stage II



stage III



stage IV
(spreads to other organs)



"We really appreciated the team's solicitation of our input. Being able to work through the different iterations of the designs with the team was especially helpful in coming up with a toolkit that will be useful in the clinic. We look forward to using these tools on a day-to-day basis. I anticipate that they'll soon become invaluable in our ongoing discussions with metastatic cancer patients."

— Dr. Jeffrey Hancock, Community Medical Oncologist



"It has been my privilege to assist in making this toolkit along with many other of my met sisters! Oh how I wish these cards had been available to me when I was first diagnosed! I truly believe it would have given me an insight into what questions I should have asked. It still would have been scary, but not as scary if these would have been given to me at the beginning."

— Theresa Meyer, Metastatic Breast Cancer Patient

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Metastatic breast cancer is a complex and terminal disease.

There is no cure.

There is no clear treatment path.

And the diagnosis is almost always unexpected.

Yet there is a lot we can do to improve the way patients learn about their disease so that they can be more in control of their future.

This report shows the Metastatic Breast Cancer Alliance's progress.



THE METASTATIC BREAST CANCER NARRATIVE

Although 90% of metastatic breast cancer patients have had breast cancer prior to their diagnosis, few expect their cancer to return. Yet their new diagnosis means not only has it returned, it has spread to other organs or bones. Most likely, it will be fatal.

Inevitably, these patients feel very alone. Unfortunately, their numbers tell another story:

- One in eight women has a chance of developing invasive breast cancer.¹
- In the U.S., more than 40,000 people will die of metastatic breast cancer in 2015.²

Metastatic breast cancer is the:

- Leading cause of cancer death in women in less developed regions (324,000 deaths, 14.3%).
- Second leading cause of cancer death in more developed regions (198,000 deaths, 15.4%) after lung cancer.
- Fifth leading cause of cancer death globally (522,000 deaths).³

Every one of these people—hundreds of thousands, worldwide—deserves the opportunity to understand their disease and treatment choices and face their metastatic breast cancer knowledgeably. Our goal is to make that possible.

1. Society, A.C., American Cancer Society. *Breast Cancer Facts & Figures 2015*. Atlanta: American Cancer Society, Inc, 2015.

2. *Ibid.*

3. International Agency for Research on Cancer. *Breast cancer: estimated incidence, mortality and prevalence worldwide in 2012*. Available at: http://globocan.iarc.fr/Pages/fact_sheets_cancer.aspx



CHANGING THE METASTATIC BREAST CANCER NARRATIVE

When you face a complicated decision, you want all the facts, neatly organized and in a format that you can readily understand.

Patients with metastatic breast cancer (MBC) confront a number of complicated decisions. They have a disease for which there is no simple answer. They face an array of treatment options—each of which typically has limited efficacy. They find that when the cancer quits responding to one treatment, their doctors will try another. So patients are forced to undergo the decision process again and again and again. It is mentally challenging, emotionally draining, physically exhausting.

To make an informed decision, these patients need to understand each treatment option, its hoped-for benefits and potential pitfalls. Yet largely, they do not. In one study, two-thirds of patients with metastatic cancers were not informed of the likely impact of a given treatment on their quality of life, and nearly one-third were unaware of the uncertainty around the described benefit.⁴ Tragically, many persist in believing that a cure is likely. There is no cure.

IDENTIFYING THE ISSUES

The medical community is neither callous nor nefarious; they are severely time-constrained. Moreover, they may not have the skills to explain things in a way that patients and their family members can easily grasp. This is further complicated by the patients' emotional trauma, lack of medical knowledge, and need to make life-altering decisions rapidly.

“As social workers, we train for months and years to learn about cancer treatments. Patients often have to absorb so much information—in usually just a matter of days before treatment begins.”

— Cancer Center Social Worker



4. Gattellari, M., et al., *When the treatment goal is not cure: are cancer patients equipped to make informed decisions?* *J Clin Oncol*, 2002, 20(2):503-13.

DESIGNING A FRESH APPROACH

Currently, MBC patients receive most information orally—and they retain very little. Print materials tend to be text heavy, jargon laden and seem particularly dense to low-literacy patients. Not surprisingly, surveys show that patients want more. They want to feel cared for and respected as individuals. They want someone to understand their challenges and address their concerns. And they want materials that can actually help them understand the crucial decisions they are making.^{5,6}

This research takes what we believe is a first-of-its-kind approach to information for MBC patients by addressing the existing communications challenges as a design problem. Led by patient and healthcare team insights and harnessing design expertise, we are investigating visuals as the means to redesign the conversation.

Our goal: To enable all people living with metastatic breast cancer to understand the disease itself and the implications of it, so they may fully participate in decision making around their treatment.

“Only 12% of U.S. adults have the health literacy skills needed to manage the demands of our complex healthcare system, and even these individuals’ ability to absorb and use health information can be compromised by stress or illness.”⁷



5. Mayer, M. and Grober, S.E. Patient Perspectives on Control of Symptoms and Side Effects of Metastatic Breast Cancer, in ABC2: Advanced Breast Cancer Second Consensus Conference. 2013: Lisbon, Portugal.

6. Harding, V., et al. 'Being there' for women with metastatic breast cancer: a pan-European patient survey. *Br J Cancer*, 2013. 109(6):1543-8.

7. Agency for Healthcare Research and Quality. AHRQ Health Literacy Universal Precautions Toolkit, Oct. 2015. Rockville, MD. Available at <http://www.ahrq.gov/professionals/quality-patient-safety/quality-resources/tools/literacy-toolkit/index.html>

BARRIERS TO COMMUNICATION

Research shows that only a very small group of patients fully understands what is happening to them. Yet additional studies show that patient outcomes improve when patients are engaged in decision making.⁸ This cannot happen if they can't understand and communicate with their physician and healthcare team.

Three key barriers often make critical diagnostic and treatment information inaccessible:



- 1. Language hurdles.** In conversations with patients, healthcare professionals often use medical terminology to explain diagnosis and treatment options. In many ways, it's a foreign language. Worse, print materials are almost entirely text and are often lengthy and dense.

*"The surgeon gave me a 50-page brochure from [a cancer organization]. It had been photocopied and it was like being handed a ream of paper."
— MBC Patient*

- 2. Emotional shock.** A National Cancer Institute (NCI) study investigated the effectiveness of hearing and accurate recall. In a non-life-threatening situation, patients remembered just 14% of their conversations with healthcare professionals.⁹ Often patients say that after hearing their cancer has spread, they remember virtually nothing.

"...if people already don't hear/comprehend everything said to them in normal life, add the MBC shock and I don't know how most of us hear anything. I took copious notes and later when I reread them I didn't remember writing a LOT of it." — MBC Patient

- 3. Time constraints.** Some oncologists have up to 400 patients,¹⁰ all with various types of cancers. Their time is extremely limited, so they may try to get to the heart of a problem quickly.

"I'm just trying to get them to understand what they've got. There's always a tension between the time you have and realizing what they can absorb. I try and give them a big picture and then I'm going to have to repeat that again and again." — Medical Oncologist

8. Robinson, A. and Thomson, R. Variability in patient preferences for participating in medical decision making: Implication for the use of decision support tools. *Quality in Health Care*, 2001. 10 (supplement 1):i34–i38.

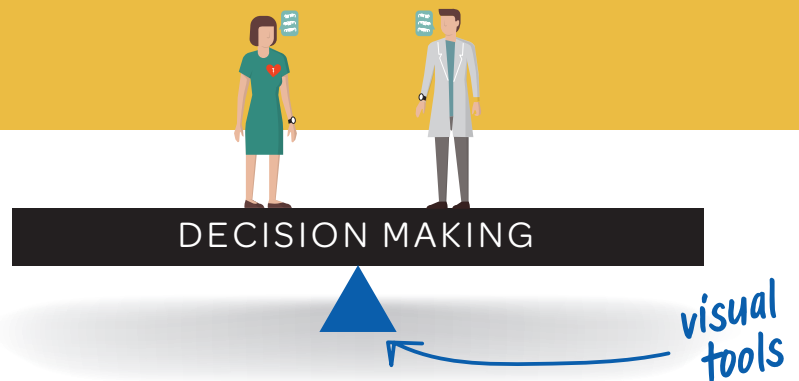
9. Houts, P.S., Witmer, J.T., Egeth, H.E., et al. Using pictographs to enhance recall of spoken medical instructions II. *Patient Educ Couns*, 2001. 43:231-42.

10. Towle, E.L., Barr, T.R., Senese, J.L. The National Practice Benchmark for Oncology, 2014 Report on 2013 Data. *J Oncol Pract*, 2014. 10:385-406. Available at <http://jop.ascopubs.org/content/10/6/385.full.pdfhtml>.

OVERCOMING COMMUNICATION BARRIERS

In order for physicians to be part of the communication solution, they must be able to make health information clear and understandable to patients—and in doing so, enable more equal participation.

Yet this is a quantum change for physicians, who “...are trained to solve patients’ problems, to ‘fix and cure’...Making routine consultations truly collaborative is a challenging shift, demanding changes not only in attitude but also in technical and ingrained consultation skills.”¹¹

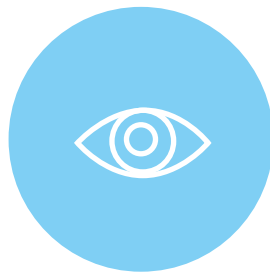


[How can we address this challenging shift? By helping physicians communicate in a way that patients can understand.]

THE POWER OF VISUALS

Physicians usually explain a diagnosis orally, yet as we know, patients retain very little of what they hear. However, in studies using pictographs, patients’ memory recall reached a mean of 80% for average-literacy populations¹² and 85% for low-literacy populations,¹³ with a 71% accurate recall four weeks later for low-literacy patients. Unfortunately, to achieve this success, volunteers spent 90 minutes with each patient, training them on the messages communicated in the visuals, making it difficult to adopt in a time-pressured setting.

71-85%
ACCURATE
RECALL



14%
ACCURATE
RECALL

11. Grazin, N. *Self-management: co-creating health*. The Health Foundation. Available at http://www.health.org.uk/news/features/selfmanagement_cch.html

12. Kessels R.P.C. *Patients’ memory for medical information*. *Journal of the Royal Society of Medicine*. 2003. 96(5):219-222.

13. Houts, P., et al. *Using pictographs to enhance recall of spoken medical instructions*. *Patient Education and Counseling*, 2001. 43:231-242.



THE CORE IDEA

What if it were possible to design a set of visual tools to communicate in a time-effective way, appeal to a wide demographic of patients of various literacy levels and increase patient engagement despite emotional distress?

THE PATH TO EFFECTIVE COMMUNICATION

While several healthcare studies^{14, 15, 16} have shown that visuals and interventions can improve patient-physician communication, the quality of the visual design of the interventions was not discussed as an influence on the effectiveness of the tool. Instead the medium of the intervention—such as whether leaflets or posters were effective—was seen as the variable factor for success.^{17, 18}

In short, these studies assume that design isn't a factor in the usefulness of communicating information to patients. But that isn't the reality.

We believe that to create visual interventions which dramatically improve the communication experience, the designer must be involved in all areas of research and development, including:

- Experiencing the communication from both the perspectives of the patient and the healthcare professional in a variety of settings.
- Diagnosing the problems in these interactions.
- Developing a prescribed visual treatment.
- Involving patients and healthcare professionals in the creation of the intervention in an iterative, collaborative way.

That visual treatment will be developed into a toolkit for healthcare professionals to use in talking with patients diagnosed with metastatic breast cancer. In later phases, we will test and refine the toolkit before disseminating it (*see Research Goals, p.11*).

14. Matteson, C. L., Merth, T. D., and Finegood, D. T. Health communication cards as a tool for behavior change. *ISRN Obesity*, 2014. 1-10. doi:10.1155/2014/579083.

15. Houts, Peter et al. Using pictographs to enhance recall of spoken medical instructions. *Patient Education and Counseling*. 2001. 43: 231-242.

16. Levine, M.N., Gafni, A., Markham, B., MacFarlane, D. A bedside decision instrument to elicit a patient's preference concerning adjuvant chemotherapy for breast cancer. *Ann Intern Med*, 1992. 117:53-8.

17. Montazeri, A., & Sajadian, A. Do women read poster displays on breast cancer in waiting rooms? *Journal of Public Health*. 2004. 26 (4):355-358.

18. Pulley, J.M., Brace, M., Bernard, G.R., Masys, D. Evaluation of the effectiveness of posters to provide information to patients about a DNA database and their opportunity to opt out. *Cell Tissue Bank*. 2007;8(3):233-241.

RESEARCH GOALS

We want to help all patients diagnosed with metastatic breast cancer thrive by:



Improving cancer knowledge for newly diagnosed metastatic breast cancer patients



Increasing patient engagement with their healthcare team regarding diagnosis and treatment decisions



Enabling patients to explain both their cancer and their treatment decisions to family and friends, who, as a result, can become better supporters

RESEARCH PHASES



Phase 1:
Gather data; review information; develop, test and refine prototype of Communications Toolkit; report findings (2015)



Phase 2:
Pilot study of toolkit; define best practices in a range of cancer care settings; develop protocols; refine tools (2016)



Phase 3:
Develop training materials for healthcare professionals (2016)



Phase 4:
Publish, market and distribute toolkits for <25 breast cancer centers (2016)



Phase 5:
Review toolkit; refine, update and distribute nationally and internationally (2016-17)

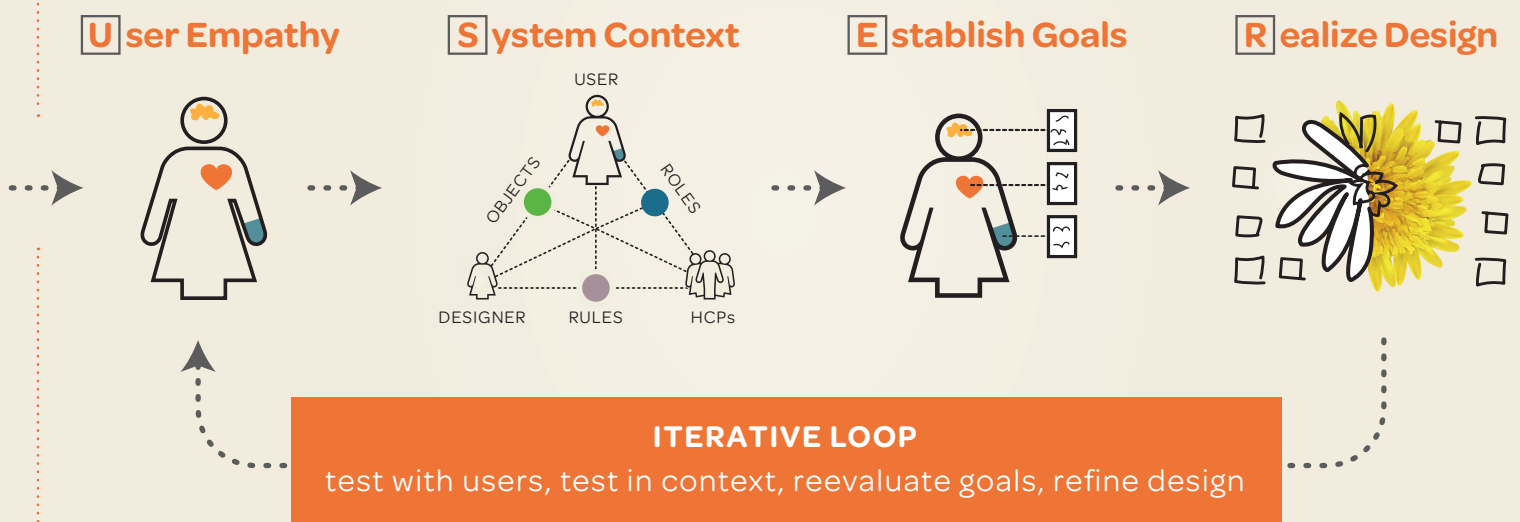
CREATING HUMAN-CENTERED COMMUNICATIONS

Design thinking is a human-centered method of identifying problems and developing solutions that involves:

- **Empathic discovery:** Where traditional research focuses on text, design thinking focuses on concrete experiences and rapid prototyping to quickly discover useful solutions. The driver for this is empathy.
- **Co-creation:** Design thinking develops solutions *with* people instead of *for* people. End-users engage in initial problem-finding activities and take active roles in development.^{19, 20}

Our research harnesses the U.S.E.R. Design Thinking Framework²¹ to navigate the design thinking process, focusing on four areas of investigation and solution development. Central to the methodology is the investigator experiencing a typical patient trajectory through role-play.

U.S.E.R. DESIGN THINKING FRAMEWORK



User Empathy: Understand the patient’s current situation from their viewpoint.

System Context: Map the patient-healthcare professional communication touch points from diagnosis to treatment discussions.

Establish Goals: Determine the key needs (cognitive, emotional, physical) for patients and members of the healthcare teams.

Realize Design: Prototype solutions, using patient and healthcare professional insight and feedback to guide development.

19. Leonard, D., & Rayport, J. F. Spark Innovation through Empathic Design. *Harvard Business Review*, 1997. Nov/Dec: 102-113.

20. Koskinen, I., & Battarbee, K. Introduction to user experience and empathic design. In K. B. Koskinen, *Empathic Design—User Experience in Product Design*. 2003: 37-50. Finland: Edita Publishing.

21. Beaumont, C. *Design Thinking in Healthcare: Developing Patient-Centred Communication Materials for Breast Cancer Detection*. PhD Thesis. 2011. Brunel University, England..

IT TAKES A VILLAGE

More than 80 people—patients, oncologists, nurses, social workers, patient navigators, advocates, researchers and information providers—were engaged in the U.S.E.R. design thinking process for Phase 1 of this project.



HUNTSMAN CANCER INSTITUTE	TETON CANCER INSTITUTE	MOUNT SINAI ST. LUKE'S	JOHNS HOPKINS BREAST CENTER
<ul style="list-style-type: none"> • 4-day residency • 11 HCP interviews • Patient role-play x2 • Communication map 	<ul style="list-style-type: none"> • 4 HCP interviews • Collaborator for best practice & design 	<ul style="list-style-type: none"> • 2 HCP interviews • Patient role-play x2 • Toolkit feedback 	<ul style="list-style-type: none"> • 3 HCP interviews • Patient role-play x2 • Nurse collaborator



MBC PATIENT INTERVIEWS	PATIENT ADVOCATES & EDUCATION EXPERTS	FACEBOOK GROUP	MBC PATIENT WORKSHOP
<ul style="list-style-type: none"> • 4 patient interviews • In-depth experiences of initial conversations 	<ul style="list-style-type: none"> • 2 MBC advocates • 4 cancer & MBC communication experts 	<ul style="list-style-type: none"> • 48 MBC members • Helped develop tools post initial prototype 	<ul style="list-style-type: none"> • 5 MBC patients • Took on oncologist role • Feedback & inspiration on initial prototype



MBC PATIENT ONLINE SURVEY

- 500 MBC patients

STEP 1: USER EMPATHY

Often our perception of someone's experience is not accurate to their actual experience. Through multiple methods, we strove to understand the patient's current experience on three levels:



1. Cognitive (what do they know; what do they want to know?)
2. Emotional (how do they feel; how do they want to feel?)
3. Physical (what is happening to them physically; how would they like to be interacted with physically?)

In the process, we identified key opportunities for enhanced communication.

INVESTIGATOR'S FIRSTHAND EXPERIENCE OF THE CURRENT COMMUNICATIONS PROCESS

Research began with a "mock diagnosis" exercise conducted over six separate sessions in which the investigator was told by an oncologist that she has metastatic breast cancer. Even while knowing it was an exercise, her experience was a powerful means of gaining empathy for the patient—and insight into the patient's needs.

"Prior to this experience, I kept away from learning too much about the disease—I didn't want to know more than the average patient going in. Having had family members and a close friend who had metastatic breast cancer, it was emotional to be in their shoes in that exam room with the oncologist. I tried to forget myself and experience it as if I were they.

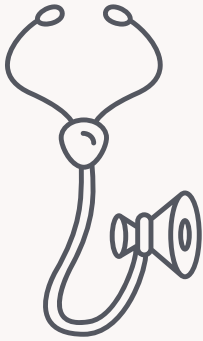
When I was told I would have to do chemotherapy, my mind went blank. I struggled to keep up with all the medical terms. At one point I cried. On the drive home, I could only remember the most positive aspects. Maybe it was denial, or hope. Even though I knew going in that it was incurable, I still left thinking 'maybe I can be the exception.'

Despite this being just an exercise, it was the most important thing I did to begin the research. I was told by six different oncologists across the country that I had metastatic breast cancer and discussed my different diagnoses and treatment options. Every time was different, and although it wasn't real, it really showed the limits of conversation in a time of crisis and what both the patient and healthcare professional are facing."

*Investigator/Designer
Corrine Ellsworth Beaumont, MFA, PhD*

OBSERVATIONS DURING ROLE-PLAY AS A PATIENT

with six oncologists:



- The emotional trauma of the experience makes understanding and recall a challenge.
- The first interaction in the physician's office was the receptionist asking, "Do you have an insurance card?"
- Positive things stood out more in memory compared to the negative.
- It wasn't clear treatment didn't mean cure.
- Prognosis questions were often skirted or generalized.
- Medical jargon made listening difficult.
- Lots of numbers and statistics were difficult to follow without context.
- Sense of urgency encouraged a feeling of conforming, rather than questioning.

HCP says:

██████ So here's just a general symptom management paper for the THP treatment, which you're receiving. This goes over the nausea meds that we would give you prescriptions for. Nausea shouldn't - most people think of chemo and just being over the toilet throwing up.

But with these drugs that shouldn't be a problem. So if there's a problem, I want you to call me. With these since you can take the Zofran every six hours. You can have Compazine every six hours, and Ativan every six hours. So technically you have something you can take every two hours for nausea if you need to.

So you can take the Zofran, two hours later if you're still feeling nauseous take the Compazine, if you're still feeling nauseous you can try the Ativan. Be careful with the Ativan and Compazine. With some people it can cause a lot of drowsiness.

So I always recommend to start with the Zofran and then go from there. Let me know if you have any problems with those medications.

Q: Okay.

Patient hears:

██████ So here's just a general symptom management paper for the ██████ treatment, which you're receiving. This goes over the nausea meds that we would give you prescriptions for. Nausea shouldn't - **most people think of chemo and just being over the toilet throwing up.**

But with these drugs that shouldn't be a problem. So if there's a problem, I want you to call me. With these since you can take the ██████ every ██████ hours. You can have ██████ every ██████ hours, and ██████ every ██████ hours. So technically you have something you can take every ██████ for nausea if you need to.

So you can take the ██████, ██████ hours later if you're still feeling nauseous take the ██████, if you're still feeling nauseous you can try the ██████. **Be careful** with the ██████ and ██████. With some people it can cause a lot of drowsiness.

So I always recommend to start with the ██████ and then go from there. Let me know if you have any problems with those medications.

Q: Okay.

A sample conversation between a patient and her oncologist with medical terms and numbers blacked out, showing that meaningful information is difficult to remember.

HEALTHCARE PROFESSIONAL PERSPECTIVES

During discussions with eight oncologists, five nurse/navigators, four health educators, a social worker and patient records team, the following issues were identified:

"Sometimes I realize that I'm the one with the need to tell them about certain aspects of their cancer, but that might not be the patient's need. I want them to know what I know, but maybe they don't need to know all of that."

– Surgical Oncologist

"[They have] 20-25 minutes with [the doctor] in regards to their disease...the stage and the treatment plan. But if your patient gets lost right when they hear 'cancer,' then you have a lot to cover with them. So as navigators we pay close attention to that information...when the doctor leaves, that's our first question. 'Do you understand what happened? Can you tell me what the doctor told you?' Quite frequently the patient will say, 'I'm not really sure what just happened. I was told that I have cancer and that it has spread.' And that's kind of like the end of their understanding. And then you go into the confusion of the doctor usually saying this can be treated but not cured..."

[Most questions are] not at that first appointment, it's the second and third appointment when patients [get] home and [think] about the information."

– Hispanic Patient Navigator

"The hardest [thing when working with a patient] is for them to understand that this is incurable. [They ask] 'Why not just take it out? And why not just do chemotherapy? Why would that not cure it?'"

– Medical Oncologist

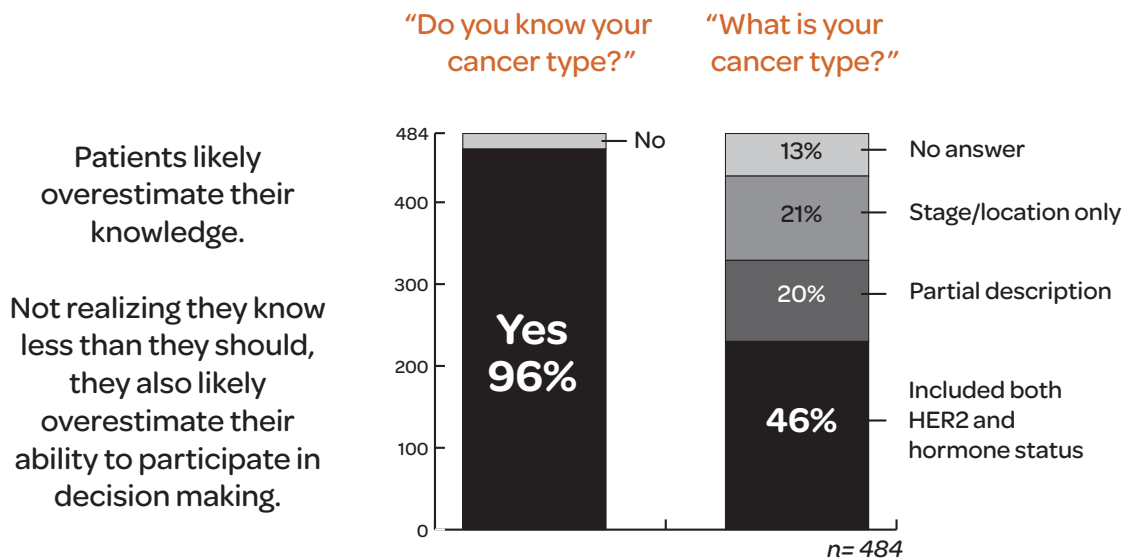
"The treatment of advanced breast cancer is very complex. There are many considerations to ensure that the right medication is recommended to the right patient each step of the way. Patients with this stage of disease require multiple tests and office visits. It is difficult for most individuals to navigate through the healthcare system, and if someone is ill and anxious, it can be even more difficult to deal with those barriers."

– Medical Oncologist

PATIENT SURVEY HIGHLIGHTS

To gain a bigger sample of patient experience and to gauge patient knowledge, an online survey was created.

Conducted with the assistance of our Alliance members, an online survey of 500 patients diagnosed with metastatic breast cancer helped clarify the current state of communications and provided a baseline for the Phase 2 pilot of the research. Preliminary findings below are a small sample of the survey findings. While the majority of survey respondents began by reporting a strong understanding of their disease and a comfort speaking with their oncologists, further questioning revealed that it was not often the case.



33%

felt they don't have enough knowledge to participate in decision making

58%

felt rushed and that starting treatment was urgent; 24% got a second opinion; 38% did not research prior to starting treatment

71%

did not recall goals and hobbies as part of pretreatment discussions

PARTICIPANT PROFILE

DEMOGRAPHICS

- 37% *de novo* patients
- 90% Caucasian
- 100% ages 40-70 (40% 50-60)
- 89% U.S. residents

EDUCATION

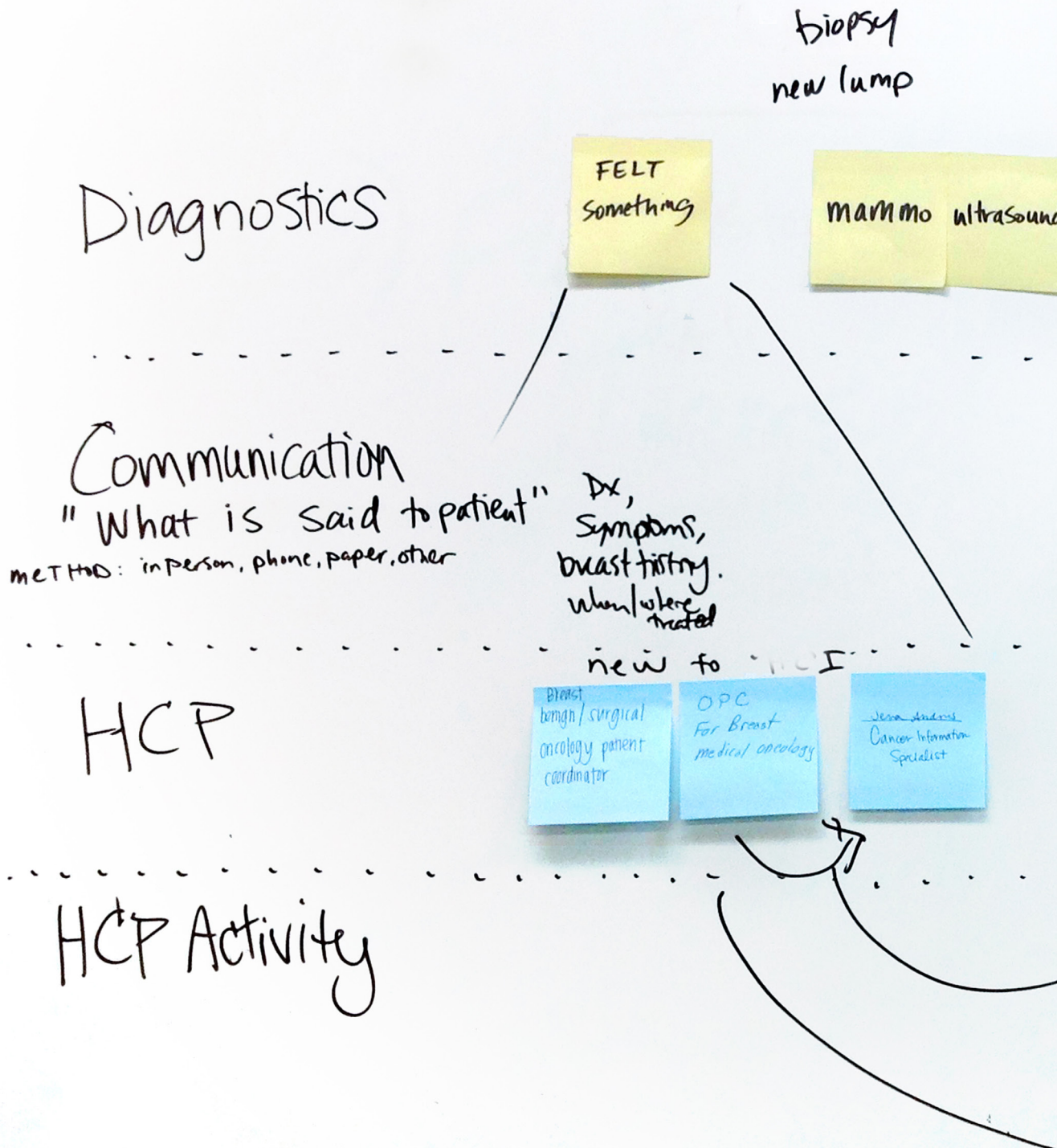
- 93% attended college
- 30% postgraduate degree

TIME SINCE DIAGNOSIS

- 5% <3 months
- 25% 4-12 months
- 25% 12-24 months
- 25% 3-5 years
- 12% 6-8 years
- 6% 9-15 years
- 1% >15 years

STEP 2: SYSTEM CONTEXT

Many roles work together to benefit the patient. Understanding the complete picture allows us to anticipate the opportunities and setbacks that may result from introducing the toolkit. Each member of the healthcare team was viewed in terms of the patient's cognitive, emotional and physical needs. The intent was to discover where patient needs are being met, and where there is an opening for improvement.



New

MAPPING CANCER CENTER COMMUNICATION PATHWAYS

Working onsite at cancer centers, we were able to visualize the entire communications process with team members taking turns moving sticky notes around the board. Often, this was the first time team members had discussed how their individual roles coordinated (or not) from the patient perspective.

you have breast cancer

Phone



Body Scan
↓
Scan

biopsy

CBC mastectomy node surgery

PET CT
or
(Bone Scan)

↓
Recurred.

"You have breast cancer again."



We are going to 'stage' you.
Make sure cancer hasn't spread to other parts of your body.

"It's spread."

"Let's talk Treatment options"

PERSON

You have breast cancer

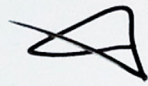
Annie

*Oncologist

Surgeon

see mets.

Coaching



CURRENT PATIENT EDUCATION MATERIALS

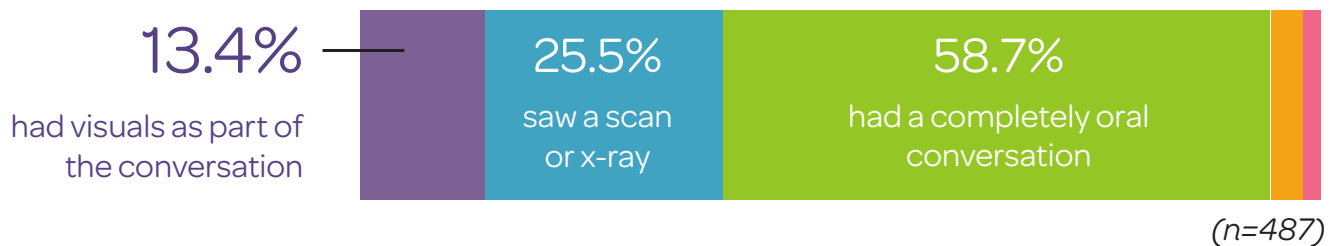
The materials we collected in Step 1 were primarily binders filled with sheets of text and standard institution-generated cancer booklets. They pose several problems:



- **Not personalized:** Patients must determine which information applies to them.
- **Potentially overwhelming:** Patients have to be mentally ready to sift through the large amount of reading.
- **Not integrated:** Oncologists rarely interact with these materials; nurses use print materials in a variety of ways, but mostly as take-home reference for the patients.

CURRENT USE OF VISUALS DURING CONSULTATION

We asked patients: "When you talked to your oncologist in person, were any visuals used to explain your diagnosis and treatment (such as drawings, 3D models or graphics) or was it a completely oral conversation?"



This revealed that only a small percentage of patients are currently educated with visuals (1 in 8) during initial discussions with their oncologist prior to starting treatment. While a quarter do see a scan or x-ray, this is to show proof of tumor.



STEP 4: REALIZE DESIGN

THE DANDELION METAPHOR

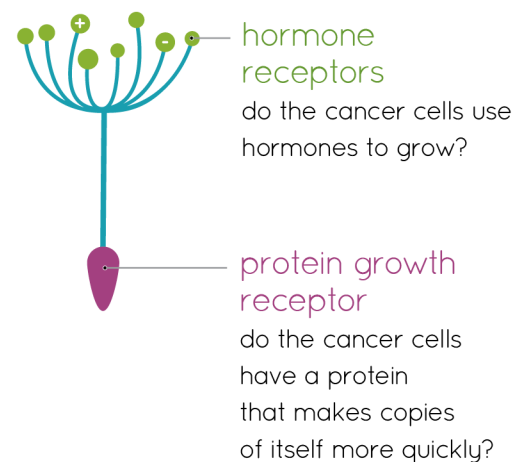
Patients need a way to ask questions about their diagnosis and treatment options without having to rely on their verbal communication skills. In response, we developed a visual metaphor—a dandelion—to help patients better picture cancer progression, then expanded the metaphor to include treatment options.



WHY A DANDELION?

To teach concepts about diagnosis and treatment to patients who are unfamiliar with medical terminology used to describe metastatic breast cancer and/or are anxious about the topic, the teaching object needs to be familiar and approachable to the patient and behave in a similar way to the disease.

A dandelion metaphor fits these criteria, both in the way it spreads and how it is controlled. While a dandelion seed doesn't physically resemble a cancer cell, the structure of a cancer cell is not information useful to the patient for decision making.



THE ONCOLOGIST MIGHT USE IT TO TALK TO THEIR PATIENT THIS WAY:

It can be difficult to understand some of the things we talk about today, so I'm going to use something you're familiar with to help explain what's going on inside your body, to give you a basic understanding of your diagnosis and treatment options.

Think of the cells in your body as if they were dandelions. A yellow dandelion is a normal cell, but when the dandelion turns to seed it becomes a cancer cell.

In earlier stages, the seed hasn't traveled anywhere else in the body. It stays in the breast. But when it travels outside the breast, that's what we call "Stage IV," or "metastatic breast cancer."

A dandelion seed has parts that help it travel and spread. A cancer cell also has characteristics that help it travel and spread. Those characteristics give us clues as to how to target it where it's weakest. We'll use that knowledge to pick the right types of treatment for you.

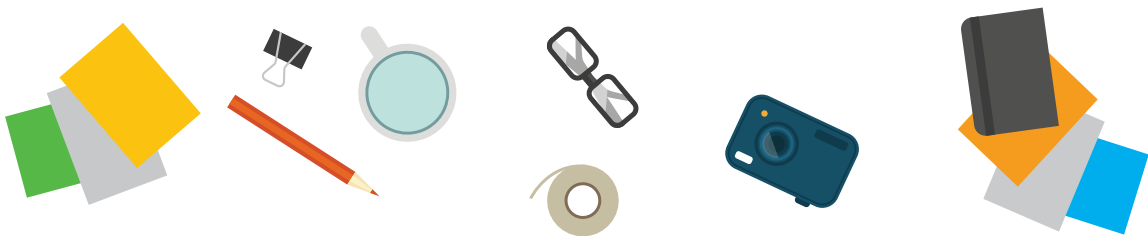
The same ways you might try to get rid of a dandelion are similar to the options we use to treat cancer. We can use chemicals, also known as chemotherapy. We can also use a chemical that only targets the dandelion or part of the seed, such as targeted therapies or hormonal therapies. We could also try to "wither" the dandelion by using rays from the sun, like radiation. Sometimes removal is possible, such as surgery. There are many options and we can go through them all to discuss the best treatment for you based on your life goals.

"We're using this because I'm ER+? Okay, tell me more about this option and how it helps with that."

Think of a cancer cell as a dandelion that has turned to seed. The same ways we treat a dandelion are a lot like the options we have for treating metastatic breast cancer...



Having gathered insights and identified meaningful problems, and with a metaphor in mind, we turned to designing a tangible solution. We first developed a prototype toolkit, then tested it with four key groups: five MBC patients in a role-playing workshop; 48 MBC patients in a Facebook group; an NCI cancer center; a private community cancer center; and a group of medical experts and health communicators. We polished, iterated and expanded it as we went, until we arrived at the version we will use in a pilot in Phase 2.



CHOOSING AN EFFECTIVE FORMAT

In Step 1, we collected materials from a range of cancer centers; we also interviewed care teams on their current practices. Based on that data, we determined an information resource could be customized specifically to a patient's cancer type and status and could fit more naturally with the conversation. Also, at a smaller, more digestible size, the tool would be a helpful starting point before considering other useful text-based information.

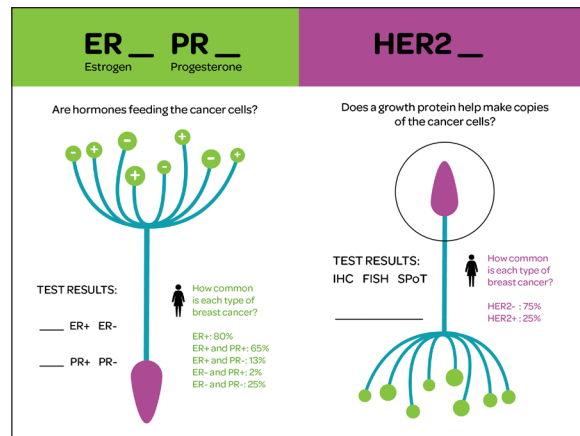
ITERATIONS

1. CARDS. We proposed a set of cards for the oncologist to use with the patient. While oncologists liked the content, the number of cards seemed onerous given physician time constraints.
2. POSTERS. We developed two wall posters to work alongside the cards. After further input, we developed four smaller tear-off versions which help visualize the diagnosis clearly, establish criteria for discussion and decision making and enable patients to understand the range of treatment options and bring the conversation home.
3. ROLES. After investigating the communication pathway, it was clear that discussion responsibilities were shared between oncologists and nurses/navigators. Working in tandem, the tear-off sheets were designated for oncologists and cards were designated for more detailed follow-up discussions with nurses/navigators.

TESTING AND ITERATING TOOLKIT PROTOTYPES IN A PATIENT WORKSHOP

In August 2015, we tested the toolkit with a group of five patients in New York City. Participants reflected a diversity of age, breast cancer subtype, race and marriage and employment status. Their time since diagnosis with metastasis was six months to five years. One patient was diagnosed *de novo*; the rest had recurred with metastatic breast cancer. The education level ranged from no degree to having a master's degree.

Participants each took turns role-playing as an oncologist using the toolkit to explain their own real-life diagnosis to another participant. The goal was to see how they used the toolkit and to gain insight for recommendations on how communication could be improved in the future pilot.



"[My prognosis] didn't seem so dire. It definitely explained the severity of it but it doesn't make it seem like 'you're going to die!' kind of thing. So that was helpful."

— MBC Patient (B)

Patient Role-play Group Toolkit Feedback

OBSERVATIONS

Participants:

- Began the discussion with the posters.
- Changed the card deck cover from "You can do this" to "This is not your fault."
- Each used the cards in a different order, showing the versatility of the set.
- Said they could see themselves bringing the cards back for future conversations with their oncologist.

"[Using the toolkit seems like] the team is more engaged in your care, more so than 'next, next' type of situation."

— MBC Patient (A), Patient Role-play Group Toolkit Feedback



Patients role-playing as oncologists with the toolkit.

I use all the nicknames myself. I think the definitions are excellent too. It's a great visual. So many of us "lifers" still don't understand NED, they think they have beaten cancer. This should also help the MD explain without using negative terms. Thank you for all your work. I'm excited for the time when we can share with others.

Unlike · Reply · 2 · October 12 at 10:16pm

Corrine Ellsworth Beaumont replied · 1 Reply

It is also a life threatening disease.
Like · Reply · 1 · October 12 at 10:17pm

April Kennedy Knowles replied · 3 Replies

No one has ever used the word regression to me!
Like · Reply · 1 · October 12 at 10:34pm

I don't think the first paragraph under goals is strong enough; average life expectancy is still only in the 3 year range. And maybe with NED say the cancer is still there but too small to see. Otherwise I love it!! Thank you for the work you're doing
Like · Reply · 3 · October 13 at 2:11am

Somewhere in there they need to understand it will kill (also I've never heard regression either and my tumors shrunk and I became NED)
Like · Reply · October 13 at 10:49am

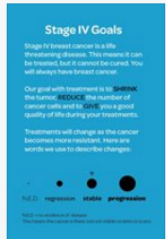
Tricia Jordan replied · 2 Replies

Corrine Ellsworth Beaumont Interesting about regression...will have to talk to the docs about this as it's clear what they say they say and what you are hearing are different. 😊
Like · Reply · 2 · October 13 at 10:34pm

I have never heard the term regression either. Are we dodging the world 'terminal' here on purpose?
Like · Reply · 2 · October 13 at 2:34pm

Corrine Ellsworth Beaumont Not dodging terminal, but trying to use words that people at any literacy level can understand.
Like · Reply · October 13 at 2:38pm

Corrine Ellsworth Beaumont Is this better?



Like · Reply · October 13 at 2:38pm

Yes, this is a big improvement. Thanks.
Like · Reply · October 13 at 2:40pm

TESTING AND ITERATING THE TOOLKIT WITH HEALTHCARE EXPERTS AND A PATIENT FACEBOOK GROUP

Alongside feedback from health professionals and cancer communication experts, we created a private Facebook group for metastatic breast cancer patients (n=48) to participate in the development of the toolkit and offer insight and feedback. Patients commented on designs, offered suggestions for text and inspired the addition of new cards to the kit as needs arose from discussions over a five-month period.

Observations and iterations

- Nurse navigators found that grouping treatment options in a single poster simplifies introducing the spectrum of treatment.
- Patients understood treatment options more easily within the context of the dandelion metaphor.
- Some patients were not aware of quality of life considerations as being part of treatment decision making; we reorganized the poster to show the balance between the two.
- Patients commented that complementary therapies are often not mentioned, and that a treatment break is not a day at the beach; we changed the image and the caption (see below).

Corrine Ellsworth Beaumont
July 29
Here is a poster illustrating the stages of breast cancer. Comments welcome. Please do not share this image outside of the group as it's still in draft form. Thank you!



4 people like this. Seen by 32

- I really really like this. I'm such a visual person and I believe that so many people are visual. It really helps to bring it to reality rather than just an idea rattling around in my brain with nothing to compare it to.
July 29 at 4:37am · Unlike · 1
- Love it Corrine! The visual picture of a dandelion is perfect, showing how breast cancer can begin in stages and eventually can spread and take over unless our oncologists can find the perfect chemo cocktail to stop or at least maintain it and keep us alive with the best quality of life we can have while fighting this beast of MBC!
July 29 at 1:51pm · Unlike · 2
- Very interesting visual. I like it too.
July 29 at 2:33pm · Unlike · 2
- I like it. The only thing that it does not address is that cancer can progress at different speeds. Sometimes people are diagnosed stage 4 right at the start and sometimes it can take many years to start to spread.
July 29 at 9:47pm · Unlike · 3
- Awesome and effective graphic. Whoever designed it is brilliant

BEFORE

treatment breaks
when side effects or
life events take priority

➔

AFTER

treatment breaks
giving yourself time to recharge

"I would have tear-off sheets...and I would draw and annotate them. Then once I'm done I'd just hand it to [the patient] and say, 'This is what we talked about today.'"

– Medical Oncologist

"That's when their nurse practitioner or physician assistant or nurse navigator steps in to use [the toolkit] to hopefully clear it up. Because [the oncologist] literally only has enough time to come in and say, 'I'm sorry Mrs. So and So, it appears that your cancer has spread to other parts of your body and we'll need to start some chemotherapy. Here are your options.'"

– Medical Oncologist

"Hopefully [this toolkit] is something to refer back to. Unless they have a recorder running, they hear it, but I guess they cannot recall it. As I always remind people, 'It's not that you'd have trouble comprehending or that your memory is bad, it's just that this is how our brains work...[they] start to shut down and immediately go into denial.' So it's nice to have [this toolkit] as a reference to go back to."

– Medical Oncologist



THE CARDS

The toolkit cards cover many topics, and patient feedback informed everything from phraseology to design and the order of presentation. A sample of the cards is shown here, alongside the input from patients and healthcare professionals who directly impacted the toolkit's development and testing.

Stage IV card (front and back)



Stage IV

Because the breast cancer has spread beyond the breast, it is now Stage IV. This is known as "metastatic" (met-a-stat-ic) breast cancer, which comes from a Greek word meaning "migration."

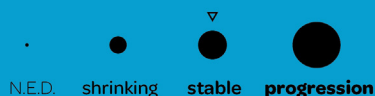


Stage IV Goals

Metastatic breast cancer can be treated, but it cannot be cured. You will always have breast cancer. Eventually the cancer will be stronger than the medicine can handle.

Our goal with treatment is to **SHRINK** the tumor, **REDUCE** the number of cancer cells and **GIVE** you a good quality of life during your treatments.

Treatments will change as the cancer becomes more resistant. Here are words we use to describe changes:



N.E.D. = no evidence of disease. This means the cancer is there but is not visible on tests or scans.

"The overall frame that many patients don't understand, at least at first, is that it's not a chronic disease. This is a progressive disease. And it's fatal."

– Patient Advocate

"Many people with MBC experience terrible quality of life—often due to their treatments. As they move from one chemo to another they experience increasing fatigue, nausea, and other debilitating effects. It's a very, very fine line between conveying hope and informing new patients that they have a terminal disease that will most likely make them feel absolutely terrible at some point."

– MBC Patient

"I think the definitions are excellent too. It's a great visual. So many of us "lifers" still don't understand NED, they [sic] think they have beaten cancer. This should also help the MD explain without using negative terms."


– MBC Patient

"...maybe we're just so concerned about protecting the patient from bad news that we hesitate, we think we have to be so positive and so hopeful and upbeat, even though we know what the outcome is going to be...even if you do introduce that right in the beginning and that's all they hear, you've introduced it... it's Stage IV, it's not like we're saying hospice right up front."

– Nurse Navigator

Patients helped phrase this conversation through offering text suggestions and giving feedback on the visuals. Some suggested stronger wording, while others suggested a softer approach. According to the patients, the final text combined both approaches well. All patients emphasized the need to be direct.

complementary therapy card



complementary therapy
emotional, physical and mental support

Complementary therapy is about living well in 3 ways: your feelings, your body and your mind. It's not easy and it's okay to ask for help. One patient says it like this:

"You are not crazy; cancer is crazy."

Although you have cancer, it doesn't have to become your whole world. It's important to do things to help you feel better.

Always check with your oncologist before starting something new, as some things can interact with what you are already taking.

Examples of complementary therapies:

- physical therapy
- diet & nutrition advice
- support groups & counseling
- relaxation techniques
- massages, acupuncture
- exercise & leisure classes

"It's super important to have support groups, to do yoga, meditation, eat well and exercise, do acupuncture... All these things have been known to help going through the cancer and kind of help you stay grounded. Because you're not crazy, cancer's crazy."

– MBC Patient
Excerpt from Oncologist Role-play Conversation

The original card had no text on the back. After the role-play, examples of complementary therapies were added, with a quote to encourage the patient accept help without the stigma of being "crazy."

cancer team card

Your Cancer Team




"I like to call it your 'cancer posse.' You can call it your team...but I want you to always remember this: You're the CEO of your body, and you're the CEO of your team. And we're all working for you."

– MBC Patient
Excerpt from Oncologist Role-play Conversation

The original card for the role-play just showed the team. Afterwards, "you're the boss" was added to the visuals to help reinforce the idea to the patient that they were in charge. It gives them permission to be in control.

not a statistic card

When you look up information about your kind of cancer, you are going to read some scary statistics. It's important to remember:

You are not a statistic.

Statistics are used to understand large groups of people, not one person. Each metastatic breast cancer is so unique, everyone is different.

If you have questions, talk to your doctor or cancer team.

"My onc told me 'I know you know the statistics. YOU are NOT a statistic!'"

– MBC Patient

Patient A: I can remember saying [to the doctor] 'I'll be alright, right? And they're like "well..." and not with the enthusiasm of "you're not a statistic."

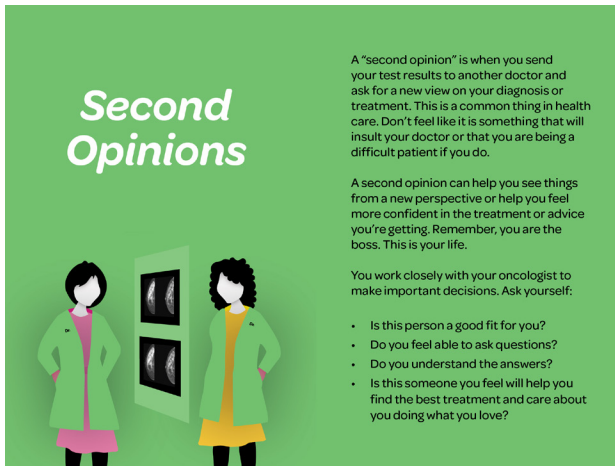
Designer: ...seeing it written out so clearly it kind of holds your attention so you believe it a little more maybe?

Patient A: Yes. Patient B: Yeah. Patient A: More hopeful.

Designer: Does it seem more believable when you see it versus hear it? Or see and hear together?

Patient A: See and hear together.

second opinion card



Second Opinions

A "second opinion" is when you send your test results to another doctor and ask for a new view on your diagnosis or treatment. This is a common thing in health care. Don't feel like it is something that will insult your doctor or that you are being a difficult patient if you do.

A second opinion can help you see things from a new perspective or help you feel more confident in the treatment or advice you're getting. Remember, you are the boss. This is your life.

You work closely with your oncologist to make important decisions. Ask yourself:

- Is this person a good fit for you?
- Do you feel able to ask questions?
- Do you understand the answers?
- Is this someone you feel will help you find the best treatment and care about you doing what you love?

The graphic features two female figures in white lab coats standing in front of a wall with two framed images, possibly X-rays.

"The second paragraph resonates with me as my second opinion doctor said he'd do the exact same thing my oncologist was already doing/ planning. It was a great boost of confidence."

– MBC Patient

"You about have convinced me to go and get a second opinion. ☺"

– MBC Patient

"I really like the second opinion card. I personally think all patients should get a second opinion at both initial diagnosis and recurrence if time permits. I found the card to be engaging and empowering for patients and I'm glad it is there."

– Cancer Education Expert

symptom & pain management card



symptom & pain management
improving life outside of the hospital

We want to manage pain and symptoms from the beginning to help you live well.

Tell us about any symptoms or pain you are feeling. This might mean adding new medications or discussing switching treatment options. This is okay.

Sometimes you or your family may also need additional help at home: grocery shopping, personal care or just someone to talk to who understands. There are services that we can offer you and are sometimes free.

At some point—hopefully as far in the future as possible—treatments will no longer work and most of the care will be focused on symptom and pain management. We are here for you whether you're actively in cancer treatment or not. Having a plan in place from the beginning can make it less stressful for you and your family, helping you focus on what matters most.

The graphic shows a green armchair with a yellow cushion and a small table with a vase of yellow flowers.

"I think this is a very important one that gets overlooked a lot. I wish more of our centers where we get our treatment would be on the same page."

– MBC Patient

"Where I am taking treatment now, no one has ever talked about physical therapy, or diet or nutrition, support groups or counseling, relaxation techniques, massage or acupuncture!"

– MBC Patient

A SURPRISING KEY MESSAGE

Patients selected the card, “This is NOT your fault” as the cover. In several instances, patients and healthcare workers emphasized the importance of this message. The design was also adjusted to suit patient preferences.



Patients in the workshop chose this card for the cover, then guided many iterations, front and back.

“This is not your fault, I find myself saying that a lot, in the conversation.”

—Medical Oncologist

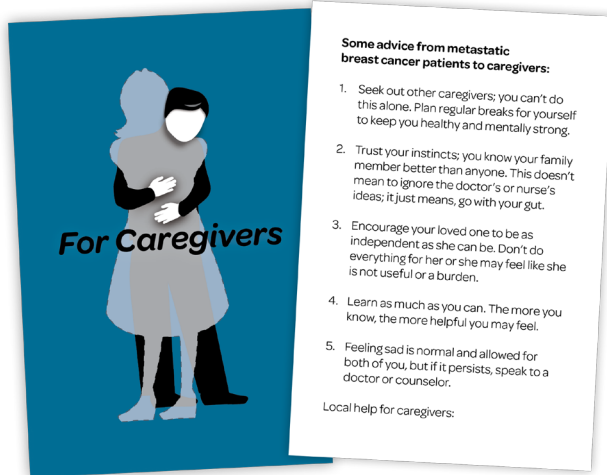
“As a preface, I think many people diagnosed with MBC end up second-guessing themselves, leading to guilt and self-blame. I’ve felt that way at times. But perhaps something you may not be aware of is that after diagnosis some of us continue to feel guilty. ‘I shouldn’t have eaten that ice cream.’ ‘I didn’t exercise today.’ ‘I didn’t eat enough vegetables at dinner.’ And so on. So the trend continues, and that’s problematic too.”

—MBC Patient



Encouragement Card

This introduces the deck, but will most likely be given at the end of the conversation after everything is reviewed with the patient. Patients can choose whether to put this at the front or at the end of their own deck—or display elsewhere as a pick-me-up.



Caregiver Card

Caregivers are a key part of care, helping patients choose treatments and supporting them through difficulty. Patients wrote this advice for caregivers to help explain what both the patient and caregiver need.

There is also a space for the navigator to write in a local resource for caregivers.



Online Research Card

Sometimes patients are misled by "miracle cures" they find online. This card explains how to spot an untrustworthy source. It can also be helpful for patients to share this card with well-intentioned friends who send them links to "miracle cures," which is a common issue.

"The designer has done an amazing job creating a teaching tool that is user-friendly, easy for patients to understand and for providers to use. It was a pleasure to collaborate on this project from the perspective of a patient, as well as a professional patient advocate. The designer listened. She put words into action. Impressive, is all I can say. I can't wait to begin using these tools with our metastatic breast cancer patients."

— Becky Boyle, BSN, RN, OCN
Oncology Nurse Navigator, Teton Cancer Institute

THE TOOLKIT



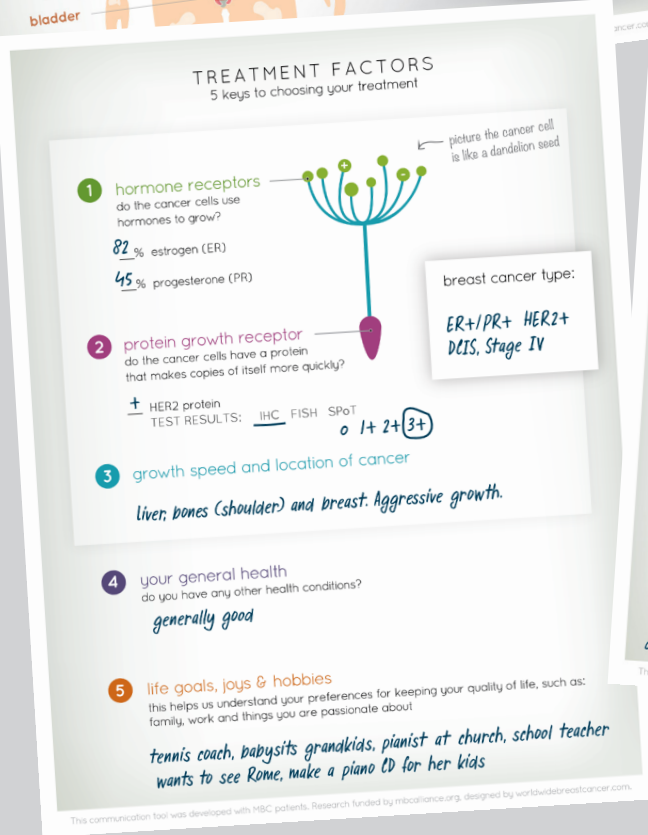
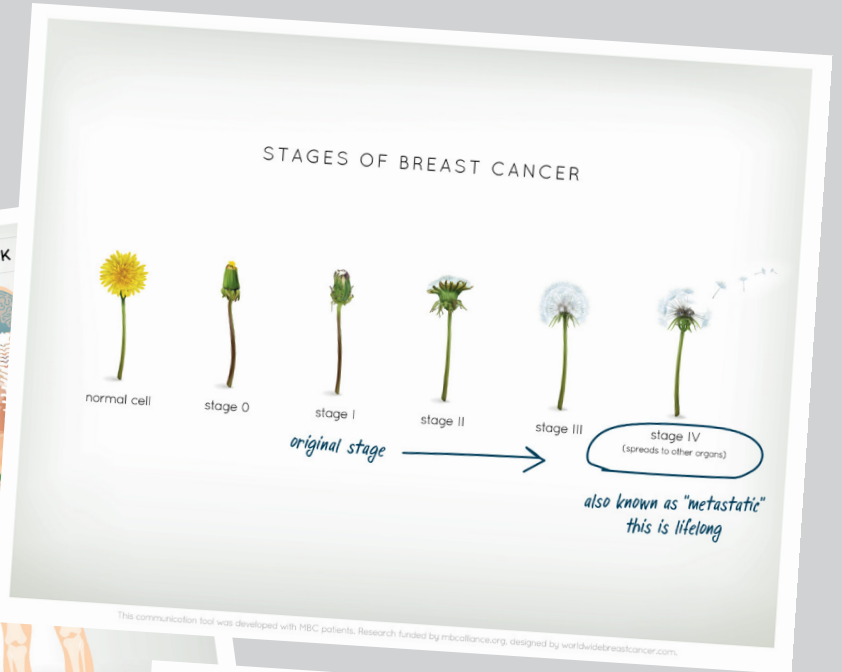
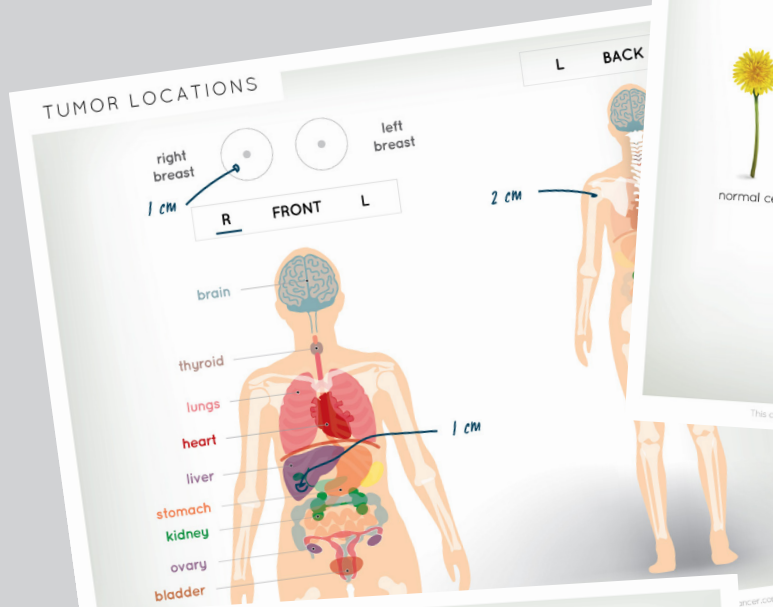
ONCOLOGIST
TEAR-OFF SHEETS



NURSE/NAVIGATOR
DISCUSSION CARDS

ONCOLOGIST TOOLKIT

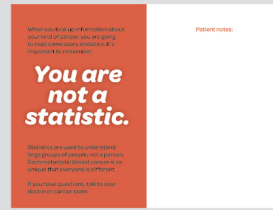
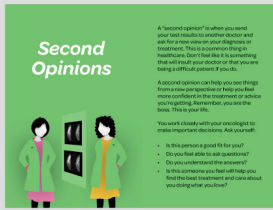
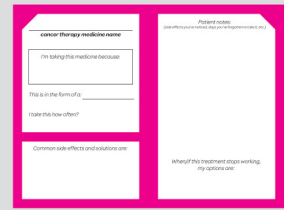
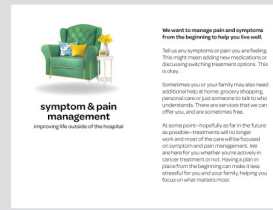
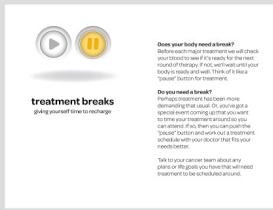
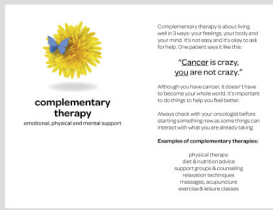
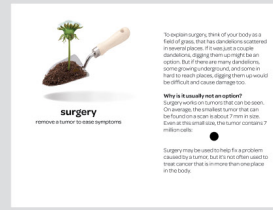
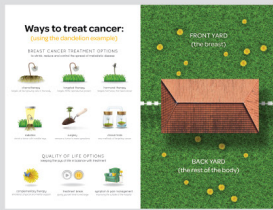
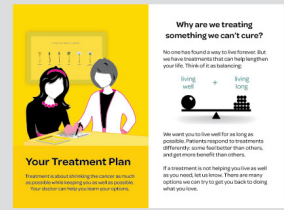
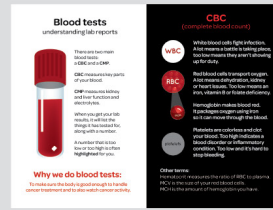
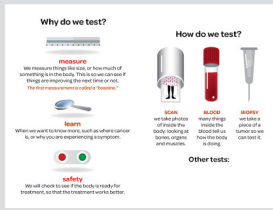
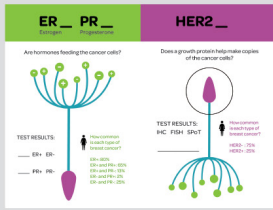
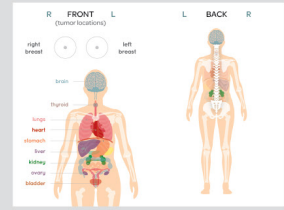
Two double-sided tear-off sheets to use during the initial diagnosis and treatment planning conversation(s). The topics cover stage, location, five factors for choosing treatment and an overview of treatment options and quality of life choices.



Simulation of an annotated set.

NURSE/NAVIGATOR TOOLKIT

A set of cards used as a tool for in-depth patient knowledge assessment and teaching after the initial conversations with oncologists. Each subject has its own card, with space to customize based on the patient's subtype. With very low text and highly visual, the tool is an introduction to concepts like hormone status, treatment options, trustworthy online sources, support groups, clinical trials, second opinions and more. This customized card set is a less overwhelming way to hear and convey difficult news. The patient keeps this card set to re-read and use with family and friends to explain what is happening to them.

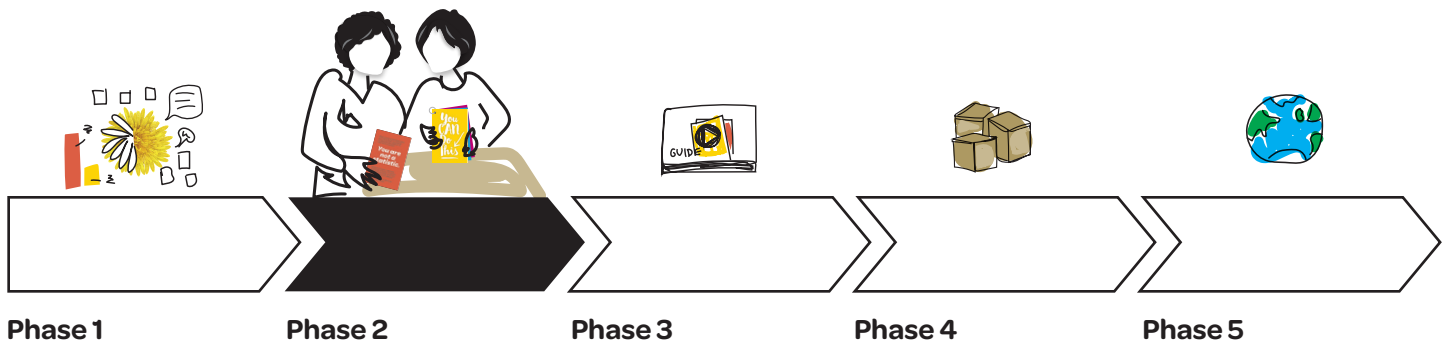


PHASE 2: COMMUNICATIONS TOOLKIT

While we developed the toolkit in close partnership with patients and their healthcare professionals, their input is still theoretical. Phase 2 is a pilot of this research, testing both English and Spanish versions of the toolkit in cancer centers nationwide to discover:

- How health practitioners use the toolkit.
- How newly diagnosed patients respond to it.

With this knowledge, we can further improve the toolkit before making it available to more patients in more locations.



In Phase 2 we will:

- Test the toolkit in a range of cancer centers (see “Join the Pilot” p. 37).
- Iterate based on feedback from newly diagnosed metastatic breast cancer patients and their healthcare teams.

Expand the toolkit to help patients:

- Identify life goals.
- Give their healthcare professionals insight into them as people.
- Explore ways of managing medications and side effects.

I'm really interested in trying to develop tools where we can understand who patients are as people before they even come into the clinic. Because it's a black box. We understand a lot about their disease. But we have no idea who they are as a person, or what their values are, or what kind of preferences they might have—because there's a lot of preference-sensitive decisions. How can we help them make a preference-sensitive decision without understanding what their preferences might be ahead of time?

—Surgical Oncologist



JOIN THE PILOT

We are delighted to expand our partnership group for the pilot in 2016 and welcome your participation in the pilot. For more information on how to get involved, please contact Katherine Crawford-Gray, Director, at:

katherine@mbcalliance.org

THANK YOU

Many people and institutions worked together to make this toolkit a reality. Our gratitude goes out to them all.

INVESTIGATOR/DESIGNER: CORRINE ELLSWORTH BEAUMONT, MFA, PhD
Founder/Director Worldwide Breast Cancer

Corrine is a designer and a health communications expert focused on addressing health disparity issues through visual metaphor. Her breast cancer detection campaign, "Know Your Lemons," distributed through the design charity Worldwide Breast Cancer, has educated millions and reached patients in even the most conservative countries. Available in 10 languages and counting, it is employed by the Turkish government, is on permanent display in the Valencia Science Museum, educates rural populations in Honduras and is used in every continent and every state in the U.S.

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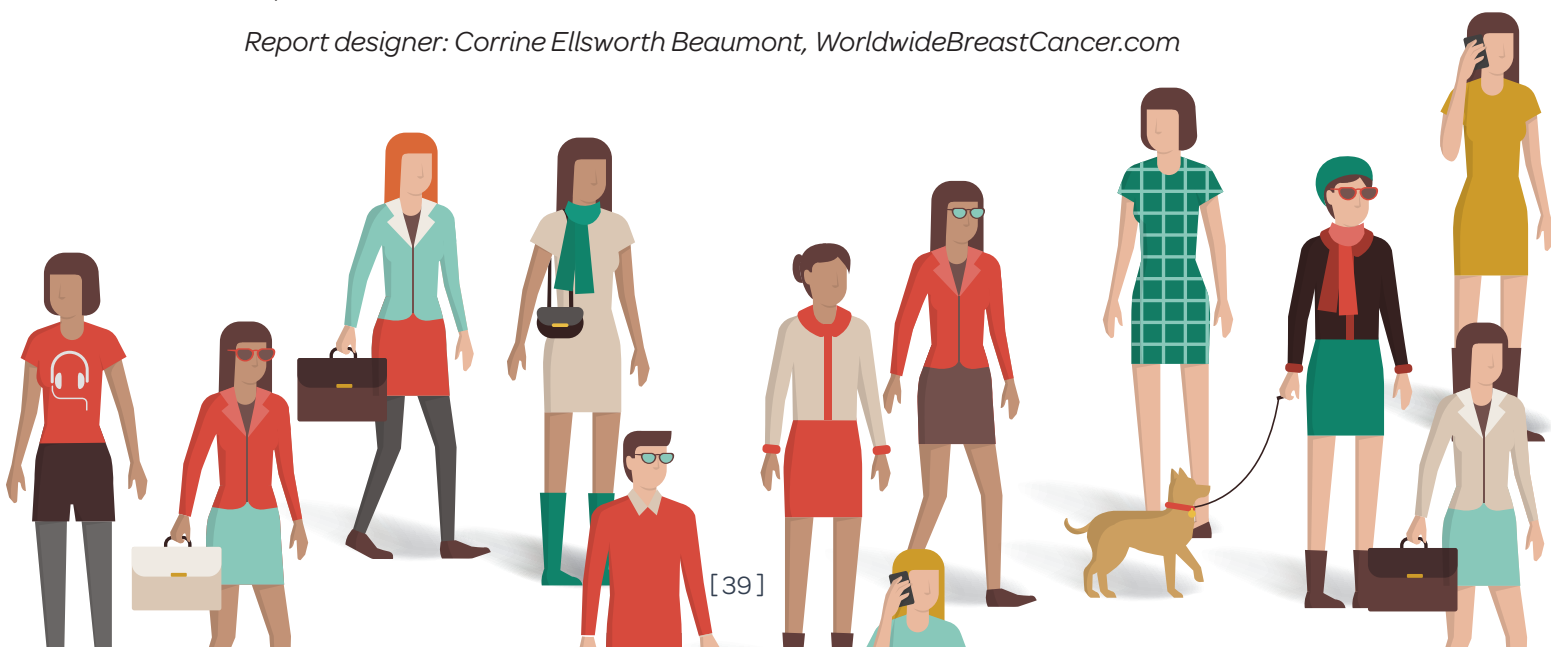
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The slogan of the Metastatic Breast Cancer Alliance—together we are stronger than the disease—is not an empty claim. Each year more than 40,000 people will die of metastatic breast cancer in the U.S. This number has remained unchanged for over a decade. Given the devastating toll this disease takes, our members—40 cancer, breast cancer nonprofits, industry partners and individuals—have come together to transform and improve the lives of people living with metastatic breast cancer. This collaboration is the largest of its kind for breast cancer, with all advocate and industry members committed to working together, openly sharing resources and information.

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AdvancedBC.org	Dr. Susan Love Research Foundation	Novartis Oncology	Triple Step Toward the Cure
American Cancer Society	Eisai	Nueva Vida	Twisted Pink
Cancer Action Network	Facing Our Risk of Cancer Empowered FORCE	Patient Advocate Foundation	Young Survival Coalition
AstraZeneca	Novartis Oncology	Pfizer	
Avon Foundation for Women	Genentech	R-Pharm US	INDIVIDUAL MEMBERS:
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BreastCancerTrials.org	Living Beyond Breast Cancer	Sharsheret	Elizabeth Frank
Canadian Cancer Survivor Network	Metastasis Research Foundation	Sisters Network, Inc.	Jane Perlmutter
Cancer Support Community	Metastatic Breast Cancer Network	Susan G. Komen	Hester Hill Schnipper
CancerCare		Theresa's Research Foundation	
Celgene Corporation		Triple Negative Breast Cancer Research Foundation	

CERTAIN ACTIVITIES OF THE ALLIANCE ARE SUPPORTED BY OUR FINANCIAL MEMBERS:

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The Breast Cancer Research Foundation is proud to lead and administrate the MBC Alliance.

“As we move to a more patient-centered course of healthcare delivery, it is crucial that educational materials are not only flexible enough to meet the needs of the patients, but are derived from the patient perspective. This toolkit merges creativity, health literacy and best clinical practice to empower patients with metastatic breast cancer. I am excited to see its use in patient education.”

—Jeff Yancey, PhD, MCHES, Associate Director of Education, Huntsman Cancer Institute

