

# Metastatic Breast Cancer Dandelion Study Phase II and III Report

2016-2019

Report, design, and research by:  
Corrine Ellsworth-Beaumont, PhD

*A special acknowledgment to MBCA for supporting this study over several years and to ACCC for making this study so widely available to its members. Thanks to Beth Burnett at Pfizer, for bringing these parties together for success, and Lillie Shockey at Johns Hopkins for believing in the work and providing the wonderful training videos for nurses and advice on content. And finally, thank you to all the patients and HCPs who provided feedback and insight and took part in this study. We will continue to work on ways to improve the patient experience and improve outcomes for all.*

[December 2019]

# Metastatic Breast Cancer Dandelion Study Report

<b>2016-2019</b>	<b>1</b>
Background	4
Mexico MBC Baseline Study	5
25 Clinics Enrolled	7
2016-2017 Cohort	7
2018 Cohort	7
2019 Cohort	7
The Intervention	8
Developing the Training	11
Training Development Process	13
Training Approach for Cohort 2: Group webinar	13
Training Approach for Cohort 3: Online Quiz/Registration and Poster	14
MBC Patient Study	15
MBC Patient Survey	15
Demographics	15
Patient Control Preferences	16
Patient Subtype	18
How patients felt about their conversations	20
Patient Experience with the Intervention	21
Patient Use	21
MBC Patient Feedback	22
MBC Patient Recommendation	22
HCP Study with MBC Patients	23
HCP Study with ACCC	26
HCP Training Preferences	30
HCP Intervention Feedback	30
HCP Recommendation	31
Limitations and Future Recommendations for Study	32
<b>Conclusion</b>	<b>33</b>
<b>APPENDIX</b>	<b>34</b>
Abstracts, Publications, and Presentations	34
2015	34
2016	35
2017	40
2018 - 2019	41
Research Protocol & Questionnaires	43

## Background

The purpose of the Dandelion study was to investigate better methods of patient-practitioner communication and shared decision-making through the use of a visual conversation aid. In 2015, the MBCA contracted Corrine Beaumont to conduct research on the use of a visual tool with metastatic breast cancer patients. The 2015 initial study focused on information pertaining to the current MBC patient experience through an online survey of 484 patients as well as developing a visual intervention to be tested through the research, known as the “Dandelion Toolkit.” The results of the initial study were published under in the Phase I report. This is a continuation of that report following the recommendations for further research in a clinical setting.

This report gives an overview of the research undertaken to study how a visual conversation aid (intervention) could be used in the clinical setting to improve patient-practitioner communication.

Four surveys were conducted in total:

1. MBC Patient Survey (2016-2019)  
Explores the patient experience with the intervention
2. HCP Survey with MBC Patients (2016-2019)  
Investigates the HCP experience with the intervention
3. HCP Survey with ACCC (2018-2019)  
Collects feedback on how the HCPs found the intervention useful alongside their patient observations with the intervention
4. Mexico MBC Patient Survey (2018)  
Serves as a baseline measurement for introducing the intervention in Mexico at a future date.

An initial target of 25 clinics to participate in the study was set. Three rounds of enrollment occurred between 2016 and 2019 to reach this target. The work involved exploring training approaches, identifying how HCPs used the intervention as well as assessing patient knowledge and experience.

This report will first cover the Mexico study as it is used to compare against results in the MBC patient survey in this report. Next, an overview of the clinics involved, the training development process, and the intervention will be described to establish what the toolkit was initially comprised of and the process of its respective development. After this, the MBC patient survey will be discussed, followed by the HCP survey with the MBC patients, and then the HCP survey with ACCC clinics. The report will conclude with limitations of the research and recommendations for future study.

## Mexico MBC Baseline Study

Working with Alejandra Platas in Mexico City at the Instituto Nacional de Cancerologia from January - December 2018, study questions were used with MBC patients (n=185) to understand their initial diagnostic experience as a baseline study. These results could be used to compare to participants who had used the intervention, as well as prepare the way for the intervention to be used in future.

The majority of patients were older than 40 years (91%) and more than half of them had been diagnosed with de novo MBC (56%). Subtype was as follows:

- hormone receptor (HR)-positive/HER2-negative, 53%
- HR-positive/HER2-positive, 18%
- HR-negative/HER2-positive, 12%
- triple negative, 12%
- unknown, 5%

Fifty-two percent of participants were aware that their disease was incurable, while 31% were not sure, and 17% believed it was curable. Likewise, 82% of patients did not know their BC subtype and 81% reported to want more information on this topic. No significant association was found between clinical variables and patients' perception that MBC was curable or their knowledge of their BC subtype.

Forty percent of patients stated they found it difficult to talk about treatments with their physician because they did not understand the options that were available to them. Additionally, 25% considered that their goals and priorities were taken into account during the selection of their treatment. No significant association was found between the moment of MBC diagnosis (de novo or recurrent) and patients' perception of having enough knowledge to participate in treatment-related dialogues.

Regarding patients' conversations with their oncologist, the most commonly discussed topics are listed below, followed by how commonly they were recommended as treatment as reported by patients:

- Discussed chemotherapy (93%), recommended (93%)
- Discussed radiotherapy (68%), recommended (66%)
- Discussed symptom and pain management (65%), recommended (39%)
- Discussed surgical management (62%), recommended (52%)
- Discussed complementary services such as nutrition, exercise, psychological support, and acupuncture (46%), recommended (38%)
- Discussed hobbies, interests and goals (49%)
- Discussed treatment pauses (48%)

Hormonal therapy was recommended as a treatment option (36%), with 71% having hormone positive MBC. This gap likely indicates a lack of understanding by patients on what hormone therapy is, as it is unlikely it would have been recommended at such a low rate.

Twenty-four percent of patients reported having discussed the existence of clinical trials with their physician and 2% received a suggestion from their doctor to participate in a trial as part of their treatment.

Sixty-four percent of participants scored their satisfaction with the provided information  $\geq 9/10$ . The most helpful source of information was the medical staff for 74% of patients, followed by printed information provided at the clinic for 24%, and the Internet for 16%.

A significant association was found between the knowledge that MBC was incurable and better patient satisfaction with the provided information ( $p=0.038$ ), as 71% of patients who answered that MBC was not curable reported high satisfaction, while fewer (56%) of those who believed MBC was curable were highly satisfied. Furthermore, better patient satisfaction was associated with older age ( $p=0.002$ ), longer time since initial BC diagnosis ( $p=0.018$ ), and longer time since the diagnosis of MBC ( $p=0.014$ ).

With additional funding the intervention can be deployed in Mexico and a comparative study could be conducted to determine if communication improves when the intervention is present.

## 25 Clinics Enrolled

The initial cohort for the study limited enrollment to newly diagnosed metastatic breast cancer patients to understand the initial diagnosis experience. This proved problematic for recruitment as fortunately a newly diagnosed breast cancer patient was a rare event in most clinics.

Partnering with ACCC helped the study expand to more centers, and the study was expanded to include all breast cancer patients. IRB was also another obstacle with some clinics taking up to 18 months to approve the study. With ACCC we also reduced the timeframe for the study and we limited the surveys to HCPs (not patients) to act as a feedback mechanism under a pilot activity. The number of clinicians trained for the study (n=64) is included at the end of each listing below.

### 2016-2017 Cohort

1. Dartmouth-Hitchcock Cancer Center, Lebanon, New Hampshire (3)
2. Huntsman Cancer Institute, Salt Lake City, Utah (2)
3. Teton Cancer Institute, Rexburg, Idaho (1)
4. Teton Cancer Institute, Idaho Falls, Idaho (2)
5. Opción Oncología, Monterrey Mexico (2)
6. İstanbul Univeritesi Onkoloji Enstitüsü, İstanbul, Turkey (4)
7. The Canberra Hospital, Breast Cancer Network Australia (8)
8. University of Texas Health Science Center, San Antonio, Texas stalled with IRB
9. Sanford Health, Fargo, North Dakota (6) withdrew after training

### 2018 Cohort

10. Adena Cancer Center, Chillicothe, Ohio (6)
11. Center for Cancer and Blood Disorders, Fort Worth, Texas (10)
12. Western Maryland Health Systems, Cumberland, Maryland (14)
13. Valley Medical Center Oncology and Hematology Clinic, Renton, Washington (2)
14. Ascension Cancer Care, Wauwatosa, Wisconsin (3)
15. Holy Family Memorial Cancer Center, Manitowoc, Wisconsin (1)

### 2019 Cohort

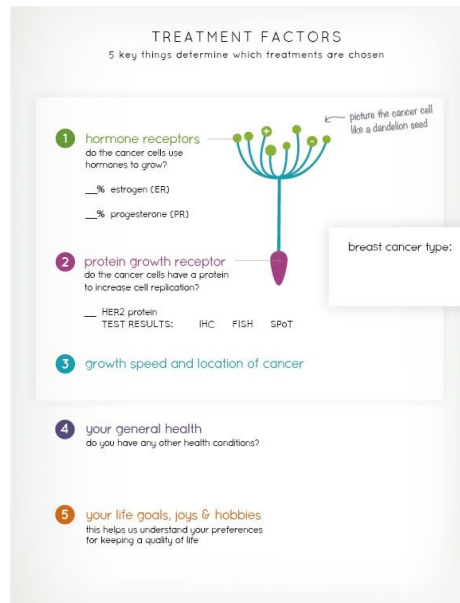
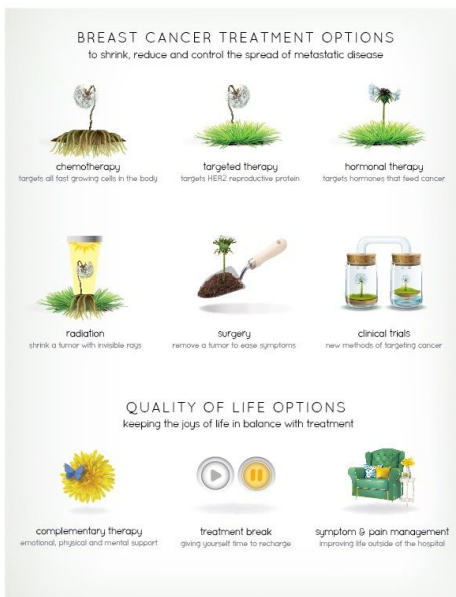
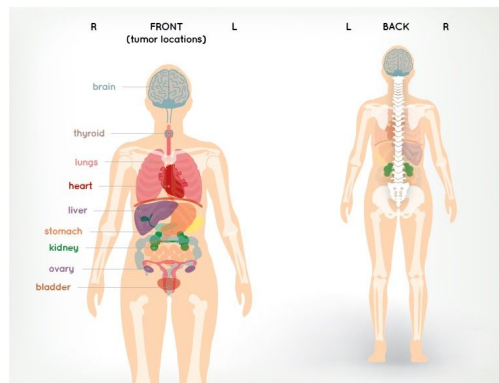
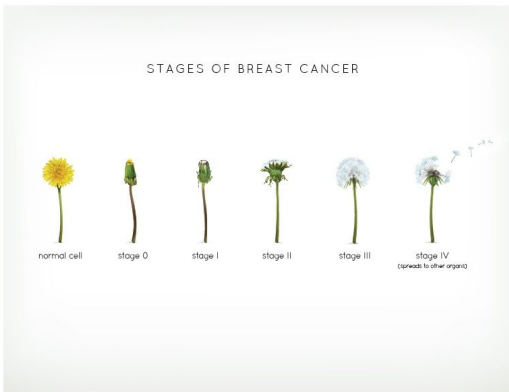
16. The Cancer Center at Ohio Valley Medical Center, Wheeling, West Virginia (1)
17. St. Mark's Hospital, Salt Lake City, Utah (1)
18. Froedtert & Medical College of Wisconsin Breast Care Clinic, Milwaukee, Wisconsin (10)
19. University of Mississippi Medical Center Cancer Institute, Jackson, Mississippi (1)
20. St. Luke's University Health Network, Bethlehem, Pennsylvania (1)
21. Centro de Cancer de Mama, Mexico (1)
22. Centro Medico Zambrano Hellion, Mexico (1)
23. Ogden Regional Medical Center, Ogden, Utah (1)
24. Metropolitan Methodist Breast Center, San Antonio, Texas (2)
25. Centro de Cáncer de Mama-TecSalud, Mexico (1)

# The Intervention

An intervention for researching patient-practitioner interaction was needed to research whether a visual communication aid could improve patient engagement and understanding between patients and HCPs.

Visuals and descriptions were developed by Dr. Beaumont that explained staging, survival and imaging information, pathology, and treatment options to make it easier to communicate complex medical topics without being reliant on text or medical terminology. This consisted of:

- An introductory set of tear-off sheets (later referred to as the “conversation card”)
- A handheld patient guide explaining breast cancer concepts in further detail than the conversation card (“card deck”).



The tear-off sheets were used to communicate basic concepts relating to diagnosis and treatment options that were easy to annotate for oncologists.

The purpose of the “card deck” was to take the introductory information from the tear-off sheets and to explain concepts in further detail. The initial premise was that a nurse or nurse navigator would sit down with the patient and go over each card together, using the tear-off sheets/conversation card as the reference material, after receiving the tear-off sheets from the oncologist.

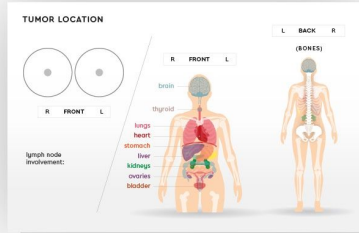


Overview of the 60 page “card deck” intervention.

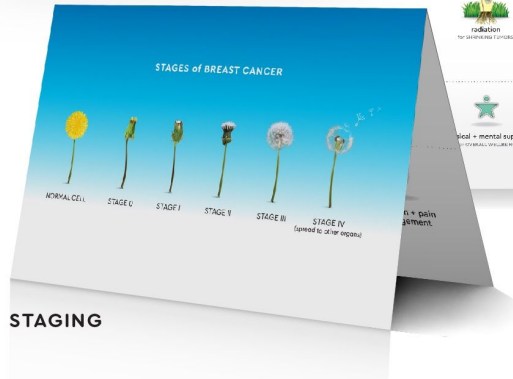
Cumulatively, the two parts of the intervention were called the “toolkit.” As results came in from the different studies, feedback on how to further develop the intervention was assessed and adjustments were made to the toolkit. The most notable was the combination of the tear-off sheets into a single card, making it easier to handle, annotate and share with patients.



## IMAGING



## PATHOLOGY



## STAGING

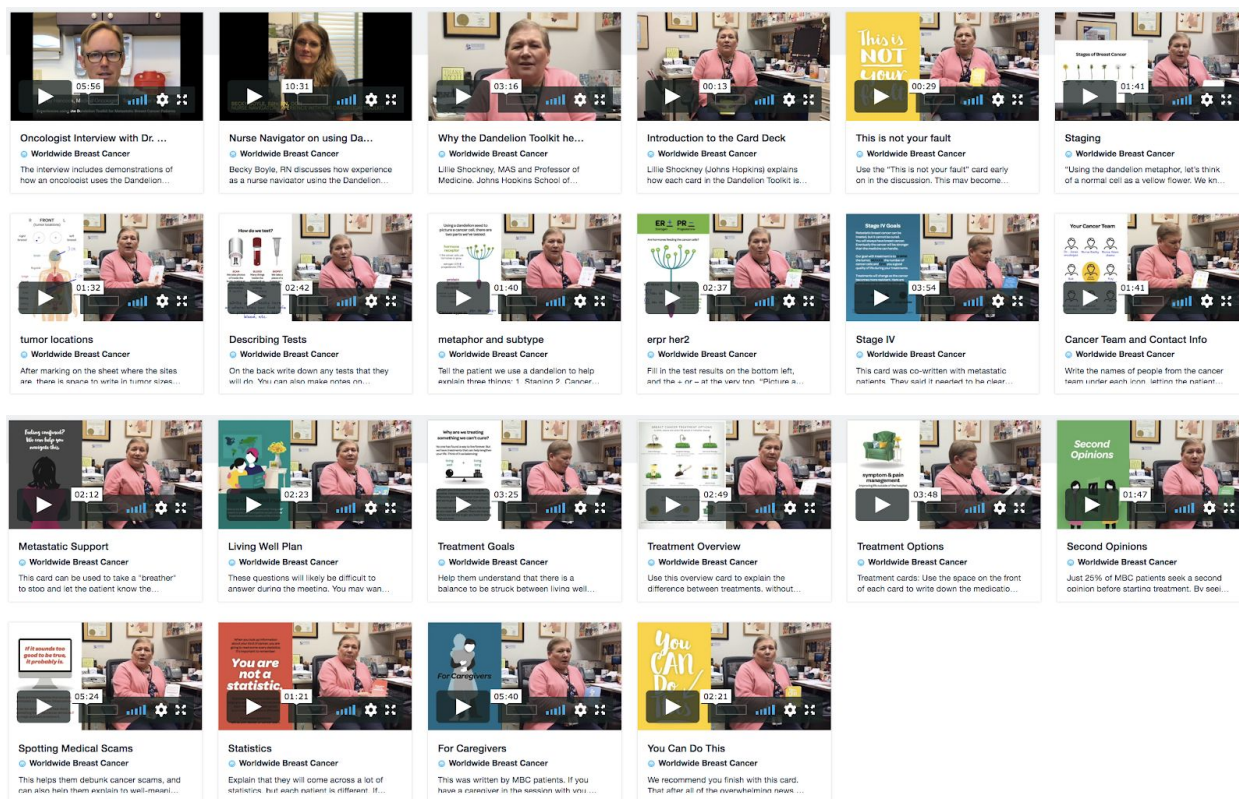
## TREATMENT OPTIONS

The “conversation card” combined and refined information from the tear-off sheets into a single piece of paper.

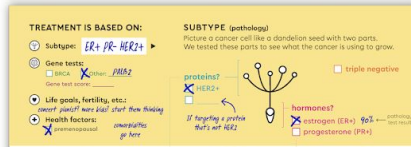
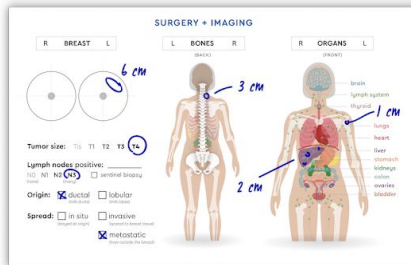
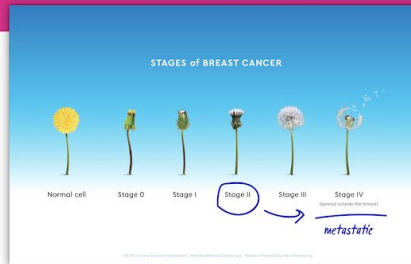
# Developing the Training

The training went through several iterations as feedback was gathered with each cohort. In the course of the research, seven tools were developed and tried with HCPs to help explain how to use intervention as part of diagnosis and treatment conversations. The training tools (available to view online in the [Dandelion Training Folder](#)) consisted of:

1. 23 Page Training Guide (4 versions developed, final version 1.4) can be viewed [here](#).
2. Powerpoint presentation can be viewed [here](#).
3. Examples of how to use the kit can be viewed [here](#).
4. A preview of the kit can be found [here](#).
5. Online assessment (quiz) can be found [here](#).
6. Large training poster (next page)
7. Online repository of 24 videos: <https://vimeo.com/showcase/4287963>  
Password: dandelion



# USE THE DANDELION CARD AS A TEAM & SAVE TIME THROUGH BETTER COMMUNICATION WITH BREAST CANCER PATIENTS



## STAGING

"How cancer spreads is a lot like a dandelion. When it is a yellow flower, we don't worry about it. But when it turns to seed, that's when it becomes cancer. Depending on how far it has spread tells us the stage. When it leaves the breast, it's called metastatic."

(This example shows how to explain staging to a patient who was previously Stage II is now Stage IV.)

## SURGERY + IMAGING

"We've done some tests to learn about where that 'seed' (or the cancer) is in the body. This is what we know."

OR: "We have some information on where the cancer is, but we need to run more tests and then we'll finish filling this out."

## PATHOLOGY

"Now we will use a dandelion seed to explain what we know about how the cancer is behaving. Think of a cancer cell as having two main parts we look for..."

[Point to the top half] "...if it's using certain proteins to grow."

[Point to the bottom half] "Or if it's using hormones to grow."

## TREATMENT OPTIONS

"Picture your body as a field of grass and the cancer as the dandelion in the grass."

Using this example, I will explain the difference between each treatment option, how it affects the body and the cancer and what is most effective based on how the cancer is behaving."

## QOL + PALLIATIVE CARE

"We will always manage your symptoms and pain. This is an important part of your care."

Stage IV patients: "At some point all of the treatments (wave hand over 6 treatment options in the Treatment Section) will be focused in this area." [point to heart icon] (this is a gentle way to bring up palliative care/hospice from the beginning rather than at the moment of crisis.)

Toolkit developed by: **worldwide** breast cancer

Research sponsored by: **MBCalliance** together we are stronger than the disease

Championed by: **ACCC** Association of Community Cancer Centers

**ASK YOUR PATIENT NAVIGATOR**

JOINING THE STUDY? [corine@worldwidebreastcancer.org](mailto:corine@worldwidebreastcancer.org)

This is what the Training Poster looked like, printed at a large size of 2x3' for clinics to hang in communal areas of the clinic.

## Training Development Process

### Training Approach for Cohort 1: Guidebook, Training Videos, One-on-one training with roleplay

The initial approach was to develop a training guide that explained each part of the kit in detail, with an accompanying set of videos presented by Lillie Shockney at Johns Hopkins. In the end, this training method proved to be too time consuming for most participants as many felt too time restrained to read the documentation or watch the videos.

Date ↕	Impressions	Views	Finishes	Avg. % Watched
2016	137	24	8	48
2017	410	78	59	92
2018	462	61	30	64
2019	125	19	0	19
<b>Totals:</b>	<b>1,134</b>	<b>182</b>	<b>97</b>	<b>69%</b>

*Reviewing the data from the videos found that there were 182 videos viewed, but only 97 videos were watched completely. The most viewed videos were the HCP testimonials.*

Participants were also given one-on-one training via a webinar where the HCP would try out the toolkit with a fictitious patient pathology and receive feedback from the trainer. While advance notice was given to practitioners to have a fictitious pathology ready to try the kit during the training session, most of them did not have time to prepare in advance, and some felt that they didn't need feedback. While the one-on-one training was helpful to understand HCP preferences and give clear instructions, it wasn't a scalable way to train multiple clinics simultaneously.

#### Cohort 1 Training Summary:

- One-on-one training in person (Idaho, Utah) or via webinar.
- A 23 page document explaining each of the cards of the kit, sample conversations, versions 1.4.
- 20 videos of Lillie Shockney discussing the kit.
- 3 videos of HCP testimonials.
- Examples of how to use the kit.
- Preview of the kit.

### Training Approach for Cohort 2: Group webinar

The next approach was to do the training via a live webinar that included a demonstration and a way to try out the kit as part of a group exercise. In some cases this worked well, it allowed the group an opportunity to share how they'd like to use the kit, practice it with colleagues and

ask questions. However due to the nature of the ACCC recruitment process, we found in some cases the group wasn't informed of what the training was about in advance of coming to the meeting, didn't view the toolkit beforehand, and had reservations about participating in a new study with the time restraints they were already facing. In other words, the group didn't always have buy-in before the training began.

The cohorts that were most engaged were ones that had a colleague to champion the study and understood the advantages of the communication aid. The setback from the group approach was that it was difficult to get the contact information of everyone in the room, as we had a strict 45 minute limit to train due to group scheduling restraints. Despite several requests for obtaining individual information for those that attended the webinars, we were only able to communicate through the admin in most cases and were not able to obtain the contact details of the HCP for follow-up surveys directly.

#### Cohort 2 Training Summary:

- Webinar with live demo.
- Powerpoint presentation.
- A 23 page document explaining each of the cards of the kit, sample conversations, versions 1.4.
- 20 videos of Lillie Shockney discussing the kit.
- 3 videos of HCP testimonials.
- Examples of how to use the kit.
- Preview of the kit.

#### Training Approach for Cohort 3: Online Quiz/Registration and Poster

A post training survey revealed that most preferred to do a short course in their own time, rather than during a lunch hour or as a group. This is when the training was set up in the form of a quiz that asked HCPs a set of questions to explain the kit and assess their understanding of how it could be used. This allowed a more flexible schedule, made it easy to gather contact information and also register information on locations and the number of kits needed. A training poster summarized key conversation prompts for the conversation card with an instruction to display it in a common area in the clinic to encourage more clinicians to try the approach.

#### Cohort 3 Training Summary:

- An online quiz
- A poster to display in the office

As will be discussed in the HCP study with ACCC, the preferred method for training by HCPs was a short online course. Elements from each of the material used for training could be combined in the future to create this course as well as provide CME credit.

## MBC Patient Study

### 2016-2017 Protocol

The initial protocol limited the study only to newly diagnosed metastatic breast cancer patients. It was also a double-arm comparison study between those who had the intervention with those who had not. In the end, this proved impractical as patient recruitment was so limited, and HCPs varied between patients making it difficult to use one group as a control and rule out variables such as individual HCP communication style.

It took nearly two years to recruit 8 patients across nine sites with only four of them submitting patient surveys to the study (Australia and Turkey continued to submit surveys through 2019). Some MBC patients were not able to participate in the study due to a short lifespan after diagnosis (such as they went into hospice immediately after diagnosis). Other delays in this cohort was securing IRB for the sites with Huntsman Cancer Institute and Sanford Health taking 12-18 months to complete due to staff changes and the nature of the approval process to survey patients. In addition, not every newly diagnosed MBC patient was assigned a staff member who was part of the study. So when a new patient was eligible to be enrolled in the study, they became ineligible as the HCP assigned to them wasn't part of the study. This full protocol used for the initial study is located in the Appendix of this report.

## MBC Patient Survey

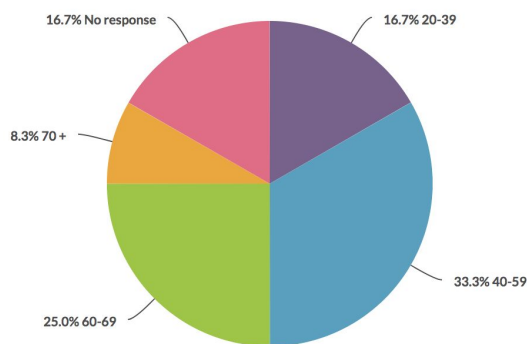
In total, 24 newly diagnosed MBC patients completed surveys that were submitted for the study from February 2016 to July 2019. The majority of patients were older than 40 years (67%) and more than half of them had been diagnosed with *de novo* MBC (52%). The average length of diagnosis prior to the study was 21 months. Subtype was as follows:

- hormone receptor (HR)-positive/HER2-negative, 75%
- HR-positive/HER2-positive, 4%
- HR-negative/HER2-positive, 0%
- triple negative, 12.5%
- unknown, 8%

### Demographics

Patients were located in the USA (5), Turkey (4) and Australia (15). The reason the most MBC patients were from Australia was due to a few factors:

- IRB approval process was quick.
- The tool was used during the duration of the study (2016-2019).
- A clear process for administering and collecting the surveys was in place.
- A changeover of staff didn't occur.
- The hospital network in Australia covered a large patient population.



The age range of patients in the MBC survey was fairly distributed. Education varied widely depending on location, with 50% of patients married or in a partnership.

## Patient Control Preferences

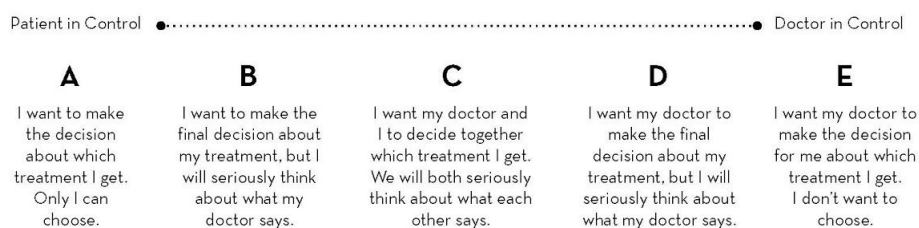
The first part of the survey assessed what level of control patients wanted in decision making. This was used to compare patient preference pre and post discussions.

The “Control Preferences” scale was developed in partnership with Dr. Jeff Sloan from the Mayo Clinic who specialized in Quality of Life (QOL) measures. The wording was modified to fit the patient audience from its original version with his input. Patients were asked to circle which level of control they wanted prior to their first discussion and after they received the intervention. This figure below shows the scale that patients were given:

Which statement below best describes the way you want to have decisions made about your treatment?

Circle one.

*The Control Preferences Scale*



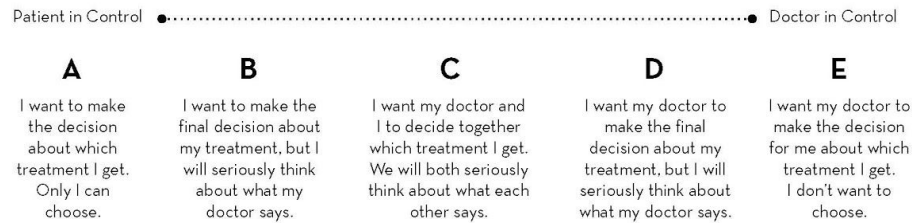
There are many factors that influence how patients want to be involved in their care; personality, perception of willingness for the HCP to discuss options, the type of immediate decisions that must be made and so on. By understanding a patient’s baseline control preferences, we could observe whether there could be a possible correlation between the intervention and their preferences in decision making.

After patients had engaged in discussions with their healthcare team, they were given a survey with a follow-up control preferences scale and additional questions to assess their knowledge and experience.

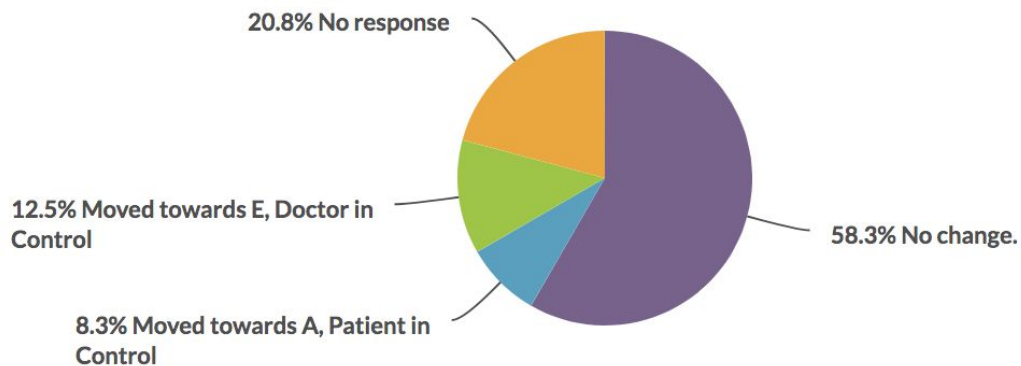
Which statement below best describes the way you have made decisions about your treatment?

Circle one.

*The Control Preferences Scale*



A pre-post comparison analysis found that there wasn't a significant change in patient control preferences in the reported sample. "No response" indicated that a pre and post control preference study was not collected. A larger sample would need to be taken to validate the findings.

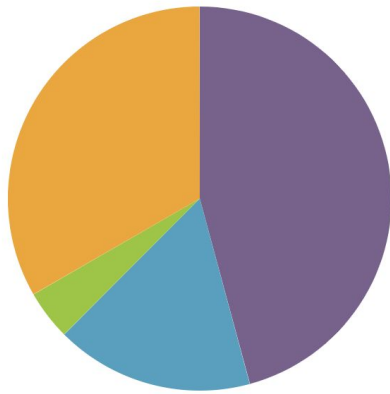


Value	Percent	Responses
No change.	58.3%	14
Moved towards A, Patient in Control	8.3%	2
Moved towards E, Doctor in Control	12.5%	3
No response	20.8%	5
<b>Totals: 24</b>		



## Patient Subtype

Knowing one's "subtype" is important as it is the basis for most treatment options. Without a knowledge of subtype, it is difficult for a patient to fully participate in decision making or understand why some treatment options have been recommended compared to others.

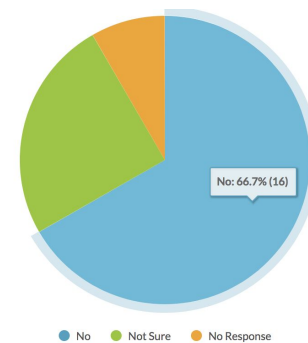


Value	Percent	Responses
Patient wrote down the correct subtype.	45.8%	11
Patient was correct about hormone status, but didn't mention PR status.	16.7%	4
Patient wrote down the incorrect subtype.	4.2%	1
Patient didn't write down any subtype.	33.3%	8

Totals: 24

## Did the patient know their correct subtype?

It was difficult to determine whether the intervention improved patient knowledge concerning subtype. It was observed in the tear-off sheets that were collected, that the subtype wasn't always annotated for the patient. The 46% figure is in line with the initial MBC baseline study published in the Phase I Report. It also wasn't necessary for patients to mention PR status if they were hormone positive. So combining the 45.8 and the 16.7 result revealed an increase in patient knowledge, but with a third of patients not writing any information for the question, it's impossible to make a conclusion. Further study is required with a broader sample of patients to confirm these findings.



Value	Percent	Responses
No	66.7%	16
Not Sure	25.0%	6
No Response	8.3%	2

Totals: 24



























## Understanding the Lifelong nature of MBC

It was clear that patients understood that an MBC diagnosis was lifelong. With no patients responding in the affirmative that was curable. However, patients didn't always feel comfortable declaring that it was incurable or curable outright. While no patients answered "yes" to the question, "Is metastatic breast cancer curable," one in four responded "not sure." One patient wrote an additional note that summarized the reason why others may have responded that way, "Depends on who you believe. Probably not but I might be more special than I think I am."

Compared to the Mexico Study where 52% of patients reported that MBC was incurable, this shows a significant improvement in understanding about the nature of metastatic disease when the intervention was used.

Patients were asked which topics were covered in their discussions with their healthcare providers to understand the content of conversations. Second opinions were rarely discussed and just one out of four patients talked about their hobbies, interests and goals as part of determining treatment. Clinical Trials was discussed with half of patients. Discussion of Targeted Therapy was low, which may have been due to fewer patients being HER2 positive.







It's clear from these results that more needs to be done to encourage discussion of these topics.

	Discussed	Recommended
Chemotherapy	 75.0%	 33.3%
Targeted therapy (HER2+)	 25.0%	 4.2%
Hormone therapy (ER+, PR+)	 70.8%	 29.2%
Radiation	 70.8%	 25.0%
Surgery	 20.8%	 4.2%
Clinical trials	 50.0%	 16.7%
Complementary therapy (nutrition, exercise, counseling, acupuncture, etc.)	 37.5%	 8.3%
Counseling	 25.0%	 4.2%
Treatment breaks (reasons to postpone a treatment)	 45.8%	 12.5%
Symptom & pain management (plan to counteract side-effects, preserve quality of life)	 50.0%	 20.8%
Second opinions	 16.7%	 12.5%
My hobbies, interests and goals	 25.0%	 8.3%
No Response	 4.2%	 45.8%

Topics discussed by the HCP as reported by the patient.

## How patients felt about their conversations

Asking patients how they felt about their conversations revealed that more patients strongly considered or got a second opinion than discussed it with their HCP. Four patients wish they knew more about their cancer type. One-third of patients found it hard to talk about treatments because they didn't understand the options available to them.

Clinical Trials were a topic discussed with my doctor		42.1%	8
I found it hard to talk about treatments because I don't understand all of the options available to me		36.8%	7
I wish I knew more about the type of cancer I have		21.1%	4
My life goals and priorities were discussed as part of my treatment options		36.8%	7
I strongly considered or got a Second Opinion		31.6%	6
This clinic is where I got my Second Opinion		15.8%	3

*MBC patient response to, "Which of the following statements are true for you based on your conversation experience?"*

## Patient Experience with the Intervention

When asked what was true with their experience with the toolkit, patients responded positively. With 65% said it helped them to understand their breast cancer type. 48% had a better understanding of what was happening inside their body. 52% reported it helped them understand why some treatments were recommended over others and 30% stated it would have been harder to understand conversations without the toolkit. It's unknown if these results would have been further improved if the intervention had been consistently used as intended (see HCP Study with ACCC).

## Patient Use

When patients were asked how they used the toolkit, 63% said they read it at home, with 25% saying they used it to explain their diagnosis to family and friends. Only one patient reported it as only using it in the clinic.

Value	Percent	Responses
The visuals helped me to understand the type of breast cancer I have.	65.2%	15
The visuals helped me to picture what was happening inside my body.	47.8%	11
The visuals helped me to understand how cancer is treated and why some treatments are better than others.	52.2%	12
It would have been harder to understand my diagnosis or treatment options without the visuals.	30.4%	7
I found the toolkit helpful, it made the conversations in the clinic better.	26.1%	6

Value	Percent	Responses
Read it at home	62.5%	15
Used it often	16.7%	4
It was my favorite information guide	8.3%	2
Used it to explain to family and friends	25.0%	6
I only used it at the clinic	4.2%	1
I only used the cards	16.7%	4
No Response	12.5%	3
<a href="#">Other - Write In (click to view)</a>	8.3%	2

Other - Write In	Count
No	1
Thought the plastic box as non-environmentally friendly	1

*Patient response to the question, "Which statements are true based on your experience with the toolkit?"*

When asked what single information source helped them the most, 80% of patients reported that conversations with their healthcare team were the most beneficial. This supported the idea that the intervention shouldn't replace conversation but be an integral part of it.

### MBC Patient Feedback

MBC patients were given the opportunity to explain what they liked best about the toolkit. Responses were:

"Graphics made understanding more accessible."

"The pitch is just right. Not too academic or too dumbed down."

"I was able to explain what was happening to family without getting confused or emotional. It meant they feel well informed."

"It was written in layman's language"

"Easy to read and positive."

"I liked how easy it was to explain to others. Remembering my medications was easier."

"The cards are basic so all family and friends can understand. You can read them in any order. Describing the cancer as a dandelion. Describing Stage IV Cancer. The overall presentation of the quality of the cards was good."

### MBC Patient Recommendation

The MBC patient response to the communication aid was very positive, with 18 out of 19 patients recommending it to other MBC patients (95%). The patient who didn't recommend it, cited the reason as wanting more detail.

## HCP Study with MBC Patients

HCPs were asked to fill out a survey in relation to the MBC patients in the first study. This was used to compare patient answers with results (such as assessing whether they had the correct subtype), as well as gain insight from the HCP in how the tool was used, their observations of how it was received by patients, and details about their conversations. Highlights from the survey were:

What was the patient interaction with the toolkit during the diagnosis discussion?

- 75% touched or pointed to a visual on the tear-off sheet
- 33% used the dandelion metaphor to communicate their understanding or probe for information
- 17% no response
- 4% used it with a spouse

This demonstrated that patients had a high level of interaction with the intervention.

Was the toolkit written on during the diagnosis discussion?

- 74% yes, by the HCP
- 26% no response

This confirmed that most HCPs in the initial study were annotating the toolkit as trained.

What was the average length of the discussions?

- diagnosis plan discussion 33 minutes (n=24).
- treatment plan discussion 26 minutes (n=23).
- follow-up discussion 20 minutes (n=22).

This provides a good marker to understand the length of time available for an intervention, which starts at roughly 30 minutes and then reduces with each subsequent visit.

What was the patient interaction with the toolkit during the treatment discussion?

- 68% touched or pointed to a visual on the tear-off sheet
- 36% used the dandelion metaphor to communicate their understanding or probe for information
- 14% no response
- 4% other

This showed a slight reduction in interaction with the toolkit during the follow-up treatment discussion.
















Was the toolkit written on during the treatment discussion?

- 59% yes, by the HCP
- 36% were offered a clinical trial or it was discussed

- 27% no response
- One patient writing on the toolkit during the discussion.

This revealed that annotation decreased during the treatment discussions. It was expected however that this is where more annotation would take place as different options were discussed and recommended.

When asked what was annotated on the treatment discussion tear-off sheet, HCPs reported:

Value		Percent	Responses
1. Hormone Receptors		54.2%	13
2. Protein Growth Receptors		41.7%	10
3. Growth Speed and location of cancer		25.0%	6
4. Your General Health		16.7%	4
5. Life goals, Joys and Hobbies		16.7%	4
Chemotherapy (top row left)		37.5%	9
Targeted Therapy (top row middle)		37.5%	9
Hormonal Therapy (top row right)		25.0%	6
Radiation (yellow rays, middle row left)		29.2%	7
Surgery (shovel, middle row middle)		20.8%	5
Clinical Trials (jars, middle row right)		29.2%	7
Complementary Therapy (dandelion w/ butterfly, bottom row left)		20.8%	5
Treatment Breaks (pause button, bottom row middle)		20.8%	5
Symptom and Pain Management (chair, bottom row right)		25.0%	6
No response		8.3%	2

The follow-up discussion using the card deck was most often led by the nurse (58%), with the oncologist (21%), one navigator and 17% other (n=24).

The average length of time between the initial diagnosis discussion and the follow-up discussion was 58 days (n=24). This meant that patients didn't get the card deck until 2 months later. This was deemed as too long of a gap between the introduction card and getting a more detailed explanation of the basic diagnosis information.

When HCPs were asked to report three things that the patient didn't remember between their initial appointment and their follow-up appointment the responses were as follows:

Response

---

*Didn't asses. Pt did comment she recalled having seen the dandelion pictures previously. She expressed gratitude for being able to take the cards home since it's hard for her to remember things.*

*Results were HER2-. Didn't remember for what purpose prescribed drugs were specifically to be used.*

*They understood everything*

*Discussion about restaging scans. - Staying on treatment as long as it is working*

*Progression of cancer (symptoms) - Side effects of meds*

*Complementary medicines - Use of radiation therapy - Use of endocrine therapy*

*Treatment (all I could make out)*

*The time of death - Medications and treatment side effects (nausea and diarrhea)*

*Suitability for trials - Use of further chemo*

*Not assessed. Did ask how she was doing & she reiterated what she had been told at the initial visit (i.e - she's not going to die in the next few months). She also shared that she found the tear-off sheets helpful.*

*Blood clots (sop tumor markers)*

*Treatment options, esp clinical trials - Goals (travel, etc) - Working together to negotiate /plan treatment*

*Medication management (esp. pain + nausea) Stress management*

*Subtype. Where it had metastasized to. Names of treatment drugs.*

*Doesn't have to have chemo if she doesn't want to*

*Nothing! She has a very good understanding having been through the hospital system and melanoma.*

*Can ask questions of specialist*



HCPs were then asked to report whether the patient had brought the toolkit back to the clinic, giving at least 30 days for observation. Of the 22 that reported, 23% came back to the clinic with the toolkit within that time frame. Five of those patients used the analogy or referred to the toolkit in discussions, four patients brought the cards and three patients brought the tear-off sheets.

HCPs were asked whether they thought the intervention helped the patient. All reported it had, apart from the case of one patient (94%, n=24). This revealed a clear belief that HCPs found the intervention was a beneficial part of patient communication.

## HCP Study with ACCC

To meet the goal of enrolling 25 clinics in the study, the protocol was adjusted to a pilot trial where HCPs were invited to try out the kit. This meant that no patients were involved in data collection, but it offered a simple way to test the tool with patients and gather HCP feedback.

### Study Protocol Adjustments

It was concluded after the difficulties in recruitment and onboarding of the study with these initial sites that the protocol had to expand in order to collect data in a more timely way. The following changes were made for the 2018-2019 cohorts:

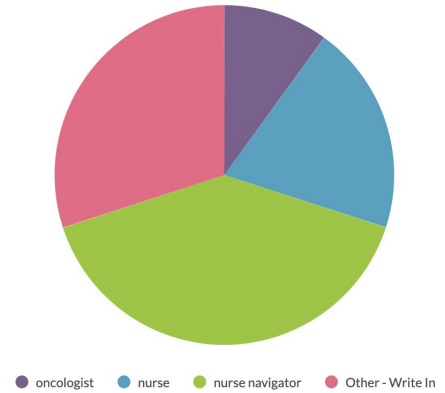
- We only asked for HCP feedback and their patient observations in using the toolkit. By not surveying patients it made the approval process significantly shorter.
- We focused on ACCC sites and smaller centers that had a shorter route for approval.
- We expanded the use of the conversation cards to be used with all breast cancer patients to provide a larger sample of patient feedback and improve the likelihood of it being remembered as a tool for MBC patients.
- We made the survey process online rather than submitting paper forms.

Although HCPs received an email and a poster with followup information and a contact number explaining it could be used with all breast cancer patients, some didn't use the kit as they mistakenly thought it couldn't be used except for with metastatic breast cancer patients.

All of the 64 HCPs that were trained on the tool were invited to complete the survey, with 20 completing the survey. Lack of response was due to a variety of reasons, such as; not having the individual emails of every HCP who was trained, some couldn't speak and write in English (Turkey), a lack of incentive to share feedback, and a number of HCPs not responding to the survey since they didn't have the opportunity to use it with an MBC patient before the study closed. Five respondents were disqualified due to not having used the toolkit with any patients.

The institutions that reported data to the survey were:

- Adena Cancer Center (1)
- Ascension Cancer Care (2)
- Center for Cancer and Blood Disorders (1)
- Australia (2)
- Dartmouth (1)
- HFM Cancer Center (1)
- Hospital Zambrano Hellion (2)
- Froedtert Hospital (2)
- Methodist Hospital (2)
- Ogden Regional Medical Center (1)
- UMMC Cancer Institute (1)
- Valley Medical Center Oncology (2)
- Western Maryland Health Systems (2)



Value	Percent	Responses
oncologist	10.0%	2
nurse	20.0%	4
nurse navigator	40.0%	8
Other - Write In (click to view)	30.0%	6
		Totals: 20

Most, 40%, were nurse navigators, 20% were nurses and 10% were oncologists. 30% reported “other” which covered nonclinical roles such as assistants, coordinators and administrators.

Respondents had been in practice for an average of 15 years, ranging from 2-26 years. Some used the kit with up to 20 patients, with four HCPs using it with only a single patient. On average, HCPs used the toolkit with 4-5 patients.

Each HCP used different aspects of the toolkit:

- 11 used the card deck
- 7 used the conversation card
- 1 said they used the tear-off sheets only

This showed that not everyone used all aspects of the toolkit, and some used it as a team. Despite training being specific on needing to annotate the conversation card, this was most often not done, with just 9 reporting they had taken part in the training (n=14):

- 6 said they didn’t write on the conversation card at all
- 2 reported they annotated the staging information
- 2 filled in the pathology and subtype section
- 2 wrote in in treatment information
- 1 annotated surgical and imaging aspects
- 1 said the patient didn’t want the toolkit

When asked how often they wrote on the toolkit or pointed to it during discussions with patients:

- 3 said always
- 7 said sometimes
- 2 stated most of the time
- 3 said never

This indicated that more work needed to be done to establish the importance of annotation with HCPs and to investigate roadblocks that were preventing them from writing on the toolkit.

When asked if patients interacted with the toolkit:

- 7 said yes
- 5 said sometimes
- 3 said never

When asked why patients didn't interact with the toolkit:

- 2 said it wasn't part of the discussion and used as a handout instead
- 2 said they didn't interact with the toolkit themselves
- 2 said the room wasn't set up in way patient's could interact with it
- 4 responded "other" (no write-in was available)

Value	Percent	Responses
it allowed a more comprehensive conversation (covering a wider range of information than usual)	21.4%	3
it allowed a more interactive conversation (patients seemed to be more involved in the discussions)	28.6%	4
it helped communicate pathology more easily	50.0%	7
it helped communicate treatment options more easily	35.7%	5
it guided the conversation in a natural way	21.4%	3
it visualized for the patient their situation/diagnosis	71.4%	10
it saved time on explanations/repetition during *subsequent* conversations	7.1%	1
it seemed to help patients in the quality of their questions	14.3%	2
it allowed me to consolidate discussions / combine appointments	14.3%	2
I found it was more ideal for low literacy patients (versus highly literate)	14.3%	2
I found it worked just as well for all patients (within reason)	21.4%	3
<u>Other - Write In (click to view)</u>	21.4%	3

HCPs were asked to describe their experiences were with the intervention. A majority (71%) cited the visualizations as the biggest benefit. 50% said it helped communicate pathology more easily. 36% said it helped them more easily communicate treatment options.

Other - Write In	Count
I don't know what impact my reviewing the cards had on subsequent visits	1
see above responses	1
was not needed at this time	1
Totals	3

## HCP Training Preferences

Just 9 respondents had said they took part in any training prior to using the toolkit. When asked on their training preferences, 75% (n=9) said they preferred a short online training course. One wanted a live group training session. One thought the toolkit was self-explanatory, and one wanted an online training course with a follow-up video conference Q&A. This lack of training was corrected in the final cohort where HCPs were required to complete the short online training prior to getting the intervention.

## HCP Intervention Feedback

HCPs were given an opportunity to share their experiences with the toolkit and provide feedback sharing what they found the most helpful and what they wanted to have improved. These things will be taken on board for future development:

“I had a patient with metastatic disease who did not understand why she needed chemotherapy when she had already had surgery. I used the toolkit to show her the dandelion and how the cancer had spread, thus the need for systemic treatment. It helped her understand and be able to make an informed decision about treatment. On the toolkit, the radiation picture caption is a bit misleading that it says radiation is for shrinking tumors. This led to a bit of confusion as radiation is used following removal of tumor.”

“The illustrations work very well to help explain the patient's situation.”

“The dandelion picture is an excellent way to communicate the differences in staging. The patient's seem to understand that mode of communication better.”

“In observing the physician interaction with the patient I think patients found the pictures helpful.”

“The toolkit simplified the discussion at a time where they were inundated with information, new terms, and stress.”

“Our medical oncology physicians also liked the tool kit.”

“2 patients took the toolkits home and used to help explain their diagnosis and treatment to their family. Both said it was very helpful as the information was simple and easy to understand.”

“Spanish (or other language) translation is of utmost importance.”

“Have a specific toolkit to generalize to all stage 4 cancers. Another toolkit for any stage breast would be incredibly helpful as well.”

“I would really find the toolkit useful for other metastatic cancers, not just breast. In fact, I did use part of it with a discussion with a metastatic lung patient.”

“I would add information about immunotherapy given it has become a standard of care in triple negative breast cancer and also more information on targeted agents like iPARPs or iCDK 4/6.”

“I would change the caption on radiation--see above. I would also change palliative care to supportive care. Patients are not receptive to palliative, but seem okay with supportive. That way, we can incorporate both palliative and hospice care.”

“The useful way it is presented to draw directly on the card and hand it out to the patient.”

“The dandelion picture was my favorite part. It was very helpful in explaining stages, specifically with stage IV patients.”

“My observation was that the physician's use of the paper sheets was helpful to the discussion. Our process of reviewing the cards was not ideal as we were not part of the clinical care team and the timing of when to go over the cards was difficult. I found it was more useful to simply orient patients to the card deck as a resource that they could review on their own at home.”

“We would be very happy to help in translation of the material and pilot it in a Mexican breast cancer center with more patients as we believe it was very helpful.”

“If the toolkit was used for all [stage] patients and [oncologists] had their own toolkit in their rooms, they would probably use it more (knowing that every breast patient had one).”

## HCP Recommendation

Finally, when HCPs were asked whether they thought the toolkit benefitted patients, the results were still overwhelmingly affirmative, with all but one HCP saying it had (93%, n=14). The same amount said they would want to continue to use the toolkit in the future after the pilot. Here is how one HCP described her experience after using it with patients:

“The study was great. I liked the cards, as it was all in one and didn’t feel as though I was giving the patient so much paperwork. If there is anything that stood out, it was when I showed the ‘stages of breast cancer’ diagram to a young woman (34 years old) with metastatic triple negative breast cancer. As soon as she saw the diagram, she pointed to Stage IV and said ‘that’s me—I get it’. A few times, I used it to show people with early breast cancer and they could see there was a difference between all of the stages, so I think that helped them understand as well.

Even though patients didn’t bring the card deck into clinic much, they referred to it and would tell me that the family had sat down and had a look through it—so I know it was useful.

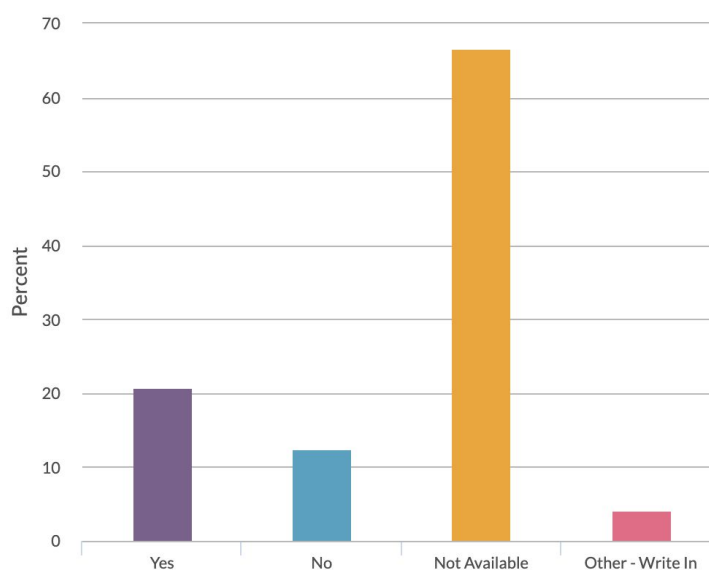
Clinically, I think it’s an excellent tool and I would be happy to use it for everyone. If I had the capacity, I would love to have used it for my own records and write down where the metastasis were and when they were treated, as that’s always difficult to find in the medical record.”

## Limitations and Future Recommendations for Study

Given the nature of MBC being a more rare event in breast cancer compared to early stage diagnosis, it presented a number of challenges in the study. Infrequency of cases meant that to gather a sufficient sample, every patient who was diagnosed at the clinic needed to be enrolled by working with an HCP who was part of the study which was difficult to manage across 25 sites with differing patient selection processes.

Not having funding as an incentive to report data was another obstacle to collecting patient and HCP surveys. Despite repeated attempts to collect data, just 15 of the 64 HCPs filled out the survey with 5 of them being disqualified for not using the toolkit with patients. It's recommended that for future studies funds would be allocated for data collection.

An analysis on the annotated intervention (tear-off sheets, n=8) found that they often had not fully been used. For example, the figure on this page shows just five out of the eight annotated tear-off sheets that were returned filled out subtype. This made it difficult to determine the correlation between the intervention and the patient survey as it wasn't consistently used as directed.



Value	Percent	Responses
Yes	20.8%	5
No	12.5%	3
Not Available	66.7%	16

*Treatment options were not often annotated in the toolkit, as well as other key information for patients.*

When patients were asked if the toolkit was used with their HCP, 25% reported that their doctor used it with them, 21% reported that no HCP used the toolkit with them, and 33% reported a nurse or other HCP used the toolkit with them (n=19).

The difficulty in having such a small sample of responses was that while some gave a clear indication of areas that were working well or needed improvement, it was difficult to make definitive conclusions on this study alone.

In hindsight, focusing on two sites that enrolled both early stage and MBC patients, where a majority of HCPs were trained and had an incentive (such as payment) for reporting data, would have yielded a better sample for the study. Monitoring two sites to ensure the intervention was used to its potential, would have also identified issues in the misuse of the intervention early on. While the training improved for the ACCC cohorts, it was difficult to collect data from them to understand whether the intervention was being used as intended, despite multiple attempts and reminders for them to contribute to the survey.

That being said, the value in being able to place the intervention in such a large number of facilities provided opportunities to test different training options, expand the use of the kit to a potential number of patients (n= ), and create a larger base of potential adopters post-study. A study is a very controlled environment that doesn't always accurately reflect how HCPs would use the materials under normal conditions where the use of the intervention was entirely optional. With this we've learned some key lessons:

1. In order to be effectively and consistently used in the clinic, a conversation aid must work for all breast cancer patients. Otherwise it isn't part of the routine and is forgotten.
2. Training needs to be a mix of a short online course with opportunities for Q&A when needed. By incorporating the videos and the quiz style of instruction it could be a scalable option.
3. HCPs prefer checkboxes over open spaces to annotate. By having a set of checkboxes or a section untouched, it signals to the patient that the conversation was missing an important topic and can prompt the patient to bring up the section in a future appointment.
4. A study and intervention that covered patients with all stages of breast cancer, and in-person training in a single clinic (such as Mexico) where most of the HCPs were participating, would result in more data collection and allow the development cycle to iterate more quickly.
5. The introduction card should be used by HCPs, while the card deck should be patient-led to enable a closer timing between the conversation(s) and more detailed information handed to them in a printed format.
6. Patients and HCPs had an overwhelmingly positive response to the intervention and it should be made available to as many HCPs and patients as possible.

## Conclusion

In conclusion, there is a positive indication that a visual intervention can help patients better communicate with their HCPs and their families. Opportunities to train HCPs on how to integrate conversation aids into their practice should be pursued. Ways to further patient-practitioner communications research with a tool to promote increased patient understanding and aid in decision making needs awful to be further explored to validate these initial findings. Investigating the needs of MBC patients during a difficult and overwhelming time to improve patient outcomes and quality of life issues is urgently needed.



# APPENDIX

## Abstracts, Publications, and Presentations

2015

SABCS December

**Poster Abstract: Communication design toolkit for metastatic breast cancer patients and their health care professionals**

Background: Low literacy rates, fear of cancer and the cultural taboos associated with death and breast cancer, create hurdles difficult to overcome for some patients. Despite a large number of education campaigns, none offer a multilingual, multicultural solution leaping these hurdles for MBC patients.

Objective: Develop a visual toolkit to help MBC patients, with little or no engagement in a treatment decision-making process, communicate on equal ground with their health care professionals (HCPs) about their diagnosis, treatment, and quality of life.

Methodology: A patient and HCP centered approach was used following the U.S.E.R. Design Thinking framework. Over 80 patients and practitioners participated in development and testing. The designer experienced and mapped out communication pathways in 6 scenarios; 53 MBC patients engaged with the design iterations of the communication tool; a survey (n=500) measured baseline attitudes and experiences prior to starting MBC treatments.

Conclusion: A visual approach to improving communication between MBC patients and their HCPs seems possible based on positive results of patient interpretation and practitioner feedback from Phase 1 research and prototype testing with MBC patients. Visual tools help HCPs engage patients with information to enable them to understand their individual disease and goals and nature of treatments so they can make informed decisions right for them.

Breakfast presentation to MBCA members.

Publication of Phase I Report.

# 2016

ONS Conference April

## **Poster Abstract: Educating metastatic breast cancer patients through visual communication aids: The Dandelion Project**

Background: Metastatic breast cancer (MBC) is different from earlier stage breast cancer—it cannot be cured and its trajectory is complicated. MBC patients have, on average, 3 years' life expectancy and are on lifelong treatment. Patients have few days to choose treatment after an unexpected diagnosis. Sadly, most of these conversations with healthcare professionals (HCPs) are oral, a communication method with low recall accuracy of 14% in non life-threatening situations (Houts, et al, 2001).

Innovation: Use an everyday metaphor in a visual communication aid (“the toolkit”) to help nurses and other HCPs better communicate with newly diagnosed MBC patients, with a range of literacy levels, about their diagnosis, treatment options, quality of life and related considerations.

Methods: A patient and HCP centered approach was used following the “U.S.E.R. Design Thinking Framework” (Beaumont, 2011); >80 patients and HCPs helped develop and test a visual communication toolkit prototype; the researcher experienced and mapped communication pathways in 6 scenarios; 53 patients informed design iterations of the toolkit; a survey (n=500) measured baseline patient communication experiences prior to starting MBC treatments to identify gaps.

Findings: One-third of patients surveyed felt they didn't have enough knowledge to participate in decision making. Patients tend to overestimate their knowledge, with just 46% including both HER2 and hormone status when asked to describe their type. Only 13% of patients surveyed (n=487) had visuals during initial discussions with their HCPs. A dandelion metaphor was visualized to explain metastasis and treatment options as the basis of the toolkit. The prototype comprises 4 sheets for oncologists to convey pathology and treatment options, and a set of customized cards for use by nurses. Patient and HCP feedback during prototype development showed high levels of engagement with the metaphor.

Discussion: A visual approach to improving communication between patients and HCPs is possible based on positive results of patient observations and practitioner feedback on the prototype. The toolkit (piloted in the U.S. and internationally in 2016), is expected to address issues of low-literacy, fear and taboo surrounding discussion of MBC and improve understanding of the disease and its treatments.

*Also had a booth at the conference.*

**Poster Abstract: Using the power of design to more effectively communicate with Metastatic Breast Cancer patients, the “Dandelion Toolkit”**

Background: Metastatic breast cancer (MBC) patients receive an overwhelming amount of information at the time of diagnosis, with most of the information transferred through oral conversations and abstract medical terminology that’s difficult for patients to understand. Oral conversations have a low accuracy memory recall of 14% (Houts et al, 2001). However, when visuals are integrated into discussions, the accurate memory recall of conversations has a median of 80% (Kessels, 2003). We ask, “How can nurse navigators help patients feel informed, empowered and more easily communicate with their healthcare team on a more equal level through using a visual toolkit to guide the discussions?”

This paper describes both the process and outcomes of developing a visual conversation aid, the “Dandelion Toolkit.” While several resources (Simonian et al, 2001; NHS, 2008; Szebeko, 2005; Breslin et al, 2008) offer advice and guidelines on how to develop materials for specific audiences, a holistic, patient-centered defined framework could help nurse navigators structure the development and testing of materials.

Objectives: i) Develop a visual aid for helping metastatic breast cancer (MBC) patients and health care providers (HCPs) improve their communication during initial diagnosis and treatment discussions; ii) Design a set of visual tools to communicate in a time-effective way, and appeal to a wide demographic of metastatic breast cancer patients of various literacy levels; and (iii) Increase patient engagement in treatment decisions despite emotional distress.

Toolkit Development Methods: The toolkit was developed following the “U.S.E.R.” (User, System, Establish, Realize) design thinking framework (Beaumont, 2011). This patient-centered, mixed-method approach used action research, iterative prototyping, interviews and co-creative methods to identify problems and develop solutions within the health system, working with >80 MBC patients and HCPs. [poster will visualize each stage and list research methods used for each stage in detail]

Results: The U.S.E.R. design process offered an organized and holistic framework to involve both MBC patients and HCPs in the development of a communication tool. User testing was done throughout the development, which resulted in an evidence-based solution delivered in a short timeframe (2 months). The design outcome was a visual metaphor that visualized the behavior, subtype and treatment options for metastatic cancer. Initial testing of the toolkit in a community cancer clinic revealed it was highly valued by patients and HCPs. HCPs who used the toolkit found the visual approach offered a better method for educating patients as opposed to oral communication alone; it aided in simplifying treatment options, managing patient anxiety and navigating difficult topics. Patients found that the metaphor helped them to understand more comprehensively what a metastatic diagnosis meant and the spectrum of treatments; the toolkit helped them navigate conversations with other health care professionals and family members, and to feel an improved sense of control.

Conclusions: Initial testing demonstrated the effectiveness of the toolkit developed with the U.S.E.R. design thinking framework, for both HCPs and MBC patients. To more fully investigate the toolkit, it is now being used in clinical trials across seven sites nationwide and internationally. This will provide data to better understand the toolkit's impact on patient knowledge, HCP effectiveness and best practices for integrating visuals into discussions for improved patient experience.

---

Breslin, M., Mullana, R. J., & Montori, V. M. (2008). The design of a decision aid about diabetes medications for use during the consultation with patients with type 2 diabetes. *Patient Education and Counseling*, 73 (3), 465-472.

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

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

NHS. (2008, 25-June). Design advice. (NHS, Producer) From NHS Brand Guidelines:

<http://www.nhsidentity.nhs.uk/all-guidelines/guidelines/general-practitioner/practice-leaflets/design-advice>

Simonian, K., Sanders, D. B., Murillo, V. E., Marks, S., E.Brown, S., Y.Kidd, C., et al. (2001). Breast Health and Breast Cancer Informational Needs of Young Women and Women of Color 40 and Older. Susan G. Komen. Susan G. Komen.

Szebeko, D. (2005). Co-designing for communications and services in the healthcare environment. *Journal of Public Mental Health*, 4 (4), 42-47.

### **Poster Abstract: Identifying gaps in metastatic breast cancer patient knowledge and their communication experiences with health care professionals**

Objectives: When a patient is told they have metastatic breast cancer (MBC), it's very difficult for them to absorb and interpret what is being told to them at the time of their terminal diagnosis. We ask, "How can nurse navigators more effectively communicate with MBC patients with these challenges in mind?" To help with this objective, we first need to clarify the current state of communication between health care professionals (HCPs) and MBC patients to identify areas for communication improvement and improved patient knowledge about their disease (Mayer, et al, 2010; Freedman et al, 2015). This can then inform the development of tools to aid in communicating with MBC patients during initial diagnosis and treatment planning discussions.

Methods: Online population survey of MBC patients (n=563) measured patient communication experiences reflecting on what conversations with HCPs were like prior to starting treatments for metastatic breast cancer. Survey recruited from November 2015 - June 2016 through metastatic breast cancer patient organizations. Segmenting factors were education level, age, racial background, marital status and time since diagnosis of MBC.

Results: More than half of respondents (56%) were diagnosed with MBC in the last 2 years. Majority of respondents were white (90%), supported (72% married and 95% insured), highly educated (30% with post graduate degree) with a larger group de novo, stage IV from beginning (37%) compared to the general MBC population in the US that has a recurrent diagnosis that progressed to metastatic disease (~10-20%).

While 96% of patients surveyed indicated they knew their cancer type, less than half (46%) included both HER2 and hormone status when asked to describe their type. One-third of patients felt they didn't have enough knowledge to participate in decision making around their treatment options; 58% of patients felt rushed and starting treatment was urgent; less than one quarter (24%) sought a second opinion; 38% did not research treatment options prior to starting therapy; 71% did not recall discussing goals/hobbies as part of their pretreatment talks; 69% said complementary therapy was not discussed by their oncologist; only 22% said treatment breaks were mentioned; and just 62% discussed pain and symptom management. Nearly two-thirds did not discuss clinical trials as part of their treatment plan. Patients are not recalling quality of life considerations during initial treatment discussions after a metastatic diagnosis.

Conclusions: Communication gaps between HCPs and MBC patients must be addressed to improve the patient experience. Patients likely overestimate their knowledge about their breast cancer subtype. Not realizing they know less than they should, they also likely overestimate their ability to participate in decision-making about their treatment. To improve patient engagement in discussions, and their confidence level in decision-making, more needs to be done to educate patients on their cancer subtype, second opinions, and participating in clinical trials. Treatments that improve quality of life, such as palliative care, complementary therapy and treatment breaks need to be better integrated in treatment discussions. Discussion and education tools could greatly impact the success of these difficult conversations.

Freedman, R. A., Kouri, E. M., West, D. W. and Keating, N. L. (2015), Racial/ethnic disparities in knowledge about one's breast cancer characteristics. *Cancer*, 121: 724–732. doi: 10.1002/cncr.28977

Mayer, M., Huñis, A., Oratz, R., Glennon, C., Spicer, P., Caplan, E., and Fallowfield, L. (2010), Living with metastatic breast cancer: a global patient survey. [Community Oncology](#) 7(9):406–412. DOI: 10.1016/S1548-5315(11)70415-6

**Poster Abstract: Can patients and health care providers communicate more equitably? An approach involving metastatic breast cancer patients and health care teams in developing an innovative communication tool.**

Objectives: i) Develop a visual aid for helping metastatic breast cancer (MBC) patients and health care providers (HCPs) improve their communication during initial diagnosis and treatment discussions; ii) Design a set of visual tools to communicate in a time-effective way, and appeal to a wide demographic of metastatic breast cancer patients of various literacy levels; and (iii) Increase patient engagement in treatment decisions despite emotional distress.

Methods: A patient and HCP centered approach was used following the “U.S.E.R. Design Thinking Framework” process (Beaumont, 2011) involving >80 MBC patients and HCPs in developing and testing a visual communication toolkit prototype. Interviews conducted with HCPs and patients; the researcher experienced and mapped communication pathways in 6 scenarios; design iterations of the toolkit were informed by 53 patients; 5 patients participated in live role-play exercises with the toolkit; a survey (n=500) measured baseline patient communication experiences prior to starting MBC treatments to identify gaps.

Results: The U.S.E.R. design process offered an organized and holistic framework to involve both MBC patients and HCPs in the development of a communication tool. The result was a communication toolkit that is highly valued by both parties because it legitimately addressed their needs. User testing was done throughout the development, which resulted in an evidence-based solution delivered in a shorter timeline. The design outcome was an easy to understand metaphor that visualized the behavior, subtype and treatment options of metastatic cancer.

Conclusions: Using a U.S.E.R. design process created a communication solution that met multiple user needs in an innovative way. HCPs found the visual approach offered a better method for educating patients as opposed to oral communication alone; it aided in simplifying treatment options, managing patient anxiety and navigating difficult topics; and caregivers were observed to be better informed. Patients found that the metaphor helped them to understand more easily what a metastatic diagnosis meant and the spectrum of treatments; the toolkit helped them navigate conversations with other health care professionals and family members, and to feel an improved sense of control.

*Had a booth at the conference, did toolkit demonstrations. Presented two papers above.*

## **SABCS**

Poster Abstract: Differences in patient knowledge and communication experiences between Spanish-speaking and English-speaking metastatic breast cancer patients [not accepted]

Poster Abstract: Improving Doctor-Patient Communication and Knowledge for Newly Diagnosed Metastatic Breast Cancer Patients [not accepted]

## **Avon Conference**

Poster Presentation of “Educating metastatic breast cancer patients through visual communication aids: The Dandelion Project.”

# 2017

**Advanced Breast Cancer 4 Conference** Lisbon, Portugal. November

## **Poster Abstract: Clinical Study to Improve Patient-HCP Communication & Engagement for Newly Diagnosed Metastatic Breast Cancer Patients**

Introduction: This clinical study determines whether a visual conversation aid designed for mBC patients and health-care professionals (HCPs) will improve shared decision-making and open communication during the initial discussions post metastatic diagnosis. Results will inform the development of an information tool kit for HCPs to better communicate with MBC patients about diagnosis and treatment decisions.

Hypothesis:

1. A simple patient-centered communication aid is feasible
2. Correlation exists between the visual aid and patient knowledge about their diagnosis and treatment options
3. Patients and HCP's find the communication aid useful in meeting their communication needs, particularly with low engagement patients.

Background: When a patient is diagnosed with mBC, they face difficult information hurdles. Diagnosis information is usually given via oral conversation, with a low retention rates. Information physically handed to the patient is text heavy and written at a high literacy level. For high anxiety or low literacy patients, this makes information inaccessible.

Significance: An important next step in this field is to study whether it is possible to improve the understanding in real world settings by improving the quality of patient-provider interaction through visual interventions focused on efficient, motivational, and empathic communication, targeted at both patients and providers. There is little information on the best patterns of communication in dealing with mBC patients, particularly in non text-based interventions. An optimal healing relationship between the patients and their HCPs includes shared decision-making, partnering between patients and clinicians in an environment of trust, and effective open communication through visual means to better address patient literacy and anxiety issues compared to text-heavy materials. An important outcome for this study is what impact the visual intervention may have on patient knowledge, engagement in discussions and decision-making, and best practices for using such interventions

Expected Results: Patients will:

1. better understand their cancer type through the use of visuals and therefore memory recall will improve
2. understand their treatment options through the use of visuals and memory recall will improve
3. find the visuals useful in sharing information with caregivers/family/friends;
4. prefer to use visually based information over text-heavy literature

5. report reading and using visuals more than text

HCP's will experience:

1. increased participation of patients due to interacting with the visuals
2. reduction in the number of times they explain the basics of the patient's cancer
3. more effective use of their time to discuss other issues;
4. overcoming misconceptions about mBC

## 2018

**World Cancer Congress** Kuala Lumpur, Malaysia

**Poster Abstract and Presentation: Identifying gaps in metastatic breast cancer patient knowledge and their communication experiences with health care professionals and developing visually based solutions to overcome those gaps.**

Background: Metastatic breast cancer (MBC) is the fifth most common cause of death from cancer globally.[1] MBC is incurable and its trajectory complicated. Patients have only a few days to choose treatments after an unexpected diagnosis, and most conversations with health care professionals (HCPs) are oral, a communication method with low retention accuracy (14%).[2] Patients and caregivers feel ill prepared and overwhelmed. Yet when visuals are introduced into HCP/patient communication, accurate recall can be as high as 85% for low-literacy populations.[3]

Aim: Test if visually based communication tools can be used by HCPs to increase MBC patient and caregiver understanding of MBC as incurable, and confidence in making treatment decisions for quality of life.

Methods: Survey of MBC patients (n=487) communication experience prior to treatment for Stage IV; interviews with HCPs (n=20) in the clinic to identify communication barriers with patients; empathy role play with HCPs and patients to clarify viewpoints (n=7); analysis of patient materials; in-depth interviews with MBC patients and communication experts (n=12); iterative design process of communication tool prototype with MBC patient group (n=48) and HCPs.

Results: Only 1 in 8 patients were educated with visuals during initial discussions with HCPs. Less than half of patients (46%) included HER2 and hormone receptor status when asked to describe their subtype. One-third of patients felt they did not have enough knowledge to participate in decision-making for treatment and 58% of patients felt rushed to start; 71% did not recall discussing goals/hobbies; and just 62% discussed pain and symptom management. HCPs want to deliver difficult news in a clear and empathetic way, reduce repetition, save time educating patients, and have better tools for caregivers; current



patient materials are impersonal and overwhelming. Iterative development and testing of the MBC Communication Toolkit prototype with HCPs and patients showed patients understood treatment options more easily with a visual metaphor while HCPs using the prototype said the images were effective for communicating symptoms and treatment options.

Conclusion: A visual approach to improving communication between MBC patients and caregivers and their HCPs seems possible based on positive results of patient interpretation and practitioner feedback. Visual tools can help HCPs engage patients with information to enable them to understand their disease, goals, and nature of treatments so they can make informed, appropriate decisions.

[1] International Agency for Research on Cancer. Breast Cancer: estimated incidence, mortality and prevalence worldwide in 2012. Available at [https://globocan.iarc.fr/Pages/factsheets\\_cancer.aspx](https://globocan.iarc.fr/Pages/factsheets_cancer.aspx)

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

[3] Ibid.

## 2019

### ASCO Conference

**Gaps in metastatic breast cancer patient knowledge and understanding in Mexico.** Presented by Alejandra Palatas.

# RESEARCH PROTOCOL & QUESTIONNAIRES

## **SAMPLING: capped at 15 per site**

**GROUP A, NO INTERVENTION:** The first group of consecutive patients (n=5) that present with newly diagnosed metastatic breast cancer will not receive the intervention (toolkit) and conversations will proceed as is standard in the clinic with no visuals being used other than medical imaging. Patients in Group A will receive the Control Preferences Scale form and Survey without Part B.

**GROUP B, WITH INTERVENTION:** After the first group of patients are complete, the next group of consecutive patients (n=10) that present with newly diagnosed metastatic breast cancer will have the intervention (toolkit) as part of their discussions and receive the Control Preferences Scale form and Survey with Part B. **Note: For institutions that expect to have 10 or fewer patients newly present with metastatic breast cancer from June-September 2016, they will only have a B group.**





*Note: This sample is not randomized to prevent the HCPs from changing their standard communication practices after using the intervention. It is also to prevent patients having concerns about not being as informed, such as seeing one patient with a toolkit and questioning why she wasn't given the same standard of care when she was diagnosed roughly at the same time. There is no bias involved in the consecutive sampling, as patients are offered it according to the time they present with metastatic breast cancer that cannot be controlled. Because diagnosis of metastatic breast cancer is a rare event that limits the sample, the study is being conducted simultaneously at multiple sites and more patients are assigned to the intervention group.*

## **BASIC OVERVIEW FOR GROUP B:**

1. Newly diagnosed metastatic patients (recurrent or *de novo*) are identified by a member of staff.
2. Patient is given a question about their patient control preferences. It is suggested that this question be offered to the patient in the waiting room before meeting with the oncologist. (see page 8)
3. Patient meets with the oncologist who discusses diagnosis and treatment options using the tear-off sheets from the toolkit. This can take place in a single discussion or multiple discussions. (short training video for staff on how to use the toolkit will be provided) A nurse/navigator is present for the conversation to observe and take notes on the patient record form. (see page 13-14)
4. The cards from the toolkit are presented to the patient in a follow-up discussion with a nurse/navigator as is standard practice for the individual clinic. (short training video provided to member of staff)
5. Between 14-60 days after receiving the cards, the patient is offered a survey and given oral consent. The paper survey is given at the clinic and the patient returns it before leaving the clinic. (see pages 9-12)
6. The patient record form is completed by the nurse/navigator. (see page 13-14)
7. All surveys and forms will be sent to Corrine Beaumont [mbcastudy@gmail.com](mailto:mbcastudy@gmail.com) who will do the data entry and analysis.

**For the group of patients without the intervention, they will be communicated to as is standard practice in the clinic, not using the toolkit, then offered the Survey (see pages 9-12) without Part B (see page 10) within the same timeframe as above.**

Overview of Intervention Procedure with Group B:

	<p><b>CONTROL PREFERENCES SCALE (page 8)</b>  <b>Taken prior to first conversation with oncologist.</b></p>	<p>Control Preferences Survey: Patient is asked to rate their desire to participate in decision making between passive and active.</p>
	<p><b>FIRST APPOINTMENT(S) WITH ONCOLOGIST</b></p>	<p>Newly diagnosed metastatic breast cancer patient meets with the oncologist to discuss diagnosis and treatment options for the first time.</p> <p>The tear-off sheets are written on by the oncologist as part of the discussion and given to the patient to take home.</p> <p>Identified nurse/navigator/social worker/HCP observes interaction and makes notes on patient form.</p>
	<p><b>HCP FOLLOW-UP WITH CARDS</b></p> <p><b>(usually prior to treatment starting or at the beginning of treatment)</b></p>	<p>Patient has a follow-up appointment with the identified nurse/navigator/social worker/HCP using the cards. These are written on and customized for the patient during the discussion. Patient is encouraged to use the cards at home and to bring them to follow-up appointments if they wish.</p>
	<p><b>PATIENT SURVEY</b></p> <p><b>(offered 14-60 days after receiving the cards, with some exceptions)</b></p>	<p>Patient is offered a survey and gives oral consent. She completes the survey and seals it in an envelope and gives it to the reception staff. A member of staff mails it to the study researcher at the end of each month, together with the patient form.</p>

Note: An oncologist can present all of the toolkit if they prefer, but they will need someone to observe the initial discussion they have with the tear-off sheets.

DETAILED DESCRIPTION for INTERVENTION, GROUP B. The toolkit is composed of 2 essential components: 1. tear-off sheets that are presented in an initial meeting discussing diagnosis of and treatment options for metastatic breast cancer (likely with the medical oncologist) and 2. a card deck that is presented at a follow-up with the HCP, usually prior to or at the start of treatment. The toolkit is used as an integral part of the conversation, acting as a guide for discussion. Notes are made on the sheets during the discussion by the HCP, a copy is made for the patient record (and this study) and the patient is given the original sheets to take home.

Q: Do all of the sheets need to be used in the initial conversations? A: Yes.

It's recommended that the *Stages of Cancer and Tumor Locations* sheet is used when discussing diagnosis/imaging results (if applicable). The *5 Keys to Choosing Treatment and Treatment Options* sheet is used during discussion of pathology results. This is also the recommended order.

In order for the sheets to have credibility, the oncologist needs to write on them during the discussion and hand them to the patient personally, encouraging them to look at it again at home.

An identified nurse/navigator/social worker/HCP is present during the conversation to note on the PATIENT RECORD FORM (see pages 13-14):

- a) that the content on the sheets have been presented
- b) whether the patient interacted with the sheets and/or displayed general interest in them
- c) the length of time of the discussion and the date

When referring to the toolkit with the patient, it should not be labeled as "new" or anything out of the ordinary.

Q: Do all of the cards need to be used in the follow-up conversations? A: No.

The card deck is more flexible and not every item will be applicable to the patient or will need to be discussed together. However, the key cards will need to be presented which are circled below:

In the follow-up appointment with the nurse/navigator/social worker (varies according to the local medical practice), the card deck is used to guide the discussion as it's written on and personalized in the appointment. Patients are encouraged to use the toolkit at home, to share it with family and to bring to future appointments as a way to aid discussion.

Within 14-60 days (roughly) after receiving the cards, the patient is to assess patient knowledge, communication experiences and toolkit use. Timing of the survey shouldn't take place earlier than 14 days after receiving the cards, to allow patients time to have used the toolkit outside of the clinic, and to assess memory retention and patient knowledge rather than immediate recall. Patients are not to be informed of the possibility of a survey, so as not to bias the patient to "study" in preparation. Suggested timings of the survey are:

- before a chemotherapy teaching session (if taking chemotherapy)
- before their next follow-up appointment (such as in the waiting room)

The survey should not be given to patients when they are emotionally distressed or otherwise distracted. The survey shouldn't be given later than 60 days after receiving the full toolkit, some exceptions within reason. Surveys should be offered at the clinic, and not taken home. This is to ensure that patients don't "look up answers" so as to better assess patient knowledge, and that surveys are not forgotten.

**RULES FOR PRESENTING TOOLKIT.** Patients must have been presented the toolkit in its entirety in their preferred language (English or Spanish, HCP does not have to speak the preferred language, but it should be noted if an interpreter is used). "Entirety" includes both sides of the 2 tear-off sheets with each item being discussed as part of the discussion (e.g. it should not be given as a handout "to look through when you get home") and the "key cards" in the toolkit (see Patient Record Form). A sample video explaining the toolkit will be provided to HCPs.

A nurse/navigator/social worker (NNSW) should be present to generally observe the interactions and responses of both the healthcare professional and patient while the toolkit is being used during appointments. This so the NNSW can verify that a) the tear-off sheets were fully presented, b) note the length of the discussion, and c) the interaction with the toolkit by all parties in the room (HCPs, caregivers, patients, etc.). Notes will be recorded on the "Patient Record Form."

TOOLKIT USE: It's understood that some items in the tear-off sheets, or cards in the toolkit may not be timely for each patient at the time of the appointment. Please use the patient record form to mark any items or cards that were not presented or discussed along with a note explaining why. This will help us understand which cards are used or not and the reasons behind it so that the toolkit can be improved.

SURVEY PARTS A/B. Patients will be offered to voluntarily participate in a survey. This will assess patient knowledge and if they find the toolkit useful. An envelope will be included for patients to seal their survey so as not to feel their answers will be shared with the staff, and to maintain anonymity.

SURVEY CONSENT: this will be given orally to the patient and also included in the opening paragraph of the patient survey (see page 9). Patients should not be informed of the study until they are offered the survey.

Patient is identified as newly diagnosed with metastatic breast cancer

Patient is given baseline "control preferences" question.

Reliant in Control ← ----- → Doctor in Control

**A** I want to make the decision about which treatment I get. Only I can choose.

**B** I want to make the final decision about my treatment, but I will seriously think about what my doctor says.

**C** I want my doctor and I to decide together which treatment I get. We will both seriously think about what each other says.

**D** I want my doctor to make the final decision about my treatment, but I will seriously think about what my doctor says.

**E** I want my doctor to make the decision for me about which treatment I get. I don't want to choose.


**GROUP A**  
(no intervention)

**GROUP B**  
(with intervention)

Diagnosis & Treatment Options Discussion(s) by oncologist, HCP observes (as is normally done)

Q. 1-5, 8-9, 12 of patient record form is answered by HCP

Diagnosis & Treatment Options Discussion(s) by oncologist, HCP observes (with intervention)




Page 1 of patient record form is filled out by HCP

Follow-up Discussion(s) with usual HCP (as is normally done, pre-treatment / beginning treatment)

Q. 13-5, 18 of patient record form is answered by HCP

Follow-up Discussion(s) with usual HCP (with intervention)



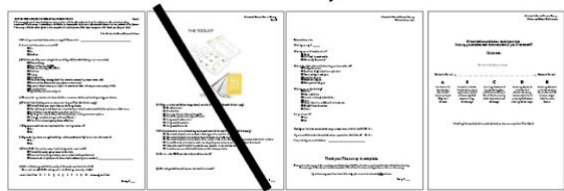
Page 2 of patient record form is filled out by HCP

14-60 days later

14-60 days later

oral consent, delivered by HCP

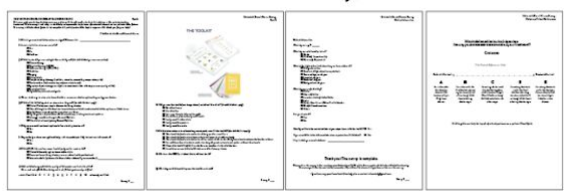
Patient is offered Survey, without Part B.



patient seals survey in envelope, gives to staff before leaving the clinic

oral consent, delivered by HCP

Patient is offered Survey, with Part B.



patient seals survey in envelope, gives to staff before leaving the clinic

Ideally the "HCP" is the same person that observes the oncologist, fills out the patient forms and has the Follow-up Discussion(s). This person can be whatever is standard for the practice: onc/nurse/navigator/social worker, etc.

envelope is marked with patient ID code, surveys + patient record forms sent to researcher at end of each month

\* please make sure patient ID codes are on all pages \*

**SURVEY FOR METASTATIC BREAST CANCER PATIENTS**

**Part A**

*This survey is to understand what your conversations with health professionals in this clinic were like prior to starting treatment. This survey is voluntary and will help us improve the experience of metastatic breast cancer patients in the future. The survey will take about 5 minutes to complete. All participants will be kept anonymous. We thank you for your help!*

– The Metastatic Breast Cancer Alliance

1. What is your metastatic breast cancer type? Please fill in the blanks with “+ or -” ----> ER \_\_ PR \_\_ HER2 \_\_  
 I don't know my cancer type       I'm guessing       Other type: \_\_\_\_\_

2. Is metastatic breast cancer curable?  
 Yes  
 No  
 Not Sure

3. Which topics did your oncologist discuss with you? (check ALL that you can remember)  
 Chemotherapy  
 Targeted therapy (HER2+)  
 Hormone therapy (ER+, PR+)  
 Radiation  
 Surgery  
 Clinical trials  
 Complementary therapy (nutrition, exercise, counseling, acupuncture, etc.)  
 Treatment breaks (reasons to postpone a treatment)  
 Symptom & pain management (plan to counteract side- effects, preserve quality of life)  
 Second opinions  
 My hobbies, interests and goals

4. Please **circle** any treatments above in question 3 that were **recommended as options for you** by your doctor.

5. Which of the following statements are true for you? (check ALL that apply)  
 Clinical Trials were a topic discussed with my doctor  
 I found it tough to talk about treatments because I don't understand all of the options available to me  
 I wish I knew more about the type of cancer I have  
 My life goals and priorities were discussed as part of my treatment options  
 I strongly considered or got a Second Opinion  
 This clinic is where I got my Second Opinion

6. Did you research treatment options before starting treatment?  
 Yes  
 No

7. Do you feel you have enough knowledge now to participate fully in treatment discussions?  
 Yes  
 No

8. Which ONE information source has helped you the most so far?  
 Printed information given to me at the clinic  
 Conversations with my doctor, nurse or other health professional  
 Internet website (please write the website address if you remember): \_\_\_\_\_  
 Other:

9. How satisfied are you with the quality of discussions so far in the clinic?  
On a scale out of 0-10. Zero being not at all, 10 being extremely satisfied.

not at all satisfied    0    1    2    3    4    5    6    7    8    9    10    extremely satisfied

Survey # \_\_\_\_

## THE TOOLKIT



10. Did you use the toolkit (see image above) after you received it? (check ALL that apply)

- Read it at home
- Used it often
- It was my favorite information guide
- Used it to explain to family and friends
- I only used it at the clinic
- I only used the posters
- I only used the cards

11. Which statements are true based on your experience with the toolkit? (check ALL that apply)

- The visuals helped me to understand the type of cancer I have.
- The visuals helped me to picture what was happening inside my body.
- The visuals helped me to understand how cancer is treated and why some treatments are better than others.
- It would have been harder to understand my diagnosis or treatment options without the visuals.
- I found the toolkit helpful, it made the conversations in the clinic better.
- I would recommend this toolkit to be used for future patients.

12. What was the BEST part about the toolkit or visuals?

13. Would you recommend the toolkit to someone else with metastatic breast cancer?

- Yes
- No --> If not, why?

14. Did your doctor use the toolkit with you?

- Yes
- No

Survey # \_\_\_\_



Patient Information

What is your age? \_\_\_\_\_

What is your relationship status?

- Single
- Married / In partnership
- Divorced / Separated

What is the highest level of education you have achieved?

- 12th grade or less
- Graduated high school or equivalent
- Some college, no degree
- Associate degree
- Bachelor's degree
- Post-graduate degree
- Other qualification

What is your race/ethnicity?

- White
- Hispanic/Latina
- American Indian/Alaska Native
- Asian
- Native Hawaiian or Other Pacific Islander
- Black/African-American
- Other:

Are you insured?

- Yes
- No

Would you like to be contacted about your experience with the toolkit?  Yes

If you would like to be informed about our report when it's finished?  Yes

If so, include your email address: \_\_\_\_\_

Thank you! The survey is complete.

**Please place the survey in the envelope provided and seal it.  
Give it to the reception desk in the clinic before leaving today.**

Your survey will then be sent to the researcher. The clinic will not see what you have written on the survey.

If you have any questions about this study, please contact [mbcastudy@gmail.com](mailto:mbcastudy@gmail.com)

Survey # \_\_\_\_

**Please fill out immediately after card discussion.****Cards Follow-up Discussion** Date \_\_/\_\_/2016

13. Length of Discussion: \_\_\_ minutes
14. Led by a:  nurse  navigator  social worker  oncologist  other: \_\_\_\_
15. Occurred how many days after initial discussion with oncologist?
16. Were all cards introduced? If not, which ones were left out and why? (cross out cards/sides not covered)



17. Explain why any cards crossed out above were not used  
(this helps us make improvements and to assess patient understanding based on whether the cards were used):

**Observations:**

18. What 3 key things did the patient not understand/remember from previous oncologist discussions based on your observation?
19. Has the patient brought the toolkit or used the toolkit in the clinic after first receiving it?  Yes  No  
*Note: please allow 30 days before reporting on this.*
- If yes, check ALL that apply:
- Patient brought the posters to future visit(s)
  - Patient brought the cards to future visit(s)
  - Patient used dandelion analogy in future discussion(s).
  - Patient referred to the toolkit orally or physically in the clinic.

20. Do you think the toolkit helped this patient?  Yes  No

Thank you. Please place this in the study envelope, together with the sealed envelope from the patient's survey.  
If you have any questions, please email [mbcastudy@gmail.com](mailto:mbcastudy@gmail.com)

HEALTH PRACTITIONER SURVEY (to be taken online)

*We are interested in your experience with the toolkit, compared to your conversations without using the toolkit.*

1. Are you a(n):  oncologist  nurse  patient navigator  other: \_\_\_\_\_
2. How many years have you been in practice? \_\_\_\_
3. Did the toolkit help you to: (check ALL that apply)
  - have a more comprehensive conversation (covering a wider range of information than usual)
  - have a more interactive conversation (patients seemed to be more involved in the discussions)
  - communicate diagnosis details more easily
  - communicate treatment options more easily
  - guide the conversation in a natural way
  - visualize for the patient their situation/diagnosis
  - save time on explanations/repetition
  - consolidate discussions/appointments
4. Which portion of the toolkit did you use:
  - tear-off sheets
  - card deck
5. Would you recommend this toolkit to other health professionals?
  - no
  - yes
  - yes, with some improvements (please write):
6. What language(s) did you use the toolkit in?
  - English
  - Spanish
7. What was the best part of using the toolkit?
8. Did the toolkit create any complications for you. If so, explain below:

Thank you for being part of this pilot. Your honest feedback is very appreciated.

If you'd like to be contacted about your experience, please include your email address below:

\_\_\_\_\_

*Please fill out immediately after discussions with patient.*

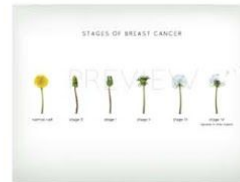
### Patient Metastatic Breast Cancer Diagnosis

1. De Novo or Recurrent How long ago was the patient diagnosed with MBC? \_\_\_\_\_
2. Breast Cancer Subtype is: ER+ PR+ HER2+ ER- PR- HER2- TNBC Other:
3. Patient preferred language: English Spanish Was an interpreter or translator used?
4. Control Preference Scale (as reported by patient): A B C D E

### Diagnosis Discussion

Date \_\_ / \_\_ / 201\_\_

5. Length of discussion: \_\_\_\_ minutes
6. Were both sides of the first sheet discussed and annotated?  
(*Stages Of Cancer, Location Of Mets*)  
 Yes  No
7. Patient interaction with the toolkit: (check all that apply)  
 Patient touched or pointed to a visual on the tear-off sheet as part of the discussion.  
 Patient used the dandelion metaphor to communicate understanding or probe for clarification.  
 Toolkit was written on during the discussion by:  the HCP  the patient  other: \_\_\_\_\_
8. Was there something that impacted the communication that should be noted?  
*Patient mental state, physical ability, distractions, language limitations, etc.*



### Treatment Plan Discussion

Date \_\_ / \_\_ / 2016

9. Length of discussion: \_\_\_\_ minutes
10. Which items on the second sheet were discussed and annotated?  
(*Keys For Choosing Treatment, Treatment Options*) Circle them -->
11. Patient interaction with the toolkit: (check all that apply)  
 Patient touched or pointed to a visual on the tear-off sheet as part of the discussion.  
 Patient used the dandelion metaphor to communicate understanding or probe for clarification.  
 Toolkit was written on during the discussion by:  the HCP  the patient  other: \_\_\_\_\_  
 Patient was offered a clinical trial or a future possibility of a trial was discussed.
12. Was there something that impacted the communication that should be noted?  
*Patient mental state, physical ability, distractions, etc.*

