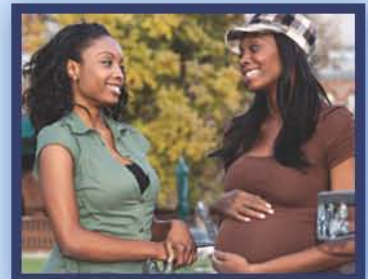




BREAST CANCER IN YOUNG WOMEN PROJECT

TOPLINE REPORT



January 2012



CONTENTS

INTRODUCTION	1
METHODOLOGY	3
Focus Group Segmentation.....	3
Focus Group Recruitment	4
PARTICIPANT ELIGIBILITY	5
Focus Group Protocol	5
Focus Group Data Analysis	6
FINDINGS.....	6
Pre-Discussion Information Sheet (PDIS).....	6
Psychosocial and Reproductive Health Information Needs.....	9
Feedback on Sharsheret’s PSN and GFL Programs	16
Access and Delivery of PSN and GFL Programs.....	18
SUMMARY OF MAJOR FINDINGS	21
MODIFICATIONS TO PSN AND GFL.....	23
REFERENCES	26
APPENDICES	
A. Recruitment Tools	
B. Informed Consent	
C. Pre-Discussion Information Sheet	
D. Observer Confidentiality Form	
E. Travel Reimbursement Request Form	
F. Resource List	
G. Discussion Charts Used During Focus Groups	
H. Topical Discussion Guides	

INTRODUCTION

Research demonstrates that following a diagnosis of breast cancer, young women may experience a more negative impact on their quality of life, emotional functioning, and reproductive health outcomes than older women (Gabriel & Domchek, 2010; Maggard et al., 2003; Chung, Chang, Bland, & Wanebo, 1996). When compared to older women, young breast cancer survivors (YBCS) often have breast cancer detected at a later stage and tumors tend to be more aggressive (Colleoni et al., 2002; Bonnier et al., 1995). As a result, treatment is often multimodal and more toxic, and side effects may be more severe. Often, YBCS do not receive counseling about premature menopause and fertility changes, and may have to make rapid treatment decisions without appropriate information to make informed decisions regarding fertility implications (Bloom, Stewart, Chang, & Banks, 2004). In addition, YBCS may have greater information needs and may prefer higher levels of collaboration with their health care providers in treatment decisions compared to older women (Thewes, Butow, Girgis, & Pendlebury, 2004).

Racial and ethnic disparities can exacerbate the negative impact of a breast cancer diagnosis. For example, although African American women experience lower breast cancer incidence rates in the United States, they experience disproportionately higher breast cancer mortality rates. African American women under the age of 45 years, however, have the highest incidence of breast cancer of any ethnic group, which may be due to disparities in cancer screening and treatment and/or the higher frequency of aggressive breast cancer types found within this population (American Cancer Society, 2009). In addition, Ashkenazi Jewish women experience a disproportionately high prevalence of genetic mutations linked to breast cancer occurrence (e.g., BRCA-1 and -2 gene mutations) and correspondingly high incidence rates (National Cancer Institute, 2009).

Given this, in September 2010, the Centers for Disease Control and Prevention (CDC) launched the Breast Cancer in Young Women (BCYW) project to identify, strengthen, and promote real-world, evidence-based interventions (EBIs) that provide psychosocial and reproductive health support to African American and Ashkenazi Jewish YBCS. As noted in the Education and Awareness Requires Learning Young Act, Sec. 10413 of the Patient Protection and Affordable Care Act (H.R. 3590), YBCS are defined as women who had a diagnosis of breast cancer before the age of 45 years. Through the BCYW project, CDC seeks to learn about and evaluate the efforts of two select national organizations providing psychosocial and reproductive health support to YBCS of

Operational Definitions for Psychosocial and Reproductive Health Support

Psychosocial Health Support

The psychological and social needs of women with breast cancer related to concerns about fear of recurrence; physical symptoms such as fatigue, trouble sleeping, pain, and memory loss (e.g., “chemo brain”); ability to work and reentry to work place, school; body image disruption; sexual dysfunction; fertility and early menopause; treatment-related anxiety and/or depression; intrusive thoughts about illness/persistent anxiety; marital/partner and family communication; feelings of vulnerability; and existential concerns regarding mortality.

Reproductive Health Support

The needs of women with breast cancer related to concerns about romantic relationships, sex life, sexual dysfunction, body image, fertility and childbearing after diagnosis, and early menopause.

African American and Ashkenazi Jewish descent. The two organizations are *Sisters Network Inc. (SNI)*, a leading voice for African American breast cancer survivorship in the United States and recognized as a critical information resource for African American women, and *Sharsheret*, a national not-for-profit organization supporting young women and their families of all Jewish backgrounds who are facing breast cancer.

One of the initial tasks for the BCYW project was to support each organization in testing existing interventions via focus groups to tailor and strengthen the interventions as necessary for implementation and evaluation. This report presents the methodology and findings from the testing of two existing interventions implemented by Sharsheret: The Peer Support Network™ (PSN) and Genetics for Life™ (GFL) interventions.

In 2001, Sharsheret was founded with the development and launch of the PSN program, a matched peer support network for Jewish women to connect with other women in similar situations (paired on a number of variables) for support and information. When the PSN was created, Sharsheret's senior and clinical staffs integrated program monitoring and evaluation (M&E) processes to obtain participants' feedback on their experiences with the program and on how to improve, expand upon, and develop new Sharsheret programs and services. Participants' feedback on the PSN was the catalyst for the development of several additional services that are now part of the Link Programs™ designed to provide psychosocial and reproductive health support to breast cancer survivors and their friends and families. One of those programs, the GFL, was developed to address the concerns of individuals who have a high risk of developing hereditary breast cancer or ovarian cancer. Participant feedback, evaluations, and focus groups provided direction in developing this program, in which callers receive nondirective, confidential counseling about options for and the implications of testing for the BRCA-1 and BRCA-2 gene mutations commonly found in 1 in 40 women of Ashkenazi Jewish descent that significantly increases the risk of developing hereditary breast cancer, ovarian cancer, and other related cancers.

PSN and GFL Programs

Sharsheret was founded in 2001 with the development and launch of the PSN program, a matched peer support network for Jewish women to connect with other women in similar situations (paired on a number of variables) for support and information. When the PSN program was created, Sharsheret's senior and clinical staffs integrated program M&E processes to obtain participants' feedback on their experiences with the program and on how to improve, expand upon, and develop new Sharsheret programs and services. Participants' feedback on the PSN was the catalyst for the development of several additional services that are now part of the Link Programs designed to provide psychosocial and reproductive health support to breast cancer survivors and their friends and families.

One of those programs, the GFL program, was developed to address the concerns of individuals who have a high risk of developing hereditary breast cancer or ovarian cancer. Participant feedback, evaluations, and focus groups provided direction in developing this innovative program, in which callers receive nondirective, confidential counseling about options for and the implications of testing for the BRCA-1 and BRCA-2 gene mutations commonly found in 1 in 40 women of Ashkenazi Jewish descent.

METHODOLOGY

In November 2011, Sharsheret conducted four focus groups to gain a deeper understanding of the psychosocial and reproductive health information needs and concerns of young Ashkenazi Jewish women and to gather their feedback on PSN and GFL program content and delivery. Sharsheret selected focus groups as the most appropriate investigative technique because of their information-rich nature. Focus group discussions, or intensive group interviews, are a flexible tool for exploring respondents' awareness, concerns, beliefs, experiences, motivation, operating practices, behaviors, and plans related to a topic and subissues (Krueger, 1994).

The project team used a deductive approach to data analysis, which involved reviewing in-depth interview notes to identify themes and patterns in the qualitative data. Team members met regularly during the analysis process to discuss findings and reach agreement on major patterns and themes found in the study data.

The specific objectives of the focus groups were to

- explore the psychosocial health needs of Ashkenazi Jewish YBCS,
- explore the reproductive health needs of Ashkenazi Jewish YBCS,
- determine available and necessary resources and programs to address the psychosocial and reproductive health needs of Ashkenazi Jewish YBCS,
- identify potential modifications to the content of Sharsheret's PSN and GFL programs,
- identify potential modifications to the delivery of Sharsheret's PSN and GFL programs.

Despite its advantages, focus group methodology is not without limitations. Findings from focus group discussions are neither quantitative nor generalizable to the population as a whole. Focus group methodology emphasizes depth and insight; therefore, it does not use a rigorous sampling methodology that would be necessary to draw wide-ranging conclusions (Krueger, 1994; Greenbaum, 1998).

FOCUS GROUP SEGMENTATION

Sharsheret conducted four focus groups of YBCS to explore the organization's PSN and GFL programs. Two focus groups addressed the needs of YBCS, PSN and GFL program content, and PSN and GFL program delivery with respect to the **psychosocial health of YBCS**. Two focus groups addressed YBCS needs, PSN and GFL program content, and PSN and GFL program delivery with respect to the **reproductive health of YBCS**. In total, 27 women—representing eight States (New York, New Jersey, Pennsylvania, Georgia, Texas, Maryland, Virginia, Connecticut) and one expatriate from London—participated in the focus groups. Table 1 presents the focus group segmentation. The cells represent the number of women who participated in that focus group.

Table 1. Focus Group Segmentation

TARGET AUDIENCE: ASHKENAZI JEWISH YBCS AGED 45 YEARS AND YOUNGER AT TIME OF DIAGNOSIS				
	FG 1 (Face-to-face) ¹ 11/1/2011	FG 2 (Face-to-face) 11/9/2011	FG 3 (Online) ² 11/15/2011	FG 4 (Online) 11/16/2011
Focus: Psychosocial Health and Reproductive Health Support for Ashkenazi Jewish YBCS in PSN	N/A	7 women	N/A	6 women
Focus: Psychosocial Health and Reproductive Health Support for Ashkenazi Jewish YBCS in GFL	7 women	N/A	7 women	N/A

FOCUS GROUP RECRUITMENT

Focus group recruitment was conducted between September and November 2011 using the following strategies.

New York's Race for the Cure. At the September 18, 2011, Komen Race for the Cure, Sharsheret recruited potential focus group participants for the face-to-face focus groups held at Sharsheret's New Jersey headquarters. Sharsheret staff described the BCYW project and purpose of the focus groups to potential participants and collected contact information for women who expressed interest in participating in the focus groups.

Sharsheret's Contact Database. Sharsheret used e-mail to recruit YBCS (see Appendix A), sending focus group descriptions to people in their existing databases of

- PSN and GFL participants,
- health care professionals who referred YBCS patients to Sharsheret,

¹ Two face-to-face focus groups were conducted in Sharsheret's Teaneck, NJ, office for New York, New Jersey, and Connecticut YBCS.

² Two focus groups were conducted virtually, using teleconference and Webinar modalities, for YBCS from areas with significant Jewish populations outside the tri-state area.

- family and friends of YBCS who forwarded a focus group description to their loved ones.

Social Media. Sharsheret used social media to recruit participants by posting a brief description of the BCYW project and the focus group recruitment effort on Sharsheret’s Facebook page and Twitter account.

Web Site. Sharsheret added a description of the focus groups in the Events section of its national Web site, inviting YBCS to contact the organization to learn more about participating in the focus groups, online or in-person.

Nine women were recruited for each focus group segment, with the goal of including six to nine participants per focus group.

PARTICIPANT ELIGIBILITY

To be eligible to participate in this study, women needed to meet the following criteria:

- Ashkenazi Jewish descent
- Under age 45 at time of diagnosis
- Breast cancer survivor
- Participated in Sharsheret’s PSN program (for PSN focus groups)
- BRCA mutation carrier who had participated in the GFL program (for GFL focus groups)
- Available to participate on the dates offered to conduct the focus group

Interested participants were sent an e-mail thanking them for their willingness to participate. Because all potential participants had at some point participated in either the PSN or GFL programs, Sharsheret had access to information about them that could be used to help determine eligibility for participation in the focus groups. For example, Sharsheret was able to determine potential participants’ age at diagnosis and Jewish affiliation. Sharsheret’s clinical staff reviewed the Sharsheret database for general demographic, diagnostic, and treatment information to determine whether the interested registrants were eligible to participate in the focus groups.

Overall, 40 women who expressed interest in participating were eligible for the focus groups and 27 women participated. Women who met all criteria were assigned to a focus group based on their participation in the PSN or GFL programs and availability on a given date. Participants were contacted 2 days before the focus groups and on the day of the focus groups to remind them of the locations and times for their focus groups.

FOCUS GROUP PROTOCOL

Two focus groups were held online using Conference Suite technology and two groups were conducted in-person at Sharsheret’s national headquarters in Teaneck, NJ. Each focus group lasted approximately 90 minutes to 2 hours. At the start of the in-person focus groups, participants were welcomed by the moderator, invited to partake in a light dinner, and asked to complete an Informed Consent Form (see Appendix B) and Pre-Discussion Information Sheet

(PDIS) (see Appendix C). (The Informed Consent Form and PDIS were e-mailed to the participants of the online focus groups to be completed prior to the start time.) Moderator, notetakers, audio technicians, and observers for each focus group were asked to sign an Observer Confidentiality Form (see Appendix D). A Travel Reimbursement Request Form was provided to participants of the in-person focus group (see Appendix E). The in-person focus groups took a 10-minute break after the first hour of discussion. Participants were also provided a handout of relevant survivorship resources for reference after the discussion (see Appendix F).

Two charts/slides were posted in the room or online to remind participants of the working definition of “psychosocial health needs” and “reproductive health needs” for purposes of this study (see Appendix G). A skilled focus group moderator used topical discussion guides specific to each focus group topic area (PSN and GFL, respectively) to conduct the groups (see Appendix H). To gather participants’ feedback on the content and delivery of Sharsheret’s PSN and GFL programs, the moderator described the program components before the discussion. The moderator also showed participants relevant resources available on the Sharsheret Web site. Topical guide questions asked no more than nine women 50% or more of the same questions. A notetaker completed charts during the focus group to record participants’ responses and serve as a reference for later discussion and data analysis. The charts were displayed on the wall or online and were visible to all focus group participants.

FOCUS GROUP DATA ANALYSIS

The focus groups provided quantitative and qualitative data. *Quantitative data* included secondary demographic data retrieved from the PDIS completed by each participant in advance of the group discussions. Those data were compiled and analyzed using Microsoft Excel. *Qualitative data* included the notes of participants’ responses to discussion questions collected by the note-taker. Qualitative data were analyzed using a notes-based thematic analysis to identify themes and patterns within and across the focus groups. Audiotaped recordings from the focus groups served as a backup to confirm specific participant and group responses.

FINDINGS

PRE-DISCUSSION INFORMATION SHEET (PDIS)

At the start of each focus group, participants were asked to complete a PDIS, which solicited demographic information, date of initial cancer diagnosis, stage at diagnosis, and treatments received. Tables 2–4 display results from the PDIS. Table 2 presents the demographic information by group and overall. Tables 3 and 4 present diagnostic information and treatments received, respectively.

Demographic Information

All participants self-identified as Ashkenazi Jewish women. Most identified as Orthodox (16) or Conservative (6). Most (24) had completed a college education, and 11 were employed full-time. The average age of participants was 40.4 years in the GFL group and 44 years in the PSN group. Most participants (23) were married. Participants had between zero and eight children. The

average number of children across participants overall was 2.78. Two participants in the GFL groups had more than five children, slightly increasing the average for this group to nearly double that of the other groups.

Table 2. Participants' Demographics

	GFL		PSN		OVERALL
	FG 1	FG 3	FG 2	FG 4	
Religious Affiliation					
Chassidic	0	0	0	0	0
Orthodox	5	5	6	0	16
Conservative	1	1	0	4	6
Reform	0	1	1	1	3
Reconstructionist	0	0	0	0	0
Traditional	0	0	0	0	0
Unaffiliated	0	0	0	1	1
Other	0	0	0	0	0
Age (Years)					
Mean current age (minimum–maximum)	38.7 (32–45)	42.0 (38–47)	44.1 (32–51)	44.0 (33–45)	42.2 (32–51)
Education Attainment					
12th grade with a high-school diploma	0	0	0	0	0
General Education Development (GED) diploma	0	0	0	0	0
Some college	2	0	1	0	3
Associate degree	0	0	0	0	0
Completed college (4-year degree)	5	4	0	2	11
Graduate degree	0	3	6	4	13
Employment Status					
Full-time	3	2	4	2	11
Part-time	1	4	2	2	9
Presently not employed outside the home, looking for work	1	0	0	1	2
Presently not employed outside the home, not looking for work	2	1	1	0	4
Disabled	0	0	0	1	1
Marital Status					
Married	6	6	6	5	23
Divorced	0	0	0	0	0
Separated	0	0	0	0	0
Never married	1	0	1	1	3
Unmarried couple	0	1	0	0	1

Table 2. Participants' Demographics (continued)

Children					
Mean number of children (minimum–maximum)	3.1 (0–8)	3.1(0–5)	3 (1–6)	1.7 (0–5)	2.7 (0–8)

Diagnostic Information

The PDIS asked participants to identify diagnostic information (see Appendix C). Most participants who provided an answer indicated that they had either a diagnosis of ductal carcinoma in situ (8) or invasive ductal carcinoma (17). It is important to note that nine participants were unable to report the details of their diagnosis, and five participants indicated having a diagnosis of both invasive and noninvasive cancer. Approximately one-half of the participants (8) had stage IIA disease. One participant had more advanced disease at diagnosis.

The mean age at diagnosis across all groups was 36.8 years. The number of years that had lapsed since participants' diagnosis ranged from 0 to 10 years. That was significant because some participants in the PSN groups had a breast cancer diagnosis before some of Sharsheret's programs were developed, thus affecting their ability to comment on some of the more recent programs and services launched by the organization.

Table 3. Summary of Participants' Diagnostic Information

	GFL		PSN		OVERALL
	<45 YEARS	<45 YEARS	<45 YEARS	<45 YEARS	
	FG 1	FG 3	FG 2	FG 4	
Timing of Diagnosis					
Mean age in years at diagnosis (minimum–maximum)	35.2 (28–39)	37.1 (30–44)	37.6 (26–44)	37.2 (41–43)	36.8 (26–44)
Mean years since diagnosis (minimum–maximum)	3.8 (0–10)	4.9 (2–10)	6.6 (3–10)	6.8 (2–10)	5.5 (0–10)
Type of Cancer Diagnosis					
Ductal carcinoma in situ	3	2	2	1	8
Invasive ductal carcinoma	4	5	5	3	17
Type missing	0	0	0	0	0
Tumor Stage at Diagnosis					
Stage 0	2	1	0	2	5
Stage I	2	0	2	0	4
Stage II (not further specified)	0	0	0	0	0
Stage IIA	0	5	1	2	8
Stage IIB	0	0	1	1	2
Stage IIIA	1	0	1	0	2
Stage IIIB	0	1	0	0	1
Stage IV	0	0	1	0	1
Stage missing	2	0	1	1	4

Information on Treatments Received

Participants were asked to select the treatments they had received from a list presented on the PDIS. Most (26) participants had received a form of surgery to treat their breast cancer; a large proportion had also received chemotherapy (21) and radiation therapy (9). Most (18) had received hormonal therapies, and a small number (3) had received targeted therapies. Two (2) women indicated that they had participated in a clinical trial. Table 4 displays the distribution of treatment types by group and overall.

Table 4. Summary of Participants' Treatment Types

	GFL		PSN		OVERALL
	FG 1	FG 2	FG 3	FG 4	
Surgical Treatment					
Breast-conserving surgery (lumpectomy)	2	3	2	1	6
Mastectomy	6	6	6	5	23
Lymph node dissection	2	3	2	1	8
Sentinel lymph node dissection	3	5	2	2	12
Prophylactic ovary removal	3	6	3	2	14
Breast reconstruction	4	7	5	1	17
Chemotherapy					
Chemotherapy	5	5	6	5	21
Radiation Therapy					
Radiation therapy	1	3	2	3	9
Hormonal Therapies					
Hormonal therapy (total)	2	4	7	5	18
Aromatase inhibitors	0	4	3	1	8
Selective estrogen receptor modulators	2	0	3	4	9
Estrogen receptor downregulators	0	0	1	0	1
Targeted Therapies					
Targeted therapies (total)	0	0	2	0	2
Herceptin (chemical name: trastuzumab)	0	0	1	1	1
Avastin (chemical name: bevacizumab)	0	0	1	0	1

The following findings represent themes in responses to the questions posed to focus group participants in each of three topical areas: (1) health information needs, (2) content of PSN and GFL programs addressing those needs, and (3) delivery of PSN and GFL programs to address those needs. Any observed differences between the group segments are discussed within the topical areas.

PSYCHOSOCIAL AND REPRODUCTIVE HEALTH INFORMATION NEEDS

Table 5 presents a listing of participants' psychosocial health support needs, as defined on page 1. Participants described the psychosocial health information they needed, as well as the type of psychosocial support they needed at the time of diagnosis, treatment, and after treatment. Notably, participants sought information about side effects and consequences of treatment and

did not request additional information about the diagnosis or treatment itself. Participants also favored peer support for themselves at the time of diagnosis, treatment, and after treatment and support groups only after treatment had ended. Also, YBCS were very concerned about support for their loved ones—partners, family members, and friends.

Table 5. Participants' Psychosocial Health Needs

STAGE	PSYCHOSOCIAL HEALTH NEEDS
Diagnosis	<p>Specific information about the following:</p> <ul style="list-style-type: none"> ■ Navigation of treatment options ■ Action plan/knowing what to expect ■ Information about hereditary cancer risks ■ Family planning ■ Stabilizing home life <p>Specific support in the following forms:</p> <ul style="list-style-type: none"> ■ Peer support at time of diagnosis ■ Spousal support ■ Support for family and friends ■ A point person to coordinate resources, childcare, research, and daily responsibilities at time of diagnosis ■ Hope and reassurance
Treatment	<p>Specific information about the following:</p> <ul style="list-style-type: none"> ■ Family planning ■ What to expect after treatment ■ Side effects ■ Communicating with treatment team ■ Managing emotions ■ Coping strategies <p>Specific support in the following forms:</p> <ul style="list-style-type: none"> ■ Peer support at time of treatment ■ Hope and reassurance ■ Stabilizing home life ■ Child care ■ Support for family and friends ■ Spousal support ■ Physical and logistical support ■ Confidentiality and privacy ■ A point person to coordinate resources, childcare, research, and daily responsibilities at time of treatment

Table 5. Participants' Psychosocial Health Needs (continued)

STAGE	PSYCHOSOCIAL HEALTH NEEDS
After Treatment	<p>Specific information about the following:</p> <ul style="list-style-type: none"> ■ Managing fear of recurrence ■ Adjusting to new body ■ Mourning loss of breast ■ Adjusting to "new normal" ■ Understanding "chemo brain" ■ Managing concerns about cancer risks to children <p>Specific support in the following forms:</p> <ul style="list-style-type: none"> ■ Peer support ■ Support group

Table 6 presents a listing of participants' reproductive health support needs, as defined on page 1. Participants described the reproductive health information they needed, as well as the type of reproductive health support they needed at the time of diagnosis, treatment, and after treatment. Notably, YBCS sought information about the effects of treatment and surgery on fertility, intimacy, and menopause. They specifically requested more time to process that information in making decisions regarding issues of fertility. Orthodox Jewish YBCS also described the need to address their questions about Jewish law regarding the effects of treatment on marital intimacy.

Table 6. Participants' Reproductive Health Needs

STAGE	REPRODUCTIVE HEALTH NEEDS
Diagnosis	<p>Specific information about the following:</p> <ul style="list-style-type: none"> ■ Anticipating changes in body image ■ Impact of breast cancer on intimacy and marriage ■ Timing of making fertility preservation decisions ■ Fertility preservation options ■ Anticipating early menopause ■ Questions of Jewish law ■ Consequences of treatment and surgery on fertility ■ Changes in sexuality and arousal ■ Long-term side effects of treatment and surgery <p>Specific support in the following forms:</p> <ul style="list-style-type: none"> ■ Peer support ■ Discussing sexuality with medical team ■ Hope

Table 6. Participants' Reproductive Health Needs (continued)

STAGE	REPRODUCTIVE HEALTH NEEDS
Treatment	<p>Specific information about the following:</p> <ul style="list-style-type: none"> ▪ Knowing what to expect during treatment ▪ Impact of treatment on fertility ▪ Fertility preservation options ▪ Changes in sexuality and arousal ▪ Treatment side effects related to sexual function ▪ Impact of cancer treatment on intimacy and marriage ▪ Long-term side effects of treatment and surgery ▪ Impact of treatment on early menopause ▪ Questions of Jewish law ▪ Anticipating menopause ▪ Changes in body image ▪ Timing of making fertility preservation decisions <p>Specific support in the following form:</p> <ul style="list-style-type: none"> ▪ Peer support
After Treatment	<p>Specific information about the following:</p> <ul style="list-style-type: none"> ▪ Timing of making fertility preservation decisions ▪ Impact of cancer treatment on intimacy and intimate relationships ▪ Treatment side effects related to sexual function ▪ Menopausal symptoms ▪ Knowing what to expect after treatment ▪ Dating ▪ Fertility and preservation options ▪ Questions of Jewish law ▪ Selecting an oncological gynecologist <p>Specific support in the following form:</p> <ul style="list-style-type: none"> ▪ Peer support

Barriers and Facilitators to Obtaining Information

Tables 7 and 8 present a listing of barriers and facilitators to obtaining psychosocial and reproductive health information identified by participants. Most importantly, participants reported that they needed increased knowledge and support to address the range of issues associated with a breast cancer diagnosis at a young age. Obstacles to addressing psychosocial health and reproductive health needs included lack of knowledge, information overload, financial constraints, and time constraints. Participants noted that Sharsheret's programs and resources were reliable and popular facilitators to obtaining the support they needed.

Table 7. Barriers and Facilitators to Obtaining Psychosocial Health Support

STAGE	BARRIERS	FACILITATORS
Diagnosis	<ul style="list-style-type: none"> ■ Not having complete information to help with decision making ■ Conflicting opinions ■ Lack of knowledge about rights in the workplace ■ Financial and insurance limitations ■ Not knowing how to focus search on internet/Information overload ■ Unhelpful advice from friends/ family ■ Communal support can be limited due to women's preference to be private about diagnosis ■ Time constraints ■ Difficulty managing emotions ■ Limited access to other young women with similar experiences ■ Communicating results of genetic testing to family members 	<ul style="list-style-type: none"> ■ Sharsheret resources/Web site ■ Sharsheret peer supporter ■ Sharsheret staff ■ Parents ■ Spouse ■ Internet ■ Medical team ■ Mental health care provider ■ Open communication with family ■ Family and friends
Treatment	<ul style="list-style-type: none"> ■ Unhelpful advice from friends/ family ■ Loss of independence ■ Difficulty managing activities of daily living ■ Medical team may not recognize impact of treatment on daily life activities ■ Lack of knowledge ■ Conflicting opinions ■ Difficulty communicating with family ■ Financial and insurance limitations ■ Lack of knowledge about rights in the workplace ■ Information overload ■ Communicating results of genetic testing to family members 	<ul style="list-style-type: none"> ■ Sharsheret resources ■ Sharsheret staff ■ Parents ■ Spouse ■ Medical Web sites ■ Jewish Family Service Agencies ■ Sharsheret peer supporter ■ Internet ■ Medical team
After Treatment	<ul style="list-style-type: none"> ■ Unhelpful advice ■ Lack of knowledge ■ Conflicting opinions ■ Financial and insurance limitations ■ Information overload ■ Difficulty communicating results of genetic testing with family members 	<ul style="list-style-type: none"> ■ Sharsheret resources ■ Internet ■ Medical team ■ Sharsheret peer support ■ Parents ■ Spouse

Table 8. Barriers and Facilitators to Obtaining Reproductive Health Support

STAGE	BARRIERS	FACILITATORS
Diagnosis	<ul style="list-style-type: none"> ■ Quality of life issues were deferred for purpose of beginning surgery or treatment quickly ■ Doctors were not concerned with fertility issues ■ Limited time and knowledge to make decisions about fertility preservation ■ Cost of fertility preservation ■ Concerns about impact on spouse ■ Difficulty discussing sexual concerns with medical team ■ Lack of libido/sexual discomfort ■ Lack of peers who understand issues of dating 	<ul style="list-style-type: none"> ■ Sharsheret genetic counselor ■ Sharsheret peer supporter ■ Speaking with women who experienced menopause ■ Medical team ■ Rebbetzin/rabbi's wife ■ Internet ■ Sharsheret resources, including Busy Box, Best Face Forward
Treatment	<ul style="list-style-type: none"> ■ Limited time to make decisions about fertility preservation ■ Cost of fertility preservation ■ Concerns about impact on spouse ■ Lack of concern from medical team about long-term consequences ■ Quality of life issues were deferred for purpose of beginning surgery or treatment quickly ■ Doctors not concerned with fertility issues ■ Lack of libido/sexual discomfort ■ Lack of information about symptoms of menopause 	<ul style="list-style-type: none"> ■ Sharsheret staff ■ Rebbetzin/rabbi's wife ■ Medical team ■ Internet ■ Sharsheret resources, including Pillow of Support, Busy Box, Best Face Forward ■ Articles about intimacy ■ Sharsheret peer supporter
After Treatment	<ul style="list-style-type: none"> ■ Obstetrician/gynecologist does not have enough knowledge about cancer-related issues ■ Lack of information about fertility preservation ■ Cost of fertility preservation ■ Concerns about impact on spouse ■ Doctors not concerned with fertility issues 	<ul style="list-style-type: none"> ■ Sharsheret resources, including peer-support ■ Rebbetzin/rabbi's wife ■ Medical team ■ Internet ■ Being your own advocate ■ Sharsheret peer supporter

Preferred Sources of Information

Focus group participants reported that they obtained information from a variety of sources, including health care providers, the Internet, and referrals (see Table 9 for preferred information sources).

Table 9. Preferred Sources of Information

INFORMATION CHANNEL	PREFERRED SOURCES
Health Care Providers	<ul style="list-style-type: none"> ■ Oncologist ■ Oncological gynecologist ■ Nurse practitioner ■ Genetic counselor ■ Fertility specialist ■ Mental health professional ■ Fertility clinicians ■ Nutritionist
Internet/Wireless	<ul style="list-style-type: none"> ■ Sharsheret ■ Search engines ■ American Cancer Society ■ Young Survival Coalition online chatroom
Support and Advocacy Groups	<ul style="list-style-type: none"> ■ Sharsheret ■ Young Survival Coalition ■ Gilda's Club ■ Chai Lifeline ■ American Cancer Society
Symposia/Teleconferences	<ul style="list-style-type: none"> ■ Sharsheret
Mass Media/Books	<ul style="list-style-type: none"> ■ Books (unspecified) ■ <i>MAMM</i> magazine ■ <i>Dr. Susan Love's Breast Book</i>
Interpersonal	<ul style="list-style-type: none"> ■ Sharsheret events ■ Peer supporter ■ Rabbi ■ Synagogues ■ Family ■ Spouse ■ Community groups ■ Friends ■ Human resource department ■ Midwife

Across all groups, participants often reported a preference for receiving information from peer supporters and medical team members.

Health Care Providers as Information Sources

Across groups, participants expressed varying levels of satisfaction with and trust in their health care providers as information sources. Though some participants reported having compassionate and responsive providers, most participants reported that they did not receive adequate psychosocial and reproductive health information from providers. The following reasons were commonly reported:

- Providers’ focus on treating the disease and keeping patients alive
- Providers’ secondary focus on patients’ emotional and social well-being
- Providers’ tendency to dismiss or ignore women’s fertility concerns
- Providers’ lack of time to spend with patients
- Providers’ apparent discomfort discussing sexual concerns

Some women noted that they allowed their health care providers to guide decision making, particularly at time of diagnosis and treatment, because they felt too fearful or overwhelmed to take the time they needed to research their options.

Many participants in both groups stressed the need for someone to help them navigate the health care system once their cancer was diagnosed. Participants stressed the need for providers to help them understand reproductive health issues and noted repeatedly that because providers did not offer information, they missed their opportunity for fertility preservation or had to proactively seek information from providers or other sources.

FEEDBACK ON SHARSHERET’S PSN AND GFL PROGRAMS

The moderator asked participants a series of questions about the following:

- Information provided to them through the PSN and GFL programs
- Most and least helpful components of the PSN and GFL programs related to providing psychosocial and reproductive health information and support
- Recommended modifications to improve PSN and GFL content/information

Tables 10 and 11 present findings from feedback on each program.

Table 10. Findings From Discussion of PSN Content

	OVERALL THOUGHTS ABOUT PROGRAM INFORMATION/CONTENT	MOST AND LEAST HELPFUL PROGRAM INFORMATION/ CONTENT	RECOMMENDED MODIFICATIONS TO PROGRAM INFORMATION/CONTENT
Psychosocial Health Information	<ul style="list-style-type: none"> ▪ Participants noted that having a Sharsheret peer supporter was reassuring and helpful in learning what to expect after a cancer diagnosis and throughout treatment ▪ Most participants found the response time to their inquiries to be very quick and reliable 	<p><u>Most helpful:</u></p> <ul style="list-style-type: none"> ▪ Peer supporter ▪ Transcripts from Sharsheret symposia and teleconferences ▪ Information kit ▪ Sharsheret’s Busy Box for parents of young children ▪ Sharsheret’s Pillow of Support for women postsurgery ▪ Sharsheret’s Best Face Forward kit addressing cosmetic side effects of treatment 	<p><u>Recommendations:</u></p> <ul style="list-style-type: none"> ▪ Stagger the delivery of the resources to decrease information overload ▪ Include an index of resources and materials to assist recipients in viewing the resources most relevant to them ▪ Color code resources based on time of diagnosis, treatment, and after treatment

Table 10. Findings From Discussion of PSN Content (continued)

	OVERALL THOUGHTS ABOUT PROGRAM INFORMATION/CONTENT	MOST AND LEAST HELPFUL PROGRAM INFORMATION/ CONTENT	RECOMMENDED MODIFICATIONS TO PROGRAM INFORMATION/CONTENT
	<ul style="list-style-type: none"> ■ Overall, participants preferred connecting with their peer supporter over the phone, though they recognized that the next generation of women may prefer e-mail, texting, or Facebook ■ Participants turned to their peer supporters for information, validation, and comfort ■ Although participants found all of the components of Sharsheret’s PSN program helpful, many felt that the timing of delivery of the resources was too close to diagnosis; receiving all the information and resources in the information kit Sharsheret mails to new callers may have been too overwhelming for some ■ Some participants expressed that there was too much information included in the information kit overall 	<ul style="list-style-type: none"> ■ Addressing hereditary concerns from a Jewish perspective ■ Women calling Sharsheret as a Jewish-specific organization found that their expectations were met and appreciated the Jewish connection, culturally and spiritually <p><u>Least helpful:</u></p> <ul style="list-style-type: none"> ■ Timing of the delivery of resources too close to diagnosis ■ Too much printed material in information packet 	<ul style="list-style-type: none"> ■ Include concrete tips and helpful hints on Sharsheret’s Web site addressing what to expect each step of the way ■ Recruit medical expert to address symptoms of menopause ■ Assemble information into one booklet/packet ■ Provide additional survivorship support and resources after treatment, including information on menopause, “chemo brain,” nutrition, screening, fertility, and life posttreatment
Reproductive Health Information	<ul style="list-style-type: none"> ■ Participants reported that having a peer supporter was most useful; posttreatment matches were the most useful ■ Participants would have liked to receive more information about reproductive health needs, including management of menopausal symptoms, information on dating, and navigating relationships with their partners 	<p><u>Most helpful:</u></p> <ul style="list-style-type: none"> ■ Peer support during diagnosis, treatment, and posttreatment <p><u>Least helpful:</u></p> <ul style="list-style-type: none"> ■ Information seemed too general, not specific 	<p><u>Recommendations:</u></p> <ul style="list-style-type: none"> ■ Provide more information about dating for single women ■ Provide resources that address intimacy and sexuality ■ Include more information on “chemo brain” ■ Recruit medical expert to address symptoms of menopause ■ Provide tips from other women for managing menopausal symptoms

Table 11. Findings From Discussion of GFL Content

	THOUGHTS ABOUT PROGRAM INFORMATION/CONTENT	MOST AND LEAST HELPFUL PROGRAM INFORMATION/CONTENT	RECOMMENDED MODIFICATIONS TO PROGRAM INFORMATION/CONTENT
Psychosocial Health Information	<ul style="list-style-type: none"> Participants noted that having a Sharsheret peer supporter was reassuring and helpful in learning what to expect after a cancer diagnosis and throughout treatment Participants found it helpful to have access to an organization and a genetic counselor Participants noted a lack of knowledge about insurance coverage for genetic testing 	<p><u>Most helpful:</u></p> <ul style="list-style-type: none"> Information kit Peer supporter Access to genetic counselor for follow-up questions <p><u>Least helpful:</u></p> <ul style="list-style-type: none"> Some women did not access the transcripts because they were too lengthy to read Lack of knowledge about insurance coverage 	<p><u>Recommendations:</u></p> <ul style="list-style-type: none"> Generate talking points on how to discuss genetic test results with family members Facilitate conference call with family to discuss hereditary breast cancer Provide additional information and screening for BRCA mutations for reproductive purposes Provide additional information about hereditary breast cancer and gene testing
Reproductive Health Information	<ul style="list-style-type: none"> Participants reported that having a peer supporter was most useful in discussing reproductive health issues, menopausal symptoms, lack of libido, and other sexual concerns 	<p><u>Most helpful:</u></p> <ul style="list-style-type: none"> Peer supporter <p><u>Least helpful:</u></p> <ul style="list-style-type: none"> There were no specific comments for this category 	<p><u>Recommendations:</u></p> <ul style="list-style-type: none"> Provide more financial and medical insurance information Provide support and information for spouse Provide additional information and screening for BRCA mutations for reproductive purposes Design resources addressing the impact of breast cancer on a Jewish home, with a focus on family, companionship, and spirituality

ACCESS AND DELIVERY OF PSN AND GFL PROGRAMS

Outreach and Access to PSN and GFL Programs

Focus group participants commonly reported that they learned about Sharsheret programs from family members and/or friends. Also, participants stated that they would commonly hear about programs and how to access the programs (by calling Sharsheret directly) from more than one individual in their support system. Participants reported that they most commonly accessed the PSN and GFL programs by calling Sharsheret and then going through the initial intake call with clinical staff, as opposed to accessing programs through Sharsheret’s Web site.

Participants also shared their thoughts about Sharsheret’s current outreach methods to improve women’s awareness and access to Sharsheret programs. They suggested that Sharsheret improve outreach by participating in clergy trainings and distributing materials at venues accessed by

young Jewish women. Participants also made recommendations about how Sharsheret can better facilitate women’s continued involvement in the PSN and GFL programs. Table 12 provides a summary of those findings. Responses that duplicated outreach that Sharsheret already performs have been omitted.

Table 12. Learning About Programs and Recommendations for Improving Outreach and Access to PSN and GFL Programs

HOW PARTICIPANTS LEARNED OF SHARSHERET PROGRAMS	RECOMMENDATIONS TO ENHANCE OUTREACH AND PARTICIPATION IN PSN AND GFL	RECOMMENDATIONS TO IMPROVE WOMEN’S CONTINUED PARTICIPATION IN PSN AND GFL
<ul style="list-style-type: none"> ■ Word of mouth (most common) ■ Internet ■ Physician referral ■ Parlor meetings ■ Brochure in Mikvah ■ Social media ■ Jewish organization ■ Rabbi/clergy 	<ul style="list-style-type: none"> ■ Distribute literature in imaging centers, Jewish community centers, spas, pediatricians’ offices, manicure salons, college campuses ■ Publicize on electronic mailing lists related to cancer and young women ■ Participate in trainings for rabbis/clergy ■ Organize mailings to school principals to share with parents 	<ul style="list-style-type: none"> ■ Generate face-to-face interactions among Sharsheret participants ■ Arrange small in-person reunions ■ Publicize individual stories/testimonials ■ Send more follow-up e-mails ■ Organize more in-person roundtable discussions ■ Publicize new advances in research and long-term follow-up care ■ Respond to conflicting reports in the media about cancer research and treatments ■ Organize activities in Jewish communities hard hit by breast cancer

Methods for Delivering Sharsheret PSN and GFL Programs

The PSN and GFL programs are initially delivered by telephone. Women describe their psychosocial and reproductive health concerns to the clinical staff, who then match callers with a peer supporter (for PSN and GFL) or Sharsheret’s genetic counselor (for GFL). Across groups, participants reported that they preferred to connect with Sharsheret over the phone rather than online, as this method of program delivery is warmer and more informative and callers have the opportunity to ask questions that are unique to their circumstances. When asked whether there were barriers to connecting to clinical staff on the telephone, participants noted that staff may be generally unavailable after ordinary business hours.

Several participants reported using Sharsheret’s Web site to learn more about Sharsheret’s programs. Participants said that an advantage of connecting to Sharsheret on the Web is that they can visit Sharsheret online at any time, particularly after business hours or when their children are in bed, to gather program information. Another value of visiting the Sharsheret Web site for program information is that women can learn about programs and resources privately. When asked whether there were barriers to connecting to the PSN or GFL programs online, participants said that women who are less technologically savvy may have difficulty using the Web site to access information and resources.

Recommendations for PSN and GFL Program Delivery Methods

In all groups, participants stressed the need to deliver the PSN and GFL programs and resources through multiple channels—both online and by telephone. Table 13 presents participants' recommendations for modifications to, or additional methods of, delivery to improve the PSN and GFL programs.

Table 13. Responses to Alternative Delivery Methods of PSN and GFL Program Components

<p>Online Intake Form (PSN, GFL)</p>	<p><i>New callers complete breast cancer histories and enter personal background information on a secure electronic form after general business hours and before a clinical staff person returns their call.</i></p> <p>Overall, participants appreciated this option to initiate the intake process but noted that they would not prefer for an online intake to replace completely the telephone intake process with clinical staff. Some women preferred an initial online contact because it alleviated some of the emotional response when speaking with a clinical staff member for the first time. Other participants noted that the online intake form allowed them to take action immediately, when they first visited the Web site, leaving them feeling empowered. Participants specified that any online intake form should be user friendly and should include checkoff boxes rather than open fields. Participants also noted that the online intake form should clearly note that all information shared online was secure and confidential.</p>
<p>Live Chat Technology (PSN, GFL)</p>	<p><i>New callers could request a live chat on Sharsheret's Web site with a clinical staff member, rather than (or in addition to) speaking with a staff member on the phone.</i></p> <p>Participants had strong reactions to the addition of live chat technology to Sharsheret's Web site. Across the board, women reported that a pop-up box asking whether they would like to speak with someone felt intrusive. Participants preferred a checkbox on the Web site navigation bar with which they could opt to speak with a live chat operator. Some participants noted they would not use this option because they were uncertain of the background or training of the operator. Participants noted that they would not want to feel as though they were connecting with a call center. Participants who appreciated this option felt that it offered immediate contact with Sharsheret and was helpful for those women who preferred greater privacy.</p>
<p>Video Testimonials (PSN)</p>	<p><i>New callers access videos of other survivors' stories posted on Sharsheret's Web site, rather than (or in addition to) connecting with peer supporters through the PSN program.</i></p> <p>Across the groups, participants most appreciated this option. Participants noted that hearing other women's stories would feel validating and hopeful. Participants suggested organizing the videos into categories, e.g., diagnosis, treatment, after treatment, surgery, addressing needs of children, intimacy, fertility, and hereditary concerns.</p>
<p>Ask-the-Expert Web Site Feature (PSN, GFL)</p>	<p><i>Callers could ask questions to online experts, rather than (or in addition to) participating in Sharsheret teleconferences on topics relevant to YBCS.</i></p> <p>Participants had mixed reactions to offering the availability of an online expert. Participants suggested that the topics need to be current and relevant to most women in the Sharsheret community. Some expressed concern that submitting a question to an expert online could jeopardize their privacy. Participants suggested that e-mail reminders be sent to encourage Sharsheret callers to visit the Web site to interact with the expert to enhance participation.</p>
<p>Online Pedigree (GFL)</p>	<p><i>Callers complete family pedigrees online, rather than (or in addition to) discussing the pedigree with Sharsheret's genetic counselor through the GFL program.</i></p> <p>In both focus groups, participants appreciated the option of completing an online pedigree as a tool to generate family histories. Participants noted the need for a disclaimer that all pedigree information would be kept secure and confidential.</p>

Table 13. Responses to Alternative Delivery Methods of PSN and GFL Program Components (continued)

<p>Family Conference (GFL)</p>	<p><i>Callers could request telephone-based conferences with family members, moderated by Sharsheret’s genetic counselor or a clinical staff member, to discuss hereditary breast cancer concerns, rather than (or in addition to) individual consultations with Sharsheret’s genetic counselor through the GFL program.</i></p> <p>Participants appreciated this option because it would alleviate some of the pressure in communicating critical genetic information with affected family members. Participants noted it was important to have a genetic counselor or clinical staff member on the call to answer questions responsibly and to help moderate the discussion. Participants also noted the benefit of communicating the same information to all family members at once, rather than having individual conversations with different family members. Although participants noted it would be preferable to have this meeting in person, a family conference could also take place over the phone if family members lived in different States.</p>
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SUMMARY OF MAJOR FINDINGS

Psychosocial health information and support needs

- Jewish YBCS need information about what to expect physically and emotionally after diagnosis. Women prefer to receive this information in a way that is tailored and most relevant to them without experiencing information overload. Women need to connect with a peer supporter immediately after diagnosis for guidance, validation, comfort, and hope.
- Across groups participants said that they need information to support their spouses and children and more guidance on the impact of the diagnosis on the family routine.
- Because Jewish women are at greater risk of BRCA-1 and BRCA-2 gene mutations, they need information about the hereditary risk of breast cancer and related cancers.
- Focus group participants commonly reported that YBCS need information about their rights as cancer survivors in the workplace.

Barriers to obtaining psychosocial health information and support

- Women noted that a barrier to obtaining psychosocial health information is feeling overwhelmed by the amount of information that they receive immediately upon diagnosis.
- Another barrier to obtaining psychosocial health information is the limited time that women have to research their treatment and health care options, coupled with feelings of fear and anxiety. Many participants said that they would appreciate a navigator or peer supporter to help them anticipate next steps in their breast cancer journey.
- Lack of financial resources and insurance limitations are obstacles in obtaining psychosocial information and support for some YBCS.
- Reluctance to sacrifice independence is a barrier to obtaining support during treatment.

Facilitators to obtaining psychosocial health information and support

- Participants commonly said that Sharsheret programs and staff are important supports and facilitators in helping address YBCS needs and providing psychosocial health information.
- Focus group participants commonly stated that they feel great warmth, compassion, and reassurance from personalized phone calls with Sharsheret’s clinical staff members and

peer supporters. Women noted that a peer supporter is often the first resource to them obtaining health information and support that they need.

- Friends and family are key to Jewish YBCS receiving important support. Additionally, women said that medical team members can help them to obtain psychosocial health information and support, however, participants not all medical teams are equally available, compassionate, and sensitive.

Reproductive health information and support needs

- YBCS need timely information regarding the impact of breast cancer treatment on fertility, fertility preservation options, and the financial costs of these options before treatment or risk losing some of those options once treatment has begun.
- Women said that they need information about the impact of breast cancer treatment on sexuality and intimacy due to changes in body image and the onset of early menopause.
- Information and resources are needed to address the side effects of early menopause.
- Participants said that women without partners need information and resources on dating and relationships during and after a diagnosis of breast cancer; YBCS with partners need resources to address the sexual and reproductive health needs of their partners.
- Jewish YBCS need information on Jewish law as related to reproductive health and fertility options.

Barriers to obtaining reproductive health information and support

- Providers' pressure for YBCS to make immediate decisions regarding surgery and treatment is a barrier to making important reproductive health decisions during or before cancer treatment.
- Lack of information on fertility preservation options before treatment is a barrier to Jewish YBCS making reproductive health decisions.
- The perception that medical team members are more concerned with life-saving treatment decisions versus YBCS quality of life and reproductive/sexual health concerns of their young patients is a barrier to talking about reproductive health issues with providers. Additionally, the perception that one's medical team lacks concern or compassion to address sexuality, menopause and intimacy is a barrier to discussing these matters with providers.
- The financial cost associated with some fertility preservation options is a barrier to exploring fertility health options.

Facilitators to obtaining reproductive health information and support

- Sharsheret staff and programs are an important resource for young women who want to obtain reproductive health information and support. Focus group participants commented on the warmth, compassion, and reassurance they receive in personalized phone calls with Sharsheret's clinical staff members and peer supporters; they stated that a peer supporter is often the first necessary resource.
- Focus group participants said that medical providers are important to helping them make informed decisions about their reproductive health.
- Spiritual leaders, rabbis, or rebbetzins (rabbis' wives) are also important facilitators for some women to get support and guidance on Jewish law relating to fertility.
- Women commonly reported using the Internet to obtain reproductive health information.

Need for multimodal sources of psychosocial and reproductive information

- Focus group participants said that they prefer to receive psychosocial and reproductive health information and support in diverse ways, including information from their health care providers, the Internet, peer supporters, support groups, symposia and teleconferences, and mass media.

Ashkenazi Jewish women's need for a culturally relevant organization

- It is important that Jewish YBCS have an organization attentive to their needs as Jewish women. Women said that having a peer supporter with a similar background helps validate them and helps them feel less isolated.
- It is imperative that Jewish YBCS have culturally appropriate counseling on genetic and BRCA mutation concerns with a genetic counselors who can help them make decisions for themselves and their families, particularly for women at high risk for breast cancer.
- Focus group participants reported that Sharsheret's culturally sensitive materials and staff are key to understanding Jewish YBCS' concerns and the need for confidentiality in diverse Jewish communities.

Expanding Sharsheret's PSN and GFL resources and outreach

- Disseminating information through word of mouth is the common (and a valued) method to share information about Sharsheret's services. Jewish YBCS often hear about Sharsheret from friends, family, medical providers, genetic counselors, Jewish organizations, and clergy.
- Focus group participants said that Sharsheret can expand its outreach efforts by placing organizational materials in locations that attract young people, including pediatricians' offices, schools, spas and manicure salons, and college campuses. Women said that Sharsheret should continue its outreach to rabbis, school principals, Jewish organizations, and health care providers.

MODIFICATIONS TO PSN AND GFL

In all focus groups participants discussed potential modifications to the content and delivery of PSN and GFL program components, including the availability of online intake forms, a live chat option on the Web site, video testimonials, an interactive expert column, the availability of online pedigrees, and family conferences with a genetic counselor or clinical staff member. Those recommendations are summarized in Table 14. Overall, participants said that it is critical for Sharsheret to maintain its warmth and personalized support while using online resources and social media, particularly as the organization explores the use of technology in alternative methods of program delivery.

Table 14. Recommended Modifications to PSN and GFL

CONCERN	RECOMMENDED MODIFICATIONS
<p>Accessing PSN and GFL Programs</p>	<ul style="list-style-type: none"> ■ Disseminate program materials where young Jewish women spend a lot of time, such as pediatricians' offices, schools, spas, and manicure salons ■ Increase the frequency of face-to-face interactions, including conferences, reunions, and roundtable discussions for YBCS ■ Modify print and online materials to include: <ul style="list-style-type: none"> – YBCS video testimonials – New advances in research for YBCS – Analysis of conflicting media reports on screening and treatment for YBCS
<p>Delivery of PSN and GFL Programs</p>	<ul style="list-style-type: none"> ■ Incorporate live chat technology to make an operator available to YBCS after hours in an effort to address the concerns of those who seek greater privacy or may need to access Sharsheret after general business hours ■ Include an online intake form on Sharsheret's Web site (with checkoff boxes rather than open fields) for YBCS to complete as the first step to receive support through the PSN and GFL programs ■ Offer family conference calls for YBCS, moderated by Sharsheret's genetic counselor or clinical staff member, to help YBCS address their psychosocial and reproductive health needs, particularly as they relate to hereditary cancers ■ Include an online pedigree on Sharsheret's Web site that YBCS can use in discussions with Sharsheret's genetic counselor or their health care providers and share with family members ■ Stagger the information presented to YBCS so that women do not receive all resources and information about treatment and survivorship at the time of diagnosis, which can result in information overload ■ Color code resources sent to YBCS based on the time of diagnosis, treatment, and posttreatment and include an index of the materials delivered in information kits sent to new callers
<p>Improving Psychosocial Health Components of the PSN and GFL Programs</p>	<ul style="list-style-type: none"> ■ Include a page of concrete tips, helpful hints, and what to expect for YBCS in new callers' information kits and online ■ Organize a teleconference to address the financial and insurance concerns of YBCS; information about finances and insurance can be included in an information kit distributed to teleconference participants. ■ Craft talking points for YBCS about how to discuss genetic test results with other family members ■ Include video testimonials online to enhance psychosocial and reproductive health support, organized by category (e.g., diagnosis, treatment, after treatment/survivorship, surgery, intimacy, children, fertility, sexuality, work, and hereditary cancer concerns) ■ Include an ask-the-expert feature online to address specific YBCS psychosocial health concerns

Table 14. Recommended Modifications to PSN and GFL (continued)

CONCERN	RECOMMENDED MODIFICATIONS
<p>Improving Reproductive Health Support Components of the PSN and GFL Programs</p>	<ul style="list-style-type: none"> ■ Develop additional information about screening for BRCA gene mutations for reproductive purposes and make this information available to YBCS online ■ Invite medical experts to address managing symptoms of early onset menopause online, via a teleconference, or in resources for YBCS to be included in new callers' information kits ■ Direct single women to the online transcript of Sharsheret's teleconference "Dating and Disclosure" at the time of first contact with Sharsheret; include a hard copy of this transcript in YBCS information kits, if preferred ■ Develop or include additional support and resources for spouses or partners of YBCS in navigating marital/intimate relationships ■ Developing a booklet that addresses issues of sexuality, intimacy, fertility, and menopause from the perspectives of both Jewish YBCS and Jewish men as part of Sharsheret's culturally relevant resource series ■ Include an ask-the-expert feature online to address specific YBCS reproductive health concerns

REFERENCES

- American Cancer Society. (2009). *Cancer facts & figures for African Americans 2009–2010*. Atlanta, GA: American Cancer Society.
- Bloom, J. R., Stewart, S. L., Chang, S., & Banks, P. J. (2004). Then and now: Quality of life of young breast cancer survivors. *Psycho-Oncology*, *13*, 147–160.
- Bonnier, P., Romain, S., Charpin, C., Lejeune, C., Tubiana, N., Martin, P.-M., et al. (1995). Age as a prognostic factor in breast cancer: Relationship to pathologic and biologic features. *International Journal of Cancer*, *62*(2), 138–144.
- Chung, M., Chang, H. R., Bland, K. I., & Wanebo, H. J. (1996). Younger women with breast carcinoma have a poorer prognosis than older women. *Cancer*, *77*, 97–103.
- Colleoni, M., Rotmensz, N., Robertson, C., Orlando, L., Viale, G., Renne, G., et al. (2002). Very young women (<35 years) with operable breast cancer: Features of disease at presentation. *Annals of Oncology*, *13*, 273–279.
- Gabriel, C. A., & Domchek, S. M. (2010). Breast cancer in young women. *Breast Cancer Research*, *12*, 212.
- Greenbaum, T. L. (1998). *The handbook for focus group research* (2nd ed.). Thousand Oaks, CA: Sage Publications, Inc.
- Krueger, R. A. (1994). *Focus groups: A practical guide for applied research* (2nd ed.). Thousand Oaks, CA: Sage Publications, Inc.
- Maggard, M. A., O'Connell, J. B., Lane, K. E., Liu, J. H., Etzioni, D. A., Ko, C. Y., et al. (2003). Do young breast cancer patients have worse outcomes? *Journal of Surgical Research*, *113*, 109–113.
- National Cancer Institute. (2009). *Genetics of breast and ovarian cancer* (PDQ). Retrieved August 16, 2010, from <http://www.cancer.gov/cancertopics/pdq/genetics/breast-andovarian/HealthProfessional>
- Thewes, B., Butow, P., Girgis, A., & Pendlebury, S. (2004). The psychosocial needs of breast cancer survivors: A qualitative study of the shared and unique needs of younger versus older survivors. *Psycho-Oncology*, *13*, 177–189.



BREAST CANCER IN YOUNG WOMEN PROJECT

APPENDICES





BREAST CANCER IN YOUNG WOMEN PROJECT

APPENDIX A

RECRUITMENT TOOLS



SiSHARSHERET FOCUS GROUPS: TESTING THE PEER SUPPORT NETWORK®
AND GENETICS FOR LIFE® PROGRAMS
RECRUITMENT SCREENING SCRIPT

Hello. My name is (insert name of recruiter) and I work with Sharsheret. We are working with the Centers for Disease Control and Prevention (CDC) and company called ICF Macro to help the CDC improve information to support the needs of young breast cancer survivors.

As part of this project we are planning a 90-minute to 2-hour focus with up to nine women. We would like for you to participate in this focus group. In this group, we will discuss young breast cancer survivors' information needs and ask your thoughts about two of Sharsheret's Links programs, the Peer Support Network® and Genetics for Life®.

Anyone who participates in the discussion will be reimbursed for reasonable travel expenses in appreciation of her time and willingness to participate. Participants will be required to present documentation of these expenses (e.g., taxi receipts, train ticket, documentation of gas/mileage), and Sharsheret will provide up to \$100 (in the form of a check made out to you) to cover them. The groups will either take place at Sharsheret's office in Teaneck, New Jersey, or online using webinar and chat technology. Would you be interested in participating?

- If yes, continue.
- If no, thank the respondent: [We regret to hear that you are not interested in participating in our focus groups, but we appreciate your interest in our project. Thank you for your time.]

1. May I ask you a few questions to determine whether or not you can participate in the focus groups?

- Yes
- No (*Thank the person and end the conversation.*)

2. What is your current age?

- Under 18 (*Read exclusion script.*)
- _____ (*write age*)
- 55+ (*Read exclusion script.*)

3. In our discussion groups, we may talk about the connection that sometimes exists between being Jewish and increased risk for breast and ovarian cancer. Some of our programs address issues of heredity and the genetics of breast and ovarian cancer associated with certain genetic mutations. These genetic mutations, often referred to as BRCA mutations, are more common among Jews of Ashkenazi ethnic descent than individuals of other backgrounds. We want to ensure that we hear the perspectives of women who are likely to encounter these issues, as well as those of women who may not. Therefore, we would like you to share with us which category best describes you. Which one of these groups would you say BEST represents your background?

- My genetic background includes Ashkenazi descent
- My genetic background does not include Ashkenazi descent
- I am unsure whether my genetic background includes Ashkenazi descent

4. **Were you diagnosed with breast cancer before your 45th birthday?**
 Yes
 No (*Read exclusion script.*)
5. **Have you participated in Sharsheret's Peer Support Network[®] or Genetics for Life[®] programs?**
 Yes, the Peer Support Network
 Yes, Genetics for Life
 Yes, both the Peer Support Network and Genetics for Life
 No (*Read exclusion script at end.*)
6. **Are you willing to participate in a discussion about the needs of breast cancer survivors?**
 Yes
 No (*Read exclusion script.*)
7. **Would you be willing and able to come to Sharsheret's offices in Teaneck, New Jersey, for a discussion group?**
 Yes (*skip to scheduling section*)
 No (*skip to question 8*)
8. **Would you be willing and able to participate in an online discussion group?**
 Yes
 No (*Read exclusion script.*)

Exclusion Script: We appreciate your willingness to answer each of these questions. Unfortunately, one of your answers does not meet our requirements for participation in the focus group. Thank you for your time.

Based upon your answers, we would like you to participate in this focus group. The discussion will last about 90 minutes to two hours.

IN-PERSON FOCUS GROUP SCRIPT

The focus group will be held at Sharsheret's offices in Teaneck, NJ. The focus groups will take place on November 1 and 9. Which of these dates are you available?

- November 1
- November 9
- None [TERMINATE, THANK PERSON FOR HIS/HER TIME AND END CONVERSATION.]

ONLINE FOCUS GROUP SCRIPT

The online focus groups will be held on November 15 and 16. We will send you an email prior to the groups with information about how to log in and participate. . Which of these dates are you available?

- November 15
- November 16

- None [TERMINATE, THANK PERSON FOR HIS/HER TIME AND END CONVERSATION.]

Thank you for your interest in a young breast cancer survivor focus group. A Sharsheret staff member will contact you again, closer to the date, to confirm your participation.

Please provide your contact information below. We will ONLY use this information to contact you about this focus group.

Full name:

Telephone:

Email Address:

Mailing address:



BREAST CANCER IN YOUNG WOMEN PROJECT

APPENDIX B

INFORMED CONSENT



SHARSHERET FOCUS GROUPS: TESTING THE PEER SUPPORT NETWORK®
AND GENETICS FOR LIFE® PROGRAMS
INFORMED CONSENT

On behalf of the Centers for Disease Control and Prevention (CDC), and in collaboration with a company called ICF Macro, Sharsheret is conducting focus groups to gain information to help us improve information to support the needs of young breast cancer survivors. We will discuss your information needs and ask your thoughts about several of the programs we offer to women like you. This focus group will take no more than 2 hours of your time. If you agree to participate in the group, here are the things you should know:

- Your participation in this focus group is voluntary. You may choose to leave the focus group at any time for any reason.
- You can choose not to answer a question at any time.
- Your name and answers to these questions will be kept confidential.
- The focus group discussion will be audio taped.
- A note-taker will observe the group to take notes. An observer from our research partner, ICF Macro, is present as well. There are no observers from CDC present today. Each observer has signed an agreement to keep everything they hear today confidential.
- Your input in this focus group poses few, if any risks to you. The risks that you may experience are feeling uncomfortable talking about your needs for information related to sexuality, fertility, and breast cancer.
- Since you and the other participants may share highly personal information, we ask that you do not discuss anything you hear with anyone who did not participate in the group.
- The benefit of this focus group to you is that your input will help Sharsheret improve the Peer Support Network® and Genetics for Life® programs, and will help CDC to understand the needs of young breast cancer survivors better.
 - You will be reimbursed for your reasonable travel expenses in appreciation of your time and willingness to participate. You will be required to present documentation of these expenses (e.g., taxi receipts, train ticket, documentation of gas/mileage), and Sharsheret will provide up to \$100 (in the form of a check made out to you) to cover them.

Contact information: If you have questions about the study, please call Ashani Johnson-Turbes, the project manager at ICF Macro at 404-321-3211 or Janet Griffith ICF Macro IRB Chair at 703-225-2243.

Please sign below to indicate that you have read the above and agree to take part in this focus group.

Please print your name _____
Please sign your name _____
Witness Signature _____
Date _____

THANK YOU



BREAST CANCER IN YOUNG WOMEN PROJECT

APPENDIX C

PRE-DISCUSSION INFORMATION SHEET



**SHARSHERET FOCUS GROUPS: TESTING THE PEER SUPPORT NETWORK
AND GENETICS FOR LIFE PROGRAMS
PRE DISCUSSION INFORMATION SHEET**

We appreciate your taking the time to give us some background information. Please complete this sheet and hand back to the discussion moderator before the focus group starts. We will not report any of your answers by name, so please do not write your name on this piece of paper.

Thank you.

1. What is your date of birth? (Month/Day/Year) _____

2. What is your highest education level completed?

- 6th Grade or less
- 7th–8th Grade
- 9th–11th Grade
- 12th Grade without a High School diploma
- 12th Grade with a High School diploma
- GED
- Some college
- Associate degree
- Completed college (4 year degree)
- Graduate or professional degree (Master's degree or higher)

3. What is your employment status? (Check all that apply)

- Full-time
- Part-time
- Presently not employed outside the home, looking for work
- Presently not employed outside the home, not looking for work
- Student
- Laid Off
- Disabled

4. What do you do for a living? What is your occupation/profession?

5. Please choose the answer that best describes your relationship status.

- Married
- Divorced
- Widowed
- Separated
- Never married
- Unmarried couple

6. Do you have any children?

a. If so, how many? _____

7. When were you diagnosed with breast cancer? (Month/Year) _____

8. What kind of breast cancer were you diagnosed with?

- DCIS – Ductal Carcinoma In Situ
- IDC – Invasive Ductal Carcinoma
- IDC - Other Type
 - Tubular Carcinoma of the Breast
 - Medullary Carcinoma of the Breast
 - Mucinous Carcinoma of the Breast
 - Papillary Carcinoma of the Breast
 - Cribriform Carcinoma of the Breast
- ILC – Invasive Lobular Carcinoma
- Inflammatory Breast Cancer
- LCIS – Lobular Carcinoma In Situ
- Paget's Disease of the Nipple
- Phyllodes Tumors of the Breast
- Unknown**

9. What was the stage of your tumor(s) at diagnosis?

- Stage 0
- Stage I
- Stage IIA
- Stage IIB
- Stage IIIA
- Stage IIIB
- Stage IIIB
- Stage IV
- Unknown**

10. Which of the following types of treatment have you received?

- Surgery
 - Breast-conserving surgery (lumpectomy)
 - Mastectomy
 - Lymph node dissection
 - Sentinel lymph node dissection
 - Prophylactic ovary removal
 - Breast reconstruction
- Chemotherapy
- Radiation Therapy
- Hormonal Therapy
 - Aromatase inhibitors:
 - Arimidex (chemical name: anastrozole)
 - Aromasin (chemical name: exemestane)
 - Femara (chemical name: letrozole)
 - SERMs (Selective Estrogen Receptor Modulators):
 - Tamoxifen

- Evista (chemical name: raloxifene)
- Fareston (chemical name: toremifene)
- ERDs (Estrogen Receptor Downregulators):
 - Faslodex (chemical name: fulvestrant)
- Targeted Therapies
 - Herceptin (chemical name: trastuzumab)
 - Tykerb (chemical name: lapatinib)
 - Avastin (chemical name: bevacizumab)
- Unknown**

Thank you!



BREAST CANCER IN YOUNG WOMEN PROJECT

APPENDIX D

OBSERVER CONFIDENTIALITY FORM



SHARSHERET FOCUS GROUPS: TESTING THE PEER SUPPORT NETWORK®
AND GENETICS FOR LIFE® PROGRAMS
OBSERVER CONFIDENTIALITY FORM

Sharsheret is conducting a series of focus groups on behalf of the Centers for Disease Control and Prevention in collaboration with ICF Macro. These groups are being held to gain information to help us improve information to support the needs of young Jewish breast cancer survivors, particularly those of Ashkenazi descent.

Because of concerns about protecting participant confidentiality and fostering an atmosphere of respect for the participants, it is important for all persons who intend to observe the focus groups to accept the following:

- Observers should refrain from any conduct that will disrupt the discussion or interfere with the focus group process.
- Observers are present to observe only and not to take part in the discussion process.
- After the focus groups, observers should not discuss who participated in the group discussion. Observers should not discuss what was said by individual participants with others who were not also observers.
- After the focus groups, observers should only have discussions about the session that are general and not specific in nature.
- Observers should refrain from engaging in conversations while the focus group is in session so as not to disturb the process of moderating or notetaking of the focus groups.

Your signature below indicates that you understand and accept these conditions.

Signature:

Date:



BREAST CANCER IN YOUNG WOMEN PROJECT

APPENDIX E

TRAVEL REIMBURSEMENT REQUEST FORM





SHARSHERET

1086 Teaneck Road, Suite 3A
Teaneck, NJ 07666
P 866 474 2774 | 201 833 2341
F 201 837 5025
www.sharsheret.org

TRAVEL REIMBURSEMENT REQUEST FOR SHARSHERET FOCUS GROUP

Name: _____

Address: _____

City/State/Zip: _____

E-mail Address: _____

Date of Travel: _____

Amount Requested for Travel Reimbursement: \$_____

Expense Description: _____

Please attach original receipts to this form and return to:

Sharsheret
1086 Teaneck Road, Suite 3A
Teaneck, NJ 07666

Thank you for participating in this evening's program. Your feedback will help us shape future Sharsheret programs and services.



BREAST CANCER IN YOUNG WOMEN PROJECT

APPENDIX F

RESOURCE LIST



SHARSHERET FOCUS GROUPS: TESTING THE PEER SUPPORT NETWORK® AND
GENETICS FOR LIFE® PROGRAMS RESOURCE LIST

Organization	Web site	Contact Information
Living Beyond Breast Cancer 354 West Lancaster Ave., Suite 224 Haverford, PA 19041	http://www.lbbc.org	Phone: 484-708-1550 or 610-645-4567 Fax: 610-645-4573 E-mail: mail@lbbc.org
Young Survival Coalition 61 Broadway, Suite 2235 New York, NY 10006	http://www.youngsurvival.org	Phone: 646-257-3000 Toll Free: 877-YSC-1011 Fax: 646-257-3030 e-mail: info@youngsurvival.org
Y-Me National Breast Cancer Organization 135 S. LaSalle St. Suite 2000 Chicago, IL 60603	http://www.y-me.org	YourShoes® 24/7 Breast Cancer Support Center: 1-800-221-2141 Phone: 312-986-8338 Fax: 312-294-8597 e-mail: See Website for email: http://www.y-me.org/contact
LiveStrong 2201 E. Sixth Street Austin, Texas 78702	http://www.livestrong.org/Get-Help/Get-One-On-One-Support	Phone: 1.855.220.7777 (One on one support line)
National Coalition for Cancer Survivorship	http://www.cansearich.org	Phone: 877-622-7937



BREAST CANCER IN YOUNG WOMEN PROJECT

APPENDIX G

DISCUSSION CHARTS USED DURING FOCUS GROUPS



Psychosocial health needs

- Fear of recurrence
- Physical symptoms: fatigue, trouble sleeping, pain, memory loss, chemo brain
- Ability to work and reenter the work place, school
- Body image disruption
- Treatment-related anxieties and/or depression
- Intrusive thoughts about illness/persistent anxiety
- Marital/partner and family communication
- Feelings of vulnerability
- Existential concerns regarding mortality

Reproductive health needs

- Sexual dysfunction
- Fertility
- Early menopause



BREAST CANCER IN YOUNG WOMEN PROJECT

APPENDIX H

TOPICAL DISCUSSION GUIDES



SHARSHERET FOCUS GROUPS: TESTING THE PEER SUPPORT NETWORK®
AND GENETICS FOR LIFE® PROGRAMS
TOPICAL MODERATOR GUIDE:

GENETICS FOR LIFE® IN-PERSON FOCUS GROUPS

Introduction to Group Processes and Procedures (10 minutes)

Thank you for taking the time to be here. My name is _____ and I work with Sharsheret. I want to take a few minutes to tell you what to expect from our discussion tonight and then I'll give everyone the chance to introduce herself.

As you may recall from when you were recruited, we are conducting this focus group study on behalf of the Centers for Disease Control and Prevention (CDC) to talk to women who were diagnosed with breast cancer at a young age about their information needs. In this group, we will discuss your information needs and ask your thoughts about Sharsheret's Peer Support Network® and Genetics for Life® programs.

My role is to simply facilitate the discussion, make sure we stay on topic, and keep us within our 2-hour time limit. I am not here to push any particular agenda or point of view, but rather to hear your frank and honest opinions. There are no right or wrong answers, and nothing to be ashamed of. We all have our own likes and dislikes, our own thoughts and feelings. We merely want to identify what factors you think play a role in why you seek medical care.

As you may have noticed, we have a note-taker in the room. She is _____ and she is a staff person with Sharsheret. She is serving as a back up to our tape recorder. We also have some observers from ICF Macro who are interested in what you all have to say.

I'm going to ask a series of questions, but mainly I want to hear from you. As I mentioned, my role is simply to guide the discussion. Sometimes we may really get going on one question, and I'll have to move you on to the next question so that we may cover everything. Please don't take it personally! We just need to hear from everyone about several topics.

I also want to remind everyone that the discussion here is private. We will not report your comments by name, and we ask that you respect one another's privacy in the same way. We don't expect you to tell us anything that you would be uncomfortable sharing with the group. But we do hope that you will be honest with your responses to the questions I ask.

Earlier you reviewed and signed the informed consent form. I want to make sure that you understand that your participation in this study is completely voluntary. That means you can leave at any time. If you are uncomfortable with a question, or if you simply don't have a response, it is fine to pass. We don't need everyone to answer every question, but we are interested in all of your perspectives and really value what you have to say. You will still get reimbursed for your reasonable travel expenses.

Also, during this discussion, a lot of questions might come up that you would like me to answer. Since we are mainly interested in hearing your thoughts and opinions, I may not be able to answer all the questions for you. But please keep track of your questions. After we finish with our discussion, there will

be someone available at Sharsheret who can answer all questions and give you additional information if you want it.

Moderator: Review ground rules

- Participate as you feel comfortable
- Allow/encourage everyone to participate
- Remember that disagreement is OK

Most importantly, please try to speak up, speak clearly, and one at a time, if possible. Remember we are audio taping the discussion so that we can have an accurate record of the discussion. Do you have any questions before we get started?

Participant Introductions and Warm-up Exercise (5 minutes)

So we can get to know each other a little, let's go around the room and introduce ourselves. Please tell us your first name, your hometown, and one nice thing that happened to you this week. Thank you. Now, let's get started with our discussion.

Information Needs

- a) Identification of information needs about breast cancer
- b) Identification of information needs about breast cancer treatment
- c) Identification of information needs about after-care
- d) Barriers to obtaining information about breast cancer, treatment and after-care
- e) Facilitators to obtaining information about breast cancer, treatment and after-care
- f) Specific information needs related to psychosocial and reproductive health concerns¹
- g) Types of psychosocial and reproductive health information received about breast cancer, treatment and after-care (i.e., What information is received)
- h) Current sources of psychosocial and reproductive health information about breast cancer, treatment and after-care (e.g., Where and from who information is currently received)
- i) Perceptions of providers ability to provide needed psychosocial and reproductive health information
- j) Preferred sources of psychosocial and reproductive health information about breast cancer, treatment and after-care (i.e., Where and from who women prefer to receive information)
- k) Knowledge of currently available resources and tools with information on breast cancer, treatment and after-care

Genetics for Life Materials and Message Testing

Content

- a) General thoughts about the information provided by Genetics for Life®
- b) Perceptions of Genetics for Life® content focused on psychosocial and reproductive health needs
- c) Extent to which Genetics for Life® meets information psychosocial and reproductive health needs

¹ Based on definition of psychosocial health needs

- d) Clarity of content related to psychosocial and reproductive health in Genetics for Life® materials
- e) Most useful aspects of Genetics for Life® (based on information needs)
- f) Least helpful aspects of Genetics for Life® materials (based on information needs)
- g) Missing aspects of Genetics for Life® materials (based on information needs)
- h) Recommendations to improve Genetics for Life®

Images and Graphics

- a) General thoughts about the appearance of Genetics for Life® materials
- b) Appeal of images, colors and graphics in Genetics for Life® materials
- c) Perceptions of the cultural appropriateness of Genetics for Life® materials
- d) Preferred colors and graphics for Genetics for Life® materials
- e) Recommendations to improve the images and graphics in Genetics for Life® materials

Intervention Access and Delivery

- a) Current methods to access psychosocial and reproductive health information related to breast cancer, treatment and after-care is obtained (e.g., providers, Internet, radio, books, etc.)
- b) Preferred methods to access psychosocial and reproductive health information related to breast cancer, treatment and after-care
- c) Barriers to accessing psychosocial and reproductive health information (via current/preferred channels)
- d) Facilitators to accessing psychosocial and reproductive health information (via current/preferred channels)
- e) Suggested ways to deliver Genetics for Life® to target audience (e.g., via Internet, peer counselors, one on one counseling, group counseling)
- f) Recommendations for delivery of Genetics for Life® messages to target audience (e.g., television, radio, print, Internet)

SHARSHERET FOCUS GROUPS: TESTING THE PEER SUPPORT NETWORK®
AND GENETICS FOR LIFE® PROGRAMS
TOPICAL MODERATOR GUIDE:

GENETICS FOR LIFE® ONLINE GROUPS

Introduction to Group Processes and Procedures (10 minutes)

Thank you for taking the time to be here. My name is _____ and I work with Sharsheret. I want to take a few minutes to tell you what to expect from our discussion tonight and then I'll give everyone the chance to introduce herself.

As you may recall from when you were recruited, we are conducting this focus group study on behalf of the Centers for Disease Control and Prevention (CDC) to talk to women who were diagnosed with breast cancer at a young age about their information needs. In this group, we will discuss your information needs and ask your thoughts about Sharsheret's Links Peer Support Network® and Genetics for Life® programs.

My role is to simply facilitate the discussion, make sure we stay on topic, and keep us within our 2-hour time limit. I am not here to push any particular agenda or point of view, but rather to hear your frank and honest opinions. There are no right or wrong answers, and nothing to be ashamed of. We all have our own likes and dislikes, our own thoughts and feelings. We merely want to identify what factors you think play a role in why you seek medical care.

In addition to participants, we will have a note-taker in this group. Her name is _____ and she is a staff person with Sharsheret. She is serving as a back up to our tape recorder. We also have some observers from CDC and ICF Macro who are interested in what you all have to say.

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I also want to remind everyone that the discussion here is private. We will not report your comments by name, and we ask that you respect one another's privacy in the same way. We don't expect you to tell us anything that you would be uncomfortable sharing with the group. But we do hope that you will be honest with your responses to the questions I ask.

Earlier you reviewed and signed the informed consent form. I want to make sure that you understand that your participation in this study is completely voluntary. That means you can leave at any time. If you are uncomfortable with a question, or if you simply don't have a response, it is fine to pass. We don't need everyone to answer every question, but we are interested in all of your perspectives and really value what you have to say. You will still get reimbursed for your reasonable travel expenses.

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Moderator: Review ground rules

- Participate as you feel comfortable
- Allow/encourage everyone to participate
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Most importantly, please try to speak up, speak clearly, and one at a time, if possible. Remember we are audio taping the discussion so that we can have an accurate record of the discussion. Do you have any questions before we get started?

Participant Introductions and Warm-up Exercise (5 minutes)

So we can get to know each other a little, let's each introduce ourselves. I will choose participants from the chat room list. After I read your name, please tell us your hometown and one nice thing that has happened to you in the last week. Thank you. Now, let's get started with our discussion.

Information Needs

- a) Identification of information needs about breast cancer
- b) Identification of information needs about breast cancer treatment
- c) Identification of information needs about after-care
- d) Barriers to obtaining information about breast cancer, treatment and after-care
- e) Facilitators to obtaining information about breast cancer, treatment and after-care
- f) Specific information needs related to psychosocial and reproductive health concerns²
- g) Types of psychosocial and reproductive health information received about breast cancer, treatment and after-care (i.e., What information is received)
- h) Current sources of psychosocial and reproductive health information about breast cancer, treatment and after-care (e.g., Where and from who information is currently received)
- i) Perceptions of providers ability to provide needed psychosocial and reproductive health information
- j) Preferred sources of psychosocial and reproductive health information about breast cancer, treatment and after-care (i.e., Where and from who women prefer to receive information)
- k) Knowledge of currently available resources and tools with information on breast cancer, treatment and after-care

Genetics for Life Materials and Message Testing

Content

- a) General thoughts about the information provided by Genetics for Life®
- b) Perceptions of Genetics for Life® content focused on psychosocial and reproductive health needs

² Based on definition of psychosocial health needs

- c) Extent to which Genetics for Life® meets information psychosocial and reproductive health needs
- d) Clarity of content related to psychosocial and reproductive health in Genetics for Life® materials
- e) Most useful aspects of Genetics for Life® (based on information needs)
- f) Least helpful aspects of Genetics for Life® materials (based on information needs)
- g) Missing aspects of Genetics for Life® materials (based on information needs)
- h) Recommendations to improve Genetics for Life®

Images and Graphics

- a) General thoughts about the appearance of Genetics for Life® materials
- b) Appeal of images, colors and graphics in Genetics for Life® materials
- c) Perceptions of the cultural appropriateness of Genetics for Life® materials
- d) Preferred colors and graphics for Genetics for Life® materials
- e) Recommendations to improve the images and graphics in Genetics for Life® materials

Intervention Access and Delivery

- a) Current methods to access psychosocial and reproductive health information related to breast cancer, treatment and after-care is obtained (e.g., providers, Internet, radio, books, etc.)
- b) Preferred methods to access psychosocial and reproductive health information related to breast cancer, treatment and after-care
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SHARSHERET FOCUS GROUPS: TESTING THE PEER SUPPORT NETWORK®
AND GENETICS FOR LIFE® PROGRAMS
TOPICAL MODERATOR GUIDE:

PEER SUPPORT NETWORK® IN-PERSON GROUPS

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- i) Perceptions of providers ability to provide needed psychosocial and reproductive health information
- j) Preferred sources of psychosocial and reproductive health information about breast cancer, treatment and after-care (i.e., Where and from who women prefer to receive information)
- k) Knowledge of currently available resources and tools with information on breast cancer, treatment and after-care

Peer Support Network Materials and Message Testing

Content

- a) General thoughts about the information provided by the Peer Support Network®
- b) Perceptions of Peer Support Network® content focused on psychosocial and reproductive health needs
- c) Extent to which the Peer Support Network® meets information psychosocial and reproductive health needs

³ Based on definition of psychosocial health needs

- d) Clarity of content related to psychosocial and reproductive health in Peer Support Network® materials
- e) Most useful aspects of the Peer Support Network® (based on information needs)
- f) Least useful aspects of the Peer Support Network® (based on information needs)
- g) Missing aspects of the Peer Support Network® (based on information needs)
- h) Recommendations to improve the Peer Support Network®

Images and Graphics

- a) General thoughts about the appearance of Peer Support Network® materials
- b) Appeal of images, colors and graphics in Peer Support Network® materials
- c) Perceptions of the cultural appropriateness of Peer Support Network® materials
- d) Preferred colors and graphics for Peer Support Network® materials
- e) Recommendations to improve the images and graphics in Peer Support Network® materials

Intervention Access and Delivery

- a) Current methods to access psychosocial and reproductive health information related to breast cancer, treatment and after-care is obtained (e.g., providers, Internet, radio, books, etc.)
- b) Preferred methods to access psychosocial and reproductive health information related to breast cancer, treatment and after-care
- c) Barriers to accessing psychosocial and reproductive health information (via current/preferred channels)
- d) Facilitators to accessing psychosocial and reproductive health information (via current/preferred channels)
- e) Suggested ways to deliver Peer Support Network® to target audience (e.g., via Internet, peer counselors, one on one counseling, group counseling)
- f) Recommendations for delivery of Peer Support Network® messages to target audience (e.g., television, radio, print, Internet)

SHARSHERET FOCUS GROUPS: TESTING THE PEER SUPPORT NETWORK®
AND GENETICS FOR LIFE® PROGRAMS
TOPICAL MODERATOR GUIDE:

PEER SUPPORT NETWORK® ONLINE GROUP

Introduction to Group Processes and Procedures (10 minutes)

Thank you for taking the time to be here. My name is _____ and I work with Sharsheret. I want to take a few minutes to tell you what to expect from our discussion tonight and then I'll give everyone the chance to introduce herself.

As you may recall from when you were recruited, we are conducting this focus group study on behalf of the Centers for Disease Control and Prevention (CDC) to talk to women who were diagnosed with breast cancer at a young age about their information needs. In this group, we will discuss your information needs and ask your thoughts about Sharsheret's Links Peer Support Network® and Genetics for Life® programs.

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I also want to remind everyone that the discussion here is private. We will not report your comments by name, and we ask that you respect one another's privacy in the same way. We don't expect you to tell us anything that you would be uncomfortable sharing with the group. But we do hope that you will be honest with your responses to the questions I ask.

Earlier you reviewed and signed the informed consent form. I want to make sure that you understand that your participation in this study is completely voluntary. That means you can leave at any time. If you are uncomfortable with a question, or if you simply don't have a response, it is fine to pass. We don't need everyone to answer every question, but we are interested in all of your perspectives and really value what you have to say. You will still get reimbursed for your reasonable travel expenses.

Also, during this discussion, a lot of questions might come up that you would like me to answer. Since we are mainly interested in hearing your thoughts and opinions, I may not be able to answer all the

questions for you. But please keep track of your questions. After we finish with our discussion, there will be someone available at Sharsheret who can answer all questions and give you additional information if you want it.

Moderator: Review ground rules

- Participate as you feel comfortable
- Allow/encourage everyone to participate
- Remember that disagreement is OK

Most importantly, please try to speak up, speak clearly, and one at a time, if possible. Remember we are audio taping the discussion so that we can have an accurate record of the discussion. Do you have any questions before we get started?

Participant Introductions and Warm-up Exercise (5 minutes)

So we can get to know each other a little, let's each introduce ourselves. I will choose participants from the chat room list. After I read your name, please tell us your hometown and one nice thing that has happened to you in the last week.

Thank you. Now, let's get started with our discussion.

Information Needs

- a) Identification of information needs about breast cancer
- b) Identification of information needs about breast cancer treatment
- c) Identification of information needs about after-care
- d) Barriers to obtaining information about breast cancer, treatment and after-care
- e) Facilitators to obtaining information about breast cancer, treatment and after-care
- f) Specific information needs related to psychosocial and reproductive health concerns⁴
- g) Types of psychosocial and reproductive health information received about breast cancer, treatment and after-care (i.e., What information is received)
- h) Current sources of psychosocial and reproductive health information about breast cancer, treatment and after-care (e.g., Where and from who information is currently received)
- i) Perceptions of providers ability to provide needed psychosocial and reproductive health information
- j) Preferred sources of psychosocial and reproductive health information about breast cancer, treatment and after-care (i.e., Where and from who women prefer to receive information)
- k) Knowledge of currently available resources and tools with information on breast cancer, treatment and after-care

Peer Support Network Materials and Message Testing

Content

- a) General thoughts about the information provided by the Peer Support Network®
- b) Perceptions of Peer Support Network® content focused on psychosocial and reproductive health needs

⁴ Based on definition of psychosocial health needs

- c) Extent to which the Peer Support Network® meets information psychosocial and reproductive health needs
- d) Clarity of content related to psychosocial and reproductive health in Peer Support Network® materials
- e) Most useful aspects of the Peer Support Network® (based on information needs)
- f) Least useful aspects of the Peer Support Network® (based on information needs)
- g) Missing aspects of the Peer Support Network® (based on information needs)
- h) Recommendations to improve the Peer Support Network®

Images and Graphics

- a) General thoughts about the appearance of Peer Support Network® materials
- b) Appeal of images, colors and graphics in Peer Support Network® materials
- c) Perceptions of the cultural appropriateness of Peer Support Network® materials
- d) Preferred colors and graphics for Peer Support Network® materials
- e) Recommendations to improve the images and graphics in Peer Support Network® materials

Intervention Access and Delivery

- a) Current methods to access psychosocial and reproductive health information related to breast cancer, treatment and after-care is obtained (e.g., providers, Internet, radio, books, etc.)
- b) Preferred methods to access psychosocial and reproductive health information related to breast cancer, treatment and after-care
- c) Barriers to accessing psychosocial and reproductive health information (via current/preferred channels)
- d) Facilitators to accessing psychosocial and reproductive health information (via current/preferred channels)
- e) Suggested ways to deliver Peer Support Network® to target audience (e.g., via Internet, peer counselors, one on one counseling, group counseling)
- f) Recommendations for delivery of Peer Support Network® messages to target audience (e.g., television, radio, print, Internet)



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