



## NEEDS ASSESSMENT SUMMARY

### Key Informant Interviews:

A total of 12 key informant interviews were conducted with nurse navigators, social workers, genetic specialists and one physical therapist.

### Focus Groups:

Five focus groups were conducted with BCRC clients, and each of these focus groups was made of up women fitting different demographic profiles. The 5 focus groups conducted included participants who fit into the following categories: Black/African American, Hispanic, Rural, Underinsured, and Metastatic. A total of 33 women participated in these focus groups.

### Statewide Surveys:

Surveys were distributed to health care providers who care for women with breast cancer and to women with breast or metastatic breast cancer across the state of Texas. BCRC partnered with numerous non-profit organizations across Texas to distribute the surveys to their eligible stakeholders and clients. BCRC also utilized the Cancer Alliance of Texas (CAT) to distribute both surveys to participating organizations, agencies, institutions, and individuals. BCRC's CDC Grant Advisory Council also distributed the surveys to their partners. Of the surveys distributed, 126 were completed by women with breast cancer (63 by women diagnosed under 45 and 63 by women diagnosed over 45) and 12 were completed by health care professionals consisting of oncologists, nurse navigators, social workers, and physical therapists.

*The following information was gathered in a community-based needs assessment conducted by the Breast Cancer Resource Center (BCRC) during Year 1 of the Centers for Disease Control and Prevention 1906 grant from May-September 2020. BCRC partnered with Heather Becker, PhD and Emily Croce RN-CPNP at the University of Texas School of Nursing and Deborah Vollmer Dahlke, DrPH at DVD Associates, LLC to assist with conducting this needs assessment consisting of five focus groups, 12 key informant interviews, and two statewide surveys distributed across Texas.*

## Action Steps from Needs Assessment

As shown in the following needs assessment analysis, there are many aspects of breast cancer diagnosis, treatment, and post-treatment that need to be addressed. Based on these findings, we have developed action items to address these needs over the next four years.

Year 2 (September 30, 2020 – September 29, 2021) Action Steps:
Increase the local linkages between clinic and non-clinical partners to improve the overall system delivery to women diagnosed with breast cancer under age 45 or metastatic breast cancer
Increase partnerships between BCRC and local providers to resolve insurance and financial barriers to psychosocial services
Identify and increase accessible resources and/or programs that support healthy lifestyles
Increase health care providers' awareness of survivorship best practices
Increase health care providers' knowledge of cancer survivorship needs for underserved populations
Increase the number of digital resources available by BCRC for survivors, caregivers, and providers
Develop a newly diagnosed program
Develop strategies to strengthen effective communication between breast cancer patients and their providers
Improve healthcare provider education to ensure they are aware of their patients' biggest concerns (physical, emotional, financial, etc.) during treatment
Collaborate with healthcare providers to identify best practices when transitioning young patients from active treatment into the post-treatment phase
Collaborate with healthcare providers to identify strategies to implement in order to address and meet the needs of their young patients diagnosed under 45 (education about/access to fertility preservation resources, concerns about intimacy, sexuality, and premature menopause)

Years 3 – 5 (September 30, 2021 – September 29, 2024) Action Steps:
Collaborate with local key stakeholders to identify ways to improve communication and collaboration among all members of a patient’s healthcare team
Strengthen relationships between BCRC and all central Texas healthcare providers working with breast cancer patients to establish BCRC as the central location of all resources for women diagnosed with breast cancer
Modify potential implicit biases within healthcare providers in the care they provide for survivors from historically marginalized groups (ex: women of color, women with disabilities, women who are LGBTQ, or women whose first language is not English)
Develop/strengthen resources to help young survivors navigate the world of insurance, including deductibles and co-pays
Develop resources to help women maximize their work situation (ex: how to work with HR departments to request appropriate accommodations)

## Results from Key Informant Interviews

- Perceptions of Existing Services
  - For specialized services not available “in house”, referrals are made, and providers expressed that not everyone who is referred makes it to the referral
  - Services mentioned by providers that they perceive to have the most frequent gaps in care include: radiation therapy, complementary therapies, genetic testing and rehabilitation/physical therapy
  - Providers mentioned that everyone has different needs and services need to be tailored to each individual. The only way to identify a need is by the patient expressing it, which providers mentioned, generally happens once they have had a chance to build rapport
  - Many providers mentioned not wanting to overwhelm their patients with too much information, too soon
  - Providers mentioned not mentioning certain support services to their patients they think might not be able to afford them
  - Health literacy was frequently brought up by providers. One provider mentioned that written information might be at a level too high for some patients, or Spanish speaking patients might have details regarding their diagnosis/treatment get lost through translation
- Barriers to Services
  - Providers mentioned geographic residence to be one of the major barriers to service they see with their patients
  - One provider mentioned that Latina women tend to not question what the doctor tells them
  - Another provider mentioned lack of access to preventative services in the Black community, which might lead to delays in care or treatment
  - One provider mentioned distrust of the health care system within the Black community as another potential barrier to services
- Provider Perceived Concerns Specific to YBCS
  - Childcare was a concern mentioned by providers
  - Providers mentioned young survivors potentially trusting social media too much and not always finding credible sources
  - Other important issues among this age group that providers mentioned include body image, femininity, and sexual issues
- Meeting Survivors’ Needs
  - Providers mentioned BCRC and navigators in general as beneficial resources to help their patients identify resources to meet their needs
  - Some providers mentioned that a lot of the time, navigators are the ones who explain diagnoses and treatment if patients received confusing information from their providers
  - Many providers mentioned wanting a more seamless and integrated system of care for their patients when asked what would be different in their “perfect world”
  - One provider mentioned having a more holistic approach to treatment at the beginning and approaching things preventively
  - Some providers mentioned that certain treatments might not be an option for some women, even if they have insurance, because the co-pays are not affordable

## Results from Focus Groups

- Useful Information Sources
  - It is necessary to identify credible online sources when researching information pertaining to their diagnosis, treatment and symptoms/side effects
  - Support groups are good sources of helpful information
  - Oncology providers were mentioned as being helpful sometimes, but were not always readily available
  - The big “cancer bible” binders are overwhelming for many participants
  - Participants mentioned there tended to be a lack of post-treatment information that was shared with them
- Needed Supports and Services
  - Many participants mentioned they would like to see better coordination of services, especially once active treatment has ended
  - For the participants who had completed active treatment, some mentioned that the support and services they had through treatment “faded away” as soon as active treatment was over
  - Some participants, many of which work during the day, mentioned the inaccessibility of support groups or other services due to them not being offered at convenient locations or times. Many women favorably mentioned the increased use of virtual platforms to offer these services. A few women mentioned that support groups for specific diagnoses would be helpful
  - Many participants said they wished there were mental health services readily available, especially following active treatment, in order to process new emotions during that period
  - Some participants expressed a need for increased access to health and nutrition information
  - Many women indicated they did not have a conversation with their provider about fertility preservation. Some women mentioned cost as a barrier, while others said they did not have enough time to make an informed decision before treatment began
  - Spousal/significant other support and support for children was also mentioned as a need among participants
- Financial Concerns
  - Women in the metastatic focus group expressed the financial burden of their ongoing treatment needs
  - Insurance not covering mental health services was mentioned in several focus groups
- Barriers to Accessing Resources
  - While there are many free and reduced-cost programs for cancer survivors, it was mentioned that women do not always have the stamina to fill out applications in the midst of active treatment
  - Many women mentioned a lack of understanding health insurance terms, and expressed interest in more education on that topic
  - Many participants mentioned their frustration of the fine line between not qualifying for financial support since they have jobs, but not having a high enough income to pay for all expenses that insurance does not cover
  - Women in the Black focus group specifically spoke about experiencing delays in treatment and receiving different treatment compared to white women
- Helpful Services and Resources
  - Patient and nurse navigators were highly praised by many participants as being helpful in guiding them to beneficial resources
  - Women said they found complementary treatments, especially mental health services, to be very helpful to them
- Communication and Relationship with Providers
  - Many women felt that their providers did not share as much information as they would have liked regarding long-term effects from treatments, and other side effects that occurred after active treatment
  - A couple women in the metastatic group commented on how they would have liked to have palliative care and conversations about end of life planning introduced to them sooner in their treatment process
  - Women expressed their concern about not being given information regarding signs and symptoms of recurrence and/or metastatic cancer
  - One woman mentioned that primary care providers and OB/GYNs need to tell their young patients that breast cancer is not just an “old lady thing”
  - Women in the metastatic group said they wished their providers would have gone into more detail about the difference between metastatic cancer and recurrence so they could prepare for the long-lasting treatment and make informed decisions

## Results from Client Statewide Survey

- Client concerns
  - When women who were diagnosed under the age of 45 were asked to rate their concerns they have/had when going through active treatment on a scale of 0 to 100, with 0 being something that does/did not at all concern them and 100 being something of extreme concern, the following are what they rated as what concerned them *most*:
    - Fear of cancer returning (average rating=82.0)
    - Reconstructive surgery (average rating=78.6)
    - Mastectomy (average rating=76.7)
    - Understanding healthcare or insurance benefits (average rating=75.4)
    - Having enough energy to make it through the day (average rating=74.1)
    - Managing pain or discomfort (average rating=73.5)
  - Women diagnosed under the age of 45 rated the following 3 concerns much higher than women diagnosed over the age of 45
    - Access to fertility preservation
    - Keeping up with school coursework
    - Continuing or completing education
- Helpfulness of Healthcare Team Addressing Needs or Referring to Resource to Address Needs
  - When women who were diagnosed under the age of 45 were asked to rate how helpful their healthcare team was in addressing their needs or referring them to a resource to address their needs on a scale of 0 to 100 with 0 being not at all helpful and 100 being extremely helpful, the following are what they rated as their healthcare team being *least* helpful with addressing:
    - Intimacy or sexuality concerns (average rating=30.8)
    - Ability to maintain relationship with significant other (average rating=31.4)
    - Ability to maintain relationship with family members or friends (average rating=32.0)
    - Keeping up with coursework in school (average rating=32.1)
    - Continuing or completing education (average rating=33.7)
  - When women who were diagnosed under the age of 45 were asked to rate how helpful their healthcare team was in addressing their needs or referring them to a resource to address their needs on a scale of 0 to 100 with 0 being not at all helpful and 100 being extremely helpful, the following are what they rated as their healthcare team being *most* helpful with addressing:
    - Concerns about reconstructive surgery (average rating=78.9)
    - Need for genetic counseling (average rating=76.6)
    - Managing pain or discomfort (average rating=76.2)
    - Concerns about mastectomy (average rating=74.9)
    - Managing all prescribed medications and treatments (average rating=74.9)
    - Using medications to manage long-term side effects (average rating=70.2)
- Healthcare Team Involvement During Transition from Treatment to Post-Treatment
  - When women who were diagnosed under the age of 45 were asked to rate the extent at which their healthcare team discussed certain topics during their transition from treatment to post-treatment on a scale of 0 to 100 with 0 being no discussion and 100 being an in-depth discussion, the following topics were discussed *least* on average:
    - Supporting spouse, children and/or family members through post treatment (average rating=20.0)
    - Concerns about remaining medical bills (average rating=20.4)
    - A need for ongoing emotional or mental support (average rating=23.3)
    - Concerns about cost for post-treatment therapies and medication (average rating=24.3)
    - Need for financial service counseling or support (average rating=25.6)
    - What to do for exercise and nutrition (average rating=36.0)
    - When to contact your oncologist vs. primary care doctor vs. OB/GYN (average rating=38.3)

## Results from Provider Statewide Survey

- Provider Perception of Patient Concerns
  - When providers were asked to rate their breast cancer patients', diagnosed under the age of 45, concerns on a scale of 0 to 100, with 0 being something that does not appear to be of concern to their patients and 100 being something that appears to be an extreme concern to their patients, the following topics are what they rated the *highest*:
    - Fear of cancer returning (average rating=86.9)
    - Uncertainty about the future (78.2)
    - Having adequate financial resources needed for treatment and recovery/post recovery (average rating=76.0)
    - Chemotherapy side effects (average rating=77.0)
    - Managing prescribed medications and therapies (average rating=73.6)
    - Mastectomy choices (average rating=73.6)
    - Managing pain (average rating=69.9)
  - When providers were asked to rate their breast cancer patients', diagnosed under the age of 45, concerns on a scale of 0 to 100, with 0 being something that does not appear to be of concern to their patients and 100 being something that appears to be an extreme concern to their patients, the following topics are what they rated the *lowest*:
    - Being able to complete coursework in school (average rating=16.9)
    - Completing education (average rating=21.7)
    - Fertility preservation (average rating=34.5)
- New Patient Visit Time
  - Providers were asked to share the average amount of time they spend during an initial visit with a new breast cancer patient
    - 50% of providers said they spend between 46-60 minutes during an initial patient visit
    - 25% of providers spend between 16-30 minutes during an initial visit
- Patient Transition to Post-Treatment
  - When transitioning patients to post-treatment care, providers were asked which areas they consider the most important to pay attention to on a scale of 0 to 100, with 0 being not an area of attention and 100 being an area for an extreme amount of attention. Areas that providers consider *most* important to pay attention to include the following:
    - Emotional, psychosocial services, support (average rating=79.8)
    - Managing post-treatment care (average rating=73.7)
    - Awareness and education on recurrence/metastatic breast cancer and symptoms to be aware of (average rating=72.6)
    - Survivorship care plan or next step summary (70.8)
    - Managing long-term side effects of treatment (average rating=69.4)
  - When transitioning patients to post-treatment care, providers were asked which areas they consider the most important to pay attention to on a scale of 0 to 100, with 0 being not an area of attention and 100 being an area for an extreme amount of attention. Areas that providers consider *least* important to pay attention to include the following:
    - Transition to primary care physician (average rating=39.5)
    - Support for children/spouse/ significant other through transition (average rating=43.1)
    - Exercise and nutrition (average rating=55.8)
    - Financial services/support (average rating=55.0)

## Conclusions

### Patient concerns during diagnosis/treatment

When comparing data from both the provider and client surveys, it seems as though there are many aspects of a breast cancer diagnosis and treatment phase that doctors understand their patients' concerns. These include managing pain and discomfort, having a mastectomy, and fear of cancer returning. There are, however, some concerns that young women with a breast cancer diagnosis have and providers did not report of high importance.

**Fertility preservation** is a concern many young women have when they receive their diagnosis. Throughout most of the focus groups conducted, women brought up their disappointment around the lack of communication with providers regarding fertility preservation. This lack of communication could be for a number of reasons including, providers not wanting to overwhelm their patients with too much information, providers not viewing fertility preservation as important compared to treating their patients' cancer, or maybe even providers thinking their patient cannot afford fertility preservation. Whatever the reasoning, young breast cancer patients view fertility preservation as an important topic to be educated on before treatment.

Many women expressed a sense of not feeling prepared and/or supported by their providers about **making important decisions**, including fertility preservation. From the focus groups, women praised their patient navigators in helping them navigate these important decisions, however, focus group participants also expressed a desire for the providers to help with these decisions as well.

Another concern young women with a breast cancer diagnosis have is the need for more education around **exercise and nutrition**. Women reported not feeling prepared with enough information about any changes they should make to their exercise/nutrition after receiving their diagnosis. Other women were interested in learning about complementary therapies including physical therapy, yoga, and massage therapy. It appears that women did not receive this information from the healthcare team and most of the time the information was transmitted through online forums or patient navigators.

Another concern seen among young women with breast cancer in both the focus groups and the survey is the need for increased **emotional support for spouses, children, and other family members**. Women in most focus groups mentioned that there are so few mental health resources for their family members. They also talked about the need for support for their family members to just discuss their diagnosis and treatment in general. When looking at data from the provider survey, there appears to be a disconnect as providers view support for their patients' family members to be of low importance.

### Helpfulness of healthcare team addressing needs/referring to resources to address needs

There are many needs women felt their healthcare team was successful with addressing during diagnosis and treatment. Some of these include addressing concerns about having a mastectomy and reconstructive surgery, identifying genetic counseling resources, and managing prescribed medications and treatments. This is consistent with the data from provider survey, indicating that providers are able to provide education and referrals to resources closely related to a diagnosis.

However, women expressed a lack of support from their healthcare team when it came to aspects that are not generally brought up during diagnosis and treatment. In the focus groups, many women spoke about their segmented care and how their oncologists only saw their cancer as the problem to solve. One woman said, *"Doctors tend to just worry about like the cancer and making sure that's under control and less about the side effects caused by like the chemotherapy and stuff."* This indicates a **need for greater coordination of care and communication between all healthcare team members to ensure every need is being met for each patient**.

### Healthcare team involvement during transition to post-treatment

Data from the needs assessment shows that areas of importance providers think they should pay attention to when transitioning patients to post-treatment are not being addressed appropriately. As seen in the survey data, providers believe the most important thing to pay attention to during this transition is emotional, psychosocial services and support, however, in focus groups, women reported feeling "abandoned" after they finished treatment and lacking psychosocial support during this time. Additionally, when women were asked about topics their healthcare team discussed as they *transitioned out of active treatment*, **ongoing emotional and mental support** was one topic women felt was not brought up.

Another main topic providers viewed as important during *transition to post-treatment* that women felt was not addressed includes **education about recurrence and metastatic cancer and what signs and symptoms to be aware of**. Many women, especially in the metastatic focus group, felt that as soon as their initial breast cancer diagnosis had been resolved, their healthcare team did not give any education about possible recurrence and metastasis. Based on this data, we believe it would be helpful for providers to spend additional time educating their patients about these possibilities.