



FORCE Programs and Resources to Support Young Individuals with or at High Risk for Breast Cancer

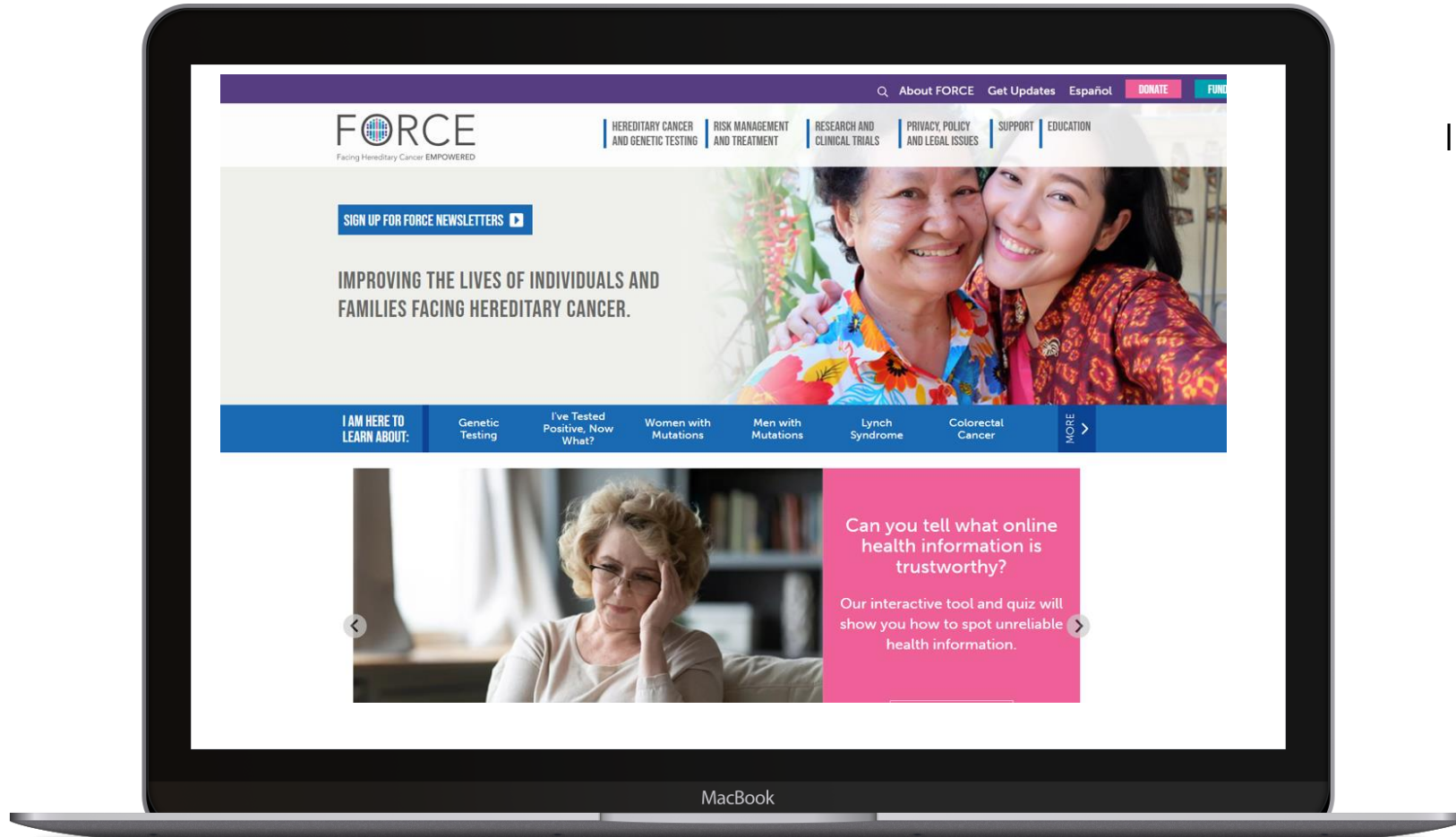
Presentation for ACBCYW
Verinda Hobbs

FORCE

Facing Hereditary Cancer EMPOWERED



ABOUT FORCE



THESE EFFORTS ARE SUPPORTED
IN PART THROUGH A COOPERATIVE
AGREEMENT FROM
THE CENTERS FOR DISEASE
CONTROL AND PREVENTION
(NU58DP006677).



2024 Survey for People at High Risk for Breast / Gynecologic Cancers: ≤45 and Female, Nonbinary or Transgender Cohort

Total N=1261/Filtered N=328

Gene: 328 respondents

Gene	#	%
BRCA2	115	35%
BRCA1	97	30%
ATM	25	8%
CHEK2	23	7%
PALB2	22	7%
RAD51C	8	2%
TP53	3	1%
RAD51D	3	1%
RAD51D	14	1.1%
TP53	13	1.0%
BARD1	1	<1%
CDH1	1	<1%
PTEN	1	<1%
Multiple	13	4%

Age: 328 respondents

Age	#	%
18-25	14	4.3%
26-30	25	7.6%
31-35	57	17.4%
36-40	111	33.8%
41-45	121	36.9%

Breast cancer survivor or high risk (Previvor): 309

Survivor/Previvor	#	%
YBCS	47	15%
Previvor/High risk	262	85%

Gender: 328 respondents

Gender	#	%
Female	318	97.0%
Nonbinary, gender-fluid, gender nonconforming	10	3%
Prefer not to share	0	0%
Prefer to self-describe	0	0%

Transgender: 328 respondents

Transgender Y/N	#	%
Yes	6	1.8%
No	321	97.9%
Prefer not to share	1	0.30%

Race/ethnicity: 327 respondents

Race / Ethnicity	#	%
Non-Hispanic White	283	87%
Hispanic / Latine	21	6.4%
Black / African American	12	3.6%
Asian / Asian American	8	2.4%
American Indian / Alaskan Native	4	1.2%
Middle Eastern	4	1.2%
Hawaiian / Pacific Islander	0	0%

FORCE Survey on Needs of People at High Risk for Breast, Endometrial, Fallopian Tube or Ovarian Cancer Due to an Inherited Mutation or Family History. 2024. Unpublished.

GENETIC TESTING RISK MANAGEMENT AND PREVIVORSHIP



“I still need peer support & financial support for previvors. Everything in funding is for cancer treatment, not prevention.”

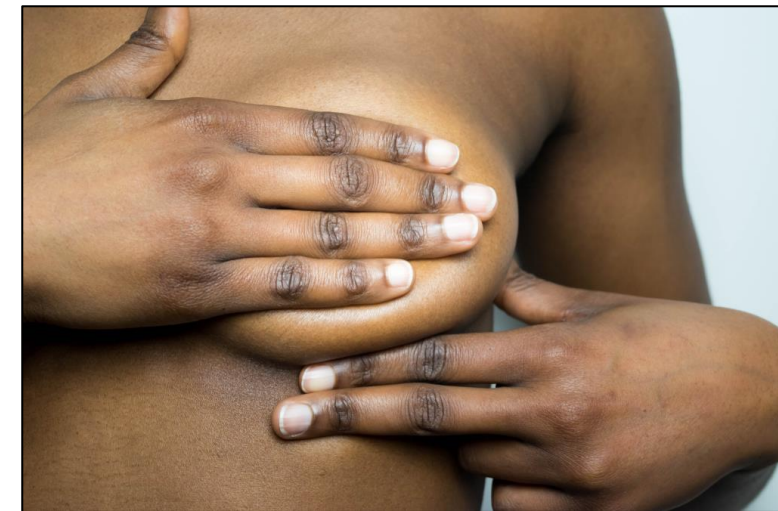
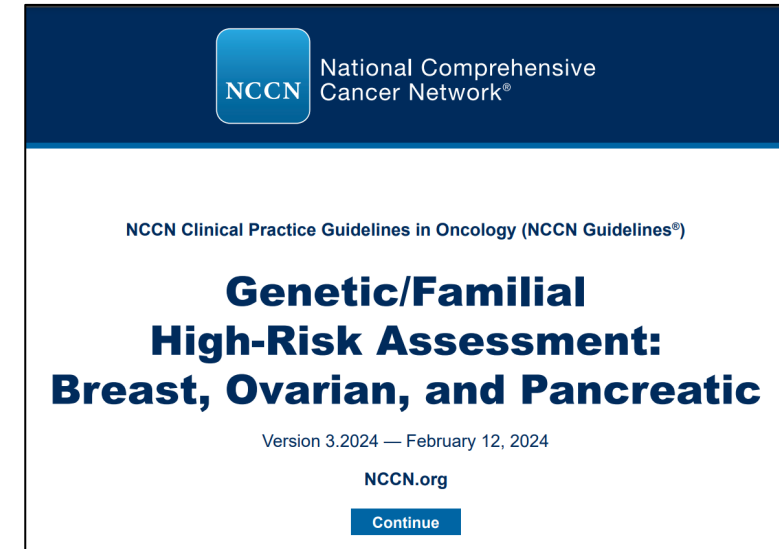


Previvors and
previvorship

Guidelines for Breast Cancer Risk Management

Breast cancer BRCA1/2 (female / AFAB)

- Breast awareness starting at age 18.
- Clinical breast exam, every 6–12 months, starting at age 25 years.
- Age 25–29 years, annual breast MRI screening with and without contrast
- Age 30–75 years, annual mammogram and breast MRI screening with and without contrast.
- Discuss benefits / risks / costs / limitations of risk-reducing mastectomy and risk-reducing medications.



Guidelines Recommend Removal of Ovaries and Tubes



National Comprehensive
Cancer Network®

NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®)

Genetic/Familial High-Risk Assessment: Breast, Ovarian, and Pancreatic

Version 3.2024 — February 12, 2024

[NCCN.org](https://www.nccn.org)

Continue

Ovarian cancer BRCA1/2

- Recommend risk-reducing salpingo-oophorectomy (RRSO).
 - BRCA1: Between 35 - 40.
 - BRCA2: Given the later onset of cancer, it is reasonable to delay RRSO until age 40 - 45.

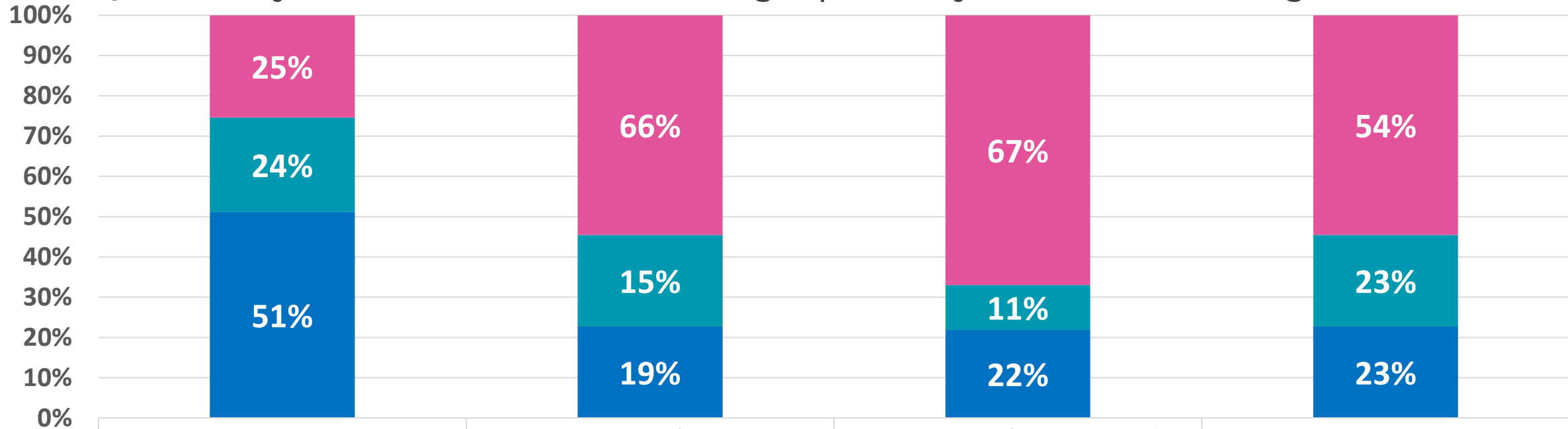
Guidelines on Use of Hormones (HRT) after RRSO



- Hormone replacement therapy is generally **not** contraindicated and should be discussed with premenopausal patients without a personal history of breast cancer
- HRT recommendations should be tailored for the individual and should involve experts in menopause care.
- Premature menopause due to RRSO can be detrimental to bone, cardiovascular, sexual, psychosocial, and neurologic health and generalized quality-of-life. Hormones can reduce these risks.

Barriers to Breast Screening

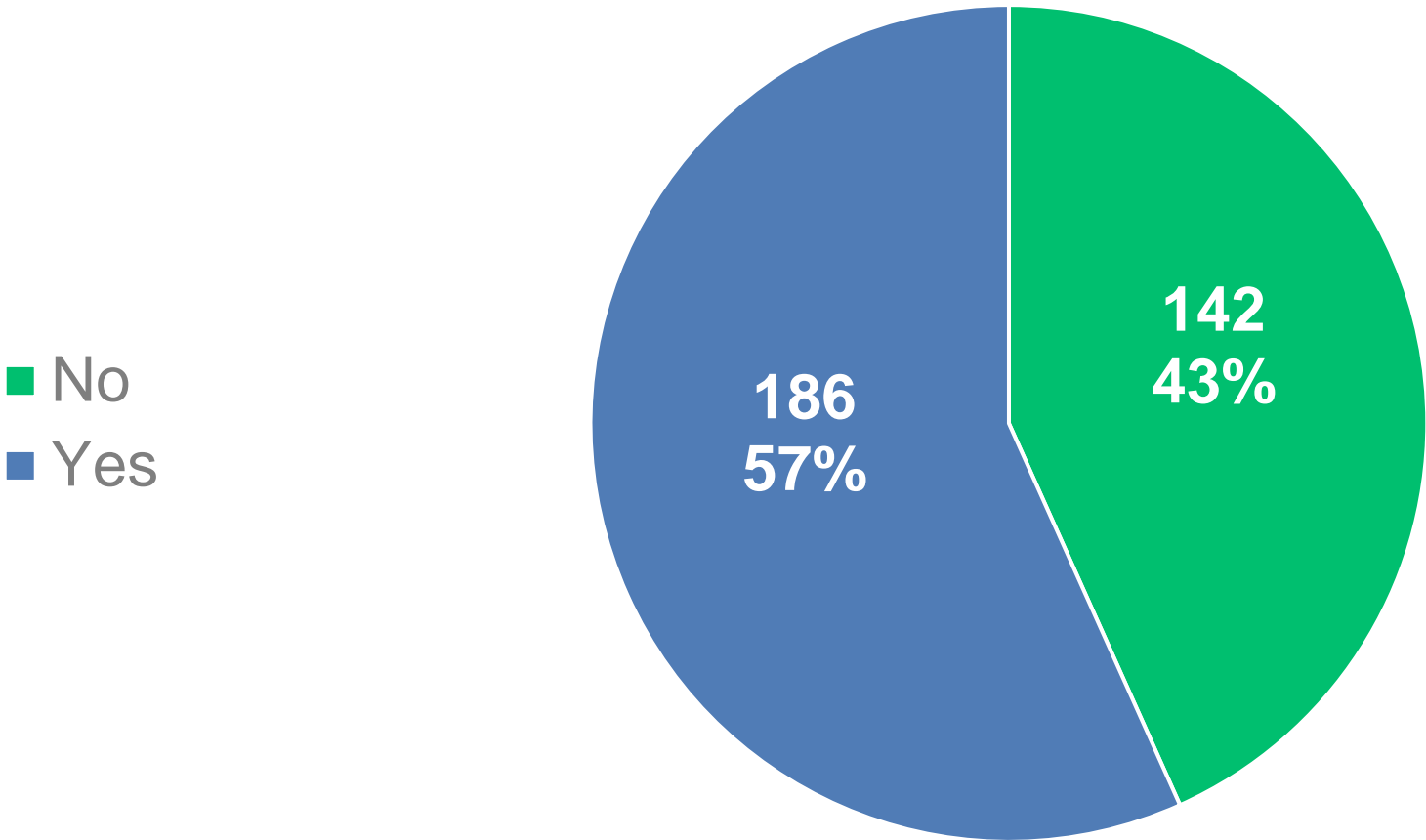
Q. How easy or difficult were the following aspects of your breast screening?



	Emotionally preparing for screening or results	Finding a facility responsive to your needs	Finding a facility with experience managing high risk people	Paying for breast screening
Easy	79	156	205	156
Neutral	73	65	34	65
Hard	159	65	67	65

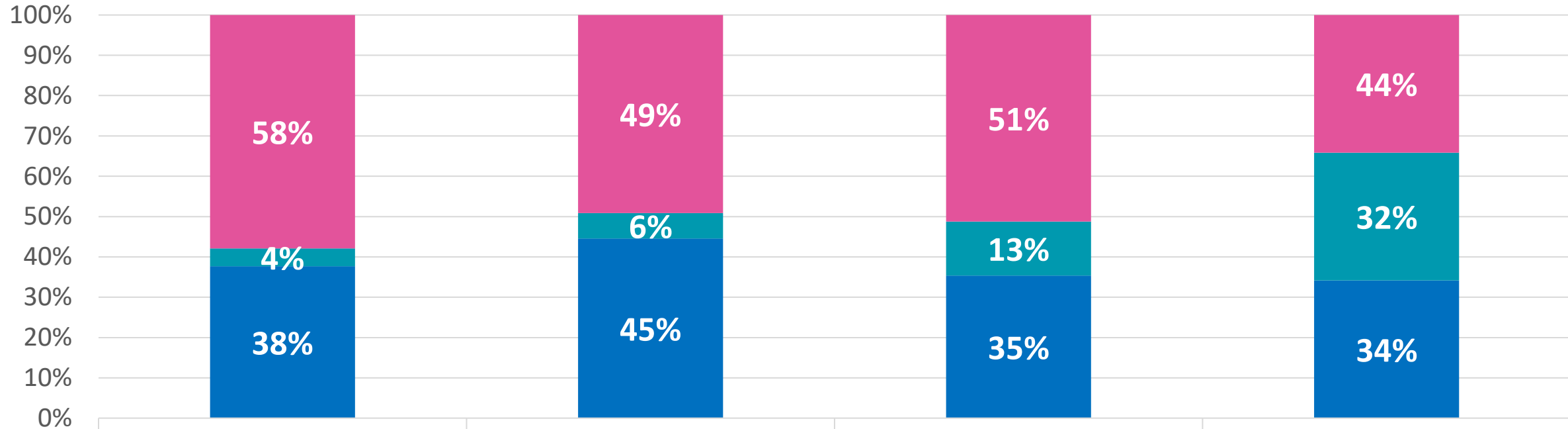
Many Respondents Chose Risk-Reducing Mastectomy (RRM)

Q. Have you had, or are you in the process of scheduling a double mastectomy with or without reconstruction?



Barriers to Risk-Reducing Mastectomy

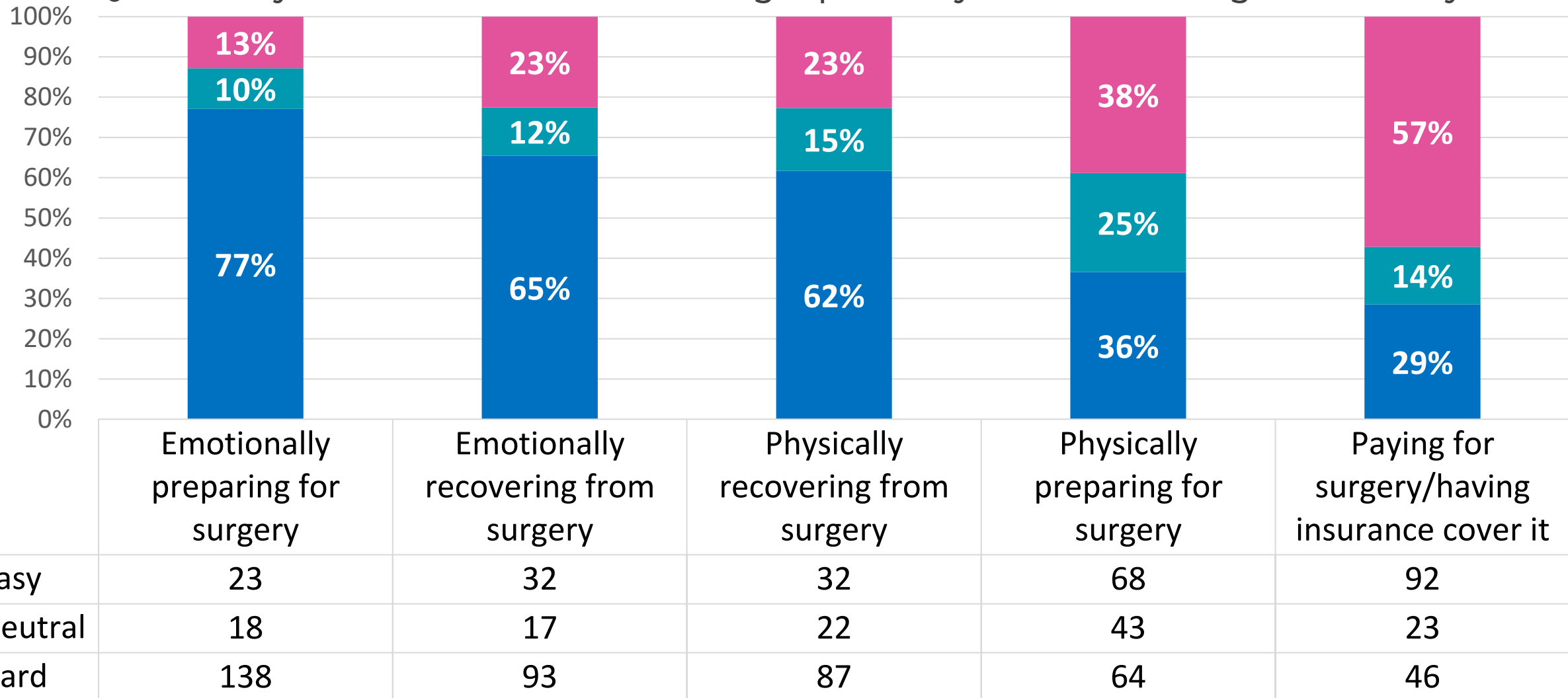
Q. How easy or difficult were the following aspects of your risk-reducing mastectomy?



	Deciding to have surgery	Choosing the type of reconstruction to have	Having the type of reconstruction you prefer	Having an aesthetic flat closure
Easy	106	86	84	14
Neutral	8	11	22	13
Hard	69	78	58	14

Barriers to Risk-Reducing Mastectomy

Q. How easy or difficult were the following aspects of your risk-reducing mastectomy?



Write In Comments on Barriers to Risk Management

Themes:

- Financial burden
- Time and travel for expert care
- Access to fertility preservation
- Scanxiety
- Inconsistent or inaccurate information

The financial burden of MRIs and ultrasounds deters me from the additional screenings that are recommended.

*I live in a services desert.
Nearest breast MRI is 3.5 hr
drive ONE WAY.*

Burden of Risk Management

*The waiting game was excruciating. I cried for two days and didn't eat. I knew that having a double mastectomy was the **ONLY** thing that would bring me peace.*

*My surgery has not been scheduled, yet. We are not ready to close the door on another baby, but my insurance does not cover fertility treatments. **The cost is about \$15,000+.** The hardest part is knowing we want another baby, not being able to afford it, yet feeling like having one naturally would be a sort of death sentence for putting the surgery off for so long.*

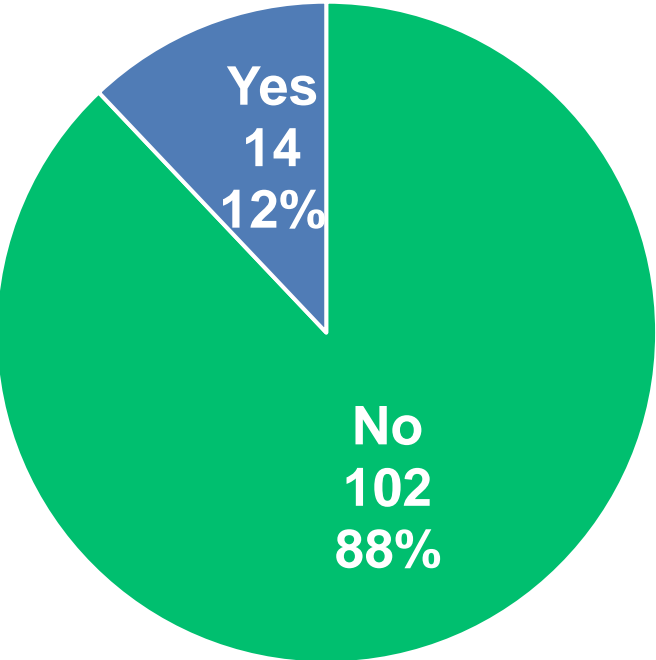
Respondents Report Medical Advice Inconsistent with Guidelines

My daughter has a BRCA 2 mutation. Her doctors are telling her she will die if she doesn't have double mastectomy and oophorectomy immediately. She is 33 and in good health.

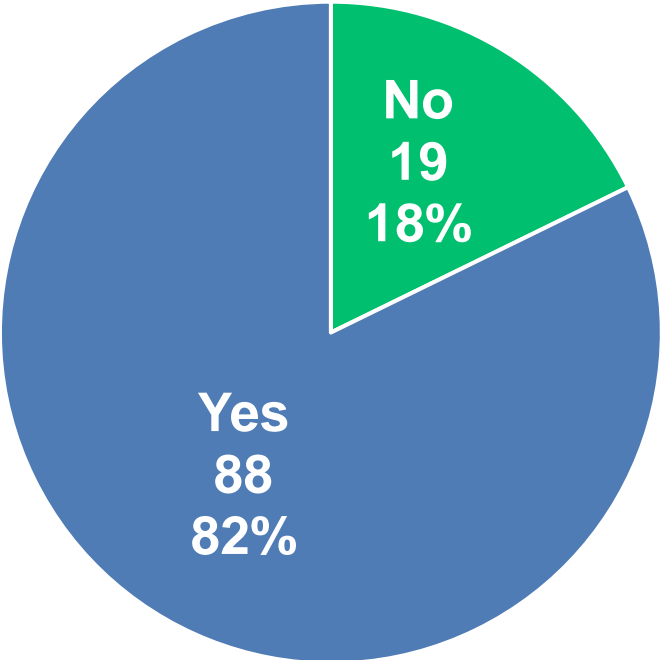
My provider was ordering regular annual screening mammograms until I sent her literature on screening recommendations for people with BRCA1 mutations.

Breast Cancer Risk Management Research

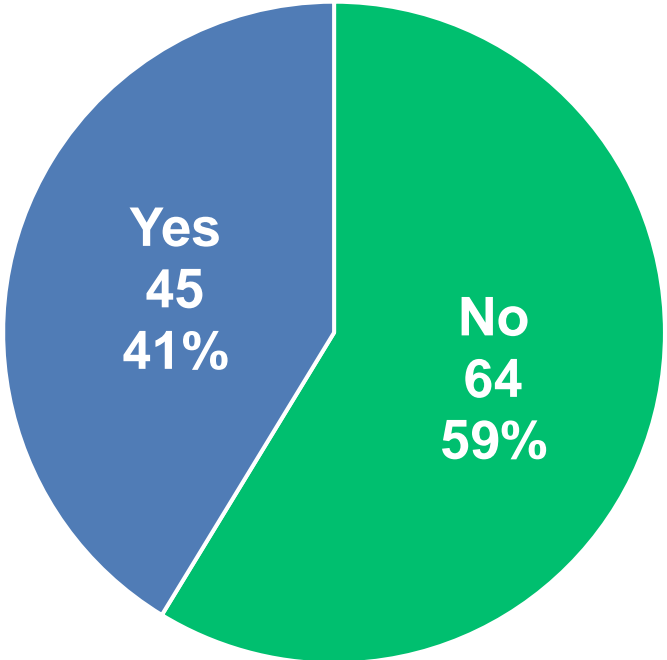
Q. Has a doctor, nurse or other healthcare provider ever spoken to you about participating in a clinical trial related to hereditary breast cancer risk management?



Q. Are you interested in participating in hereditary breast cancer risk management clinical trials?



Q. Do you know how to find hereditary breast cancer risk management clinical trials?*



*Many of the respondents indicated that they knew about clinical trials because of FORCE.

CAREGIVING AND FAMILY



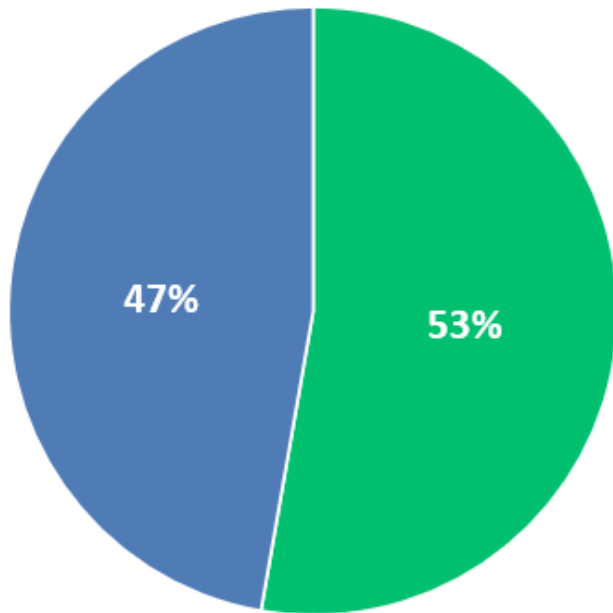
“I provided care for my mother as she was dying of cancer as I was ending my own cancer treatment and learning about my BRCA2 options. Tough times.”

Large Hereditary Cancer Caregiver Burden

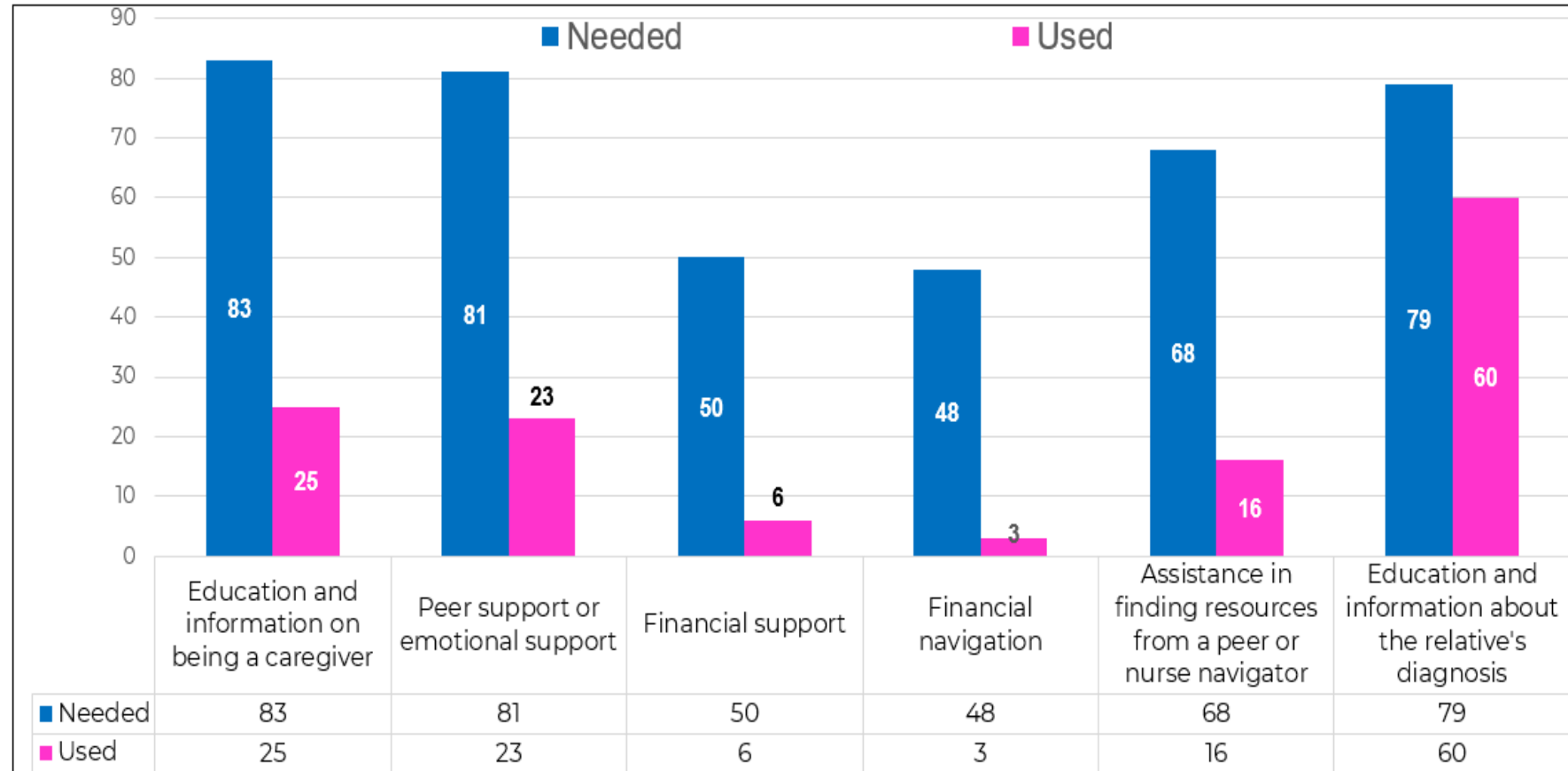
Gap between resources needed and used

53% of respondents provided care to a relative with cancer

Q Have you ever provided support or care for a relative with cancer? N=328



■ Yes ■ No



120 Write-In Comments About Caregiving

Themes:

- Generational trauma
- Caregiving for multiple relatives at the same time
- Going through personal diagnosis at same time as caring for a relative
- Gaps in information and support

A devastating experience losing my mom to cancer and a few months later losing my sister also to cancer. Most of it a daze.

I was a child 8-10 years old taking care of my grandmother taking turns with my siblings. I expect this is not uncommon and children caring for relatives rarely get support.

FORCE PROGRAMS THAT ADDRESS NEEDS OF YOUNG SURVIVORS & PREVIVORS



“I really appreciate having this information readily available. It makes it easier to find relevant studies, without having to sort through the whole NIH website.”

Expert Information on Hereditary Breast Cancer

- Many respondents received conflicting information about their medical options.
- We have treatment and risk-management guidelines and resources organized by cancer type and situation.

1 Stages and subtypes 2 Standard therapy 3 Biomarkers, targeted and immunotherapies
4 Inherited mutations

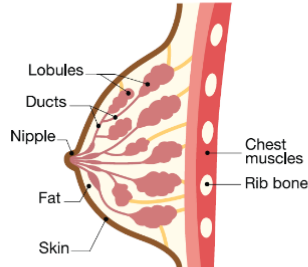
Breast cancer subtypes

Cell types

Breasts are made up of two main types of cells; the breast lobules, which make milk, and the breast ducts which carry the milk to the nipple.

- Ductal carcinoma is cancer that starts in the ducts. This is the most common type of breast cancer.
- Lobular carcinoma starts in the breast lobules. This is less common than ductal carcinoma.

There are other, very rare types of breast cancer. Inflammatory breast cancer is a very fast growing type of ductal carcinoma. Paget's disease of the breast is a type of ductal carcinoma that affects the nipple and areola. Phyllodes tumors start in the connective tissue of the breast.



anatomy of the breast

Stages

The **stage** of a cancer refers to whether the cancer has spread beyond the breast. Measuring the stage of breast cancer helps doctors decide how to treat it and how far it can grow and spread:




Breast Cancer Risk

Who is at risk for breast cancer?

Every person is at risk for breast cancer. The average lifetime risk for breast cancer in women is about 13 percent. This means that one out of every eight women will get breast cancer in their lifetime, usually after age 60. Men can get breast cancer, however, the average risk for male breast cancer is very low, less than 1 percent. People with an **inherited mutation** in the genes listed below have a higher-than-average risk for breast cancer, often at a younger age. The risk varies based on multiple factors, including:

- age
- gender
- presence of a gene mutation
- personal and family history of cancer
- other risk factors

In the News



Study : Genetic testing among people with cancer can find mutations that may affect treatment and prevention

Is breast cancer hereditary?

About 10 percent of people with breast cancer have an inherited mutation linked to increased cancer risk. Inherited mutations in the genes below increase the risk for breast cancer and can cause cancer to run in families. Some of these genes also increase the breast cancer risk in men and people assigned male at birth. [Genetic counseling and testing](#) can help people learn if they are at high risk.

Genes that Increase Breast Cancer Risk in Women and People Assigned Female at Birth	Genes that Increase Breast Cancer Risk in Men and People Assigned Male at Birth
ATM , BRCA1 , BRCA2 , CDH1 , CHEK2 , NF1 , PALB2 , PTEN , RAD51C , RAD51D , STK11 , TP53	BRCA1 , BRCA2 , CHEK2 , PALB2

Other genes have been linked to an increase in breast cancer risk. Most of these are rare.

Individual Guidelines for Each High-Risk Gene

Information for People with an Inherited PALB2 Mutation

What are the cancer risks for people with a PALB2 mutation?

People with an inherited mutation in PALB2 have increased risk for certain cancers, including:

- breast cancer (male and female)
- pancreatic
- fallopian tube
- ovarian

What can people with a PALB2 mutation do?

People with a PALB2 mutation have options for screening, prevention and treatment of hereditary cancer. There are expert guidelines and clinical trials that focus on:

- screening and early detection
- risk-reduction
- treatment

There may be other medical concerns for people with a PALB2 mutation, including a rare childhood disease known as Fanconi anemia which can happen in people who inherit a mutation in both copies of their PALB2 gene.

Each of these topics is outlined in more detail in the sections highlighted below.

In the News



Update : A breast cancer vaccine for people with an inherited BRCA1, BRCA2 or PALB2 mutation



Study : H. pylori bacteria infection and risk of stomach cancer in mutation carriers



INFORMATION BY MUTATION TYPE:

(Mutations in alphabetical order)



BRCA2

CHEK2

CDH1

EPCAM

MLH1



Cancer Treatment for People with Inherited BRCA1 Mutations

Testing positive for an inherited BRCA1 mutation may affect your treatment options or eligibility for clinical trials studying which treatments work best. The following are examples of situations where a BRCA1 mutation may play a part in treatment decision-making. Note that when we use "men" and "women" we are referring to the sex you were assigned at birth.

- [Breast cancer](#)
- [Pancreatic cancer](#)
- [Ovarian cancer](#)
- [Prostate cancer](#)

Breast Cancer

Surgical decisions

Because of the very high risk for a second (or third) breast cancer diagnosis, women who are diagnosed with breast cancer who test positive for an inherited mutation in BRCA1 often choose [bilateral mastectomy](#) rather than lumpectomy and radiation. Mutation carriers who undergo mastectomy are less likely to develop a second breast cancer.

Unlike women, the risk for a second breast cancer diagnosis in men with a BRCA1 mutation is low. For this reason, bilateral mastectomy may not be recommended.

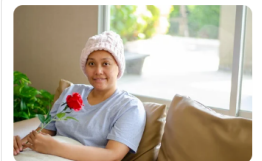
Treatment options for metastatic breast cancer

The PARP inhibitors, Lynparza (also known as olaparib) and Talzenna (also known as talazoparib) both have received FDA approval for treating metastatic breast cancer caused by a BRCA mutation.

Treatment options for early-stage, high-risk breast cancer

The PARP inhibitor, Lynparza is FDA approved to treat people with early-stage, HER2-negative breast cancer who have an inherited BRCA mutation and who are at high risk for recurrence.

In the News



Topic : Progress in the treatment of triple-negative breast cancer

Information on High Priority Topics

- 67% needed information about early-onset menopause
- 44% found it hard to make decisions about breast reconstruction

Managing Menopause with Hormones

You should talk with your health care provider who can help you make a decision about whether hormone replacement is right for you. Note that when we use "women" we are referring to people assigned female at birth.

Benefits and risks of hormone replacement therapy

The decision to take hormone replacement after menopause is a very personal decision. There are benefits and risks for hormone replacement that depend on your personal situation. Hormone replacement can improve many of the symptoms and side effects of menopause, including:

- hot flashes
- osteopenia and osteoporosis
- vaginal side effects
- sexual side effects

However, hormone replacement has risks, including:

- Oral estrogen has been linked to an increased risk for blood clots and stroke. Estrogen skin patches do not appear to increase these risks.
- When estrogen is combined with systemic progesterone it can lead to an increased risk of breast cancer after several years of use.
- When estrogen is used without progesterone, there is an increased risk for uterine cancer.

*Note: much of the research on these risks studied older women who took hormone replacement after natural menopause.

- For healthy, high risk previvors (women who never had a cancer diagnosis) who have had their ovaries removed before age 45, most experts believe the benefits of hormone replacement outweigh the risks, even in women with intact breasts.
- For people who have been diagnosed with breast cancer, most experts believe the benefits of hormone replacement outweigh the risks.

Once you have made a decision to take hormone replacement, there are additional considerations, including:

- the type of hormones contained in the preparation

Find a Menopause Expert



The Menopause Society
The Menopause Society has a tool to help people find practitioners with expertise in managing menopause.

[click here](#)

Reconstruction > Tissue Transfer

About my surgery

Bilateral prophylactic nipple-sparing mastectomy

Photos

Click an image below to view a larger image



Pregnancy After a Cancer Diagnosis

Research suggests that it is safe for many cancer survivors to become pregnant after treatment. However, the exact risks for pregnancy in cancer survivors vary depending on the woman's health, the type of cancer she had, and the treatment she received. For women diagnosed with breast cancer, pregnancy has not been linked to an increase in the risk of recurrence for most survivors. Further, breast cancer treatment does not appear to affect the long term health of children conceived after treatment has ended.

There are several topics that women considering pregnancy after treatment should discuss with her health care provider before becoming pregnant, including:

- when it is safe to become pregnant
- any medical issues caused by cancer or treatment that may affect her pregnancy
- risk for cancer recurrence
- risk for a second cancer diagnosis and recommendations for managing this risk

In the News



Study: Pausing hormone therapy to pursue pregnancy does not increase the short-term risk of early-stage cancer recurrence
Women who paused hormone therapy treatment of early-stage hormone receptor-positive (HR-positive) breast cancer to attempt...

eXamining the Relevance of Articles for You (XRAY)


FORCE's XRAY Program helps people look behind the headlines by providing plain language summaries of relevant research.

Yearly breast MRI screening improves outcomes for women with inherited BRCA mutations

SUMMARY

An international research study of yearly breast MRI screening among women with BRCA1 and BRCA2 gene mutations found that BRCA1 carriers who had MRI screenings were less likely to die of breast cancer than those who did not. Additional studies with more BRCA2 mutation carriers are needed to determine if yearly breast MRIs reduce deaths from breast cancer in this group. (Posted 6/24/24)

Este artículo está disponible [en español](#).

Printer Friendly Page 

Read the Original Article



[The Basics](#) [Bottom Line](#) [Ask Your Dr](#) [Guidelines](#) [Research](#) [Resources](#)

RELEVANCE

Most relevant for: People with a BRCA1 or BRCA2 mutation who are considering breast MRI screening.
It may also be relevant for:

- people with breast cancer
- previvors
- people with a genetic mutation linked to cancer risk



[Relevance Rating Details](#)

Curated Resources for Previvors

INFORMATION AND RESOURCES FOR PREVIVORS

Previvors are people living with an increased risk for cancer. Previvors have unique information and support needs that are different from cancer survivors and people in treatment.

Stay up to date on research and information

[Sign Up for FORCE Newsletters](#)

Previvor

What is a Cancer Previvor?

The meaning of the word "previvor" is a "survivor of a predisposition to cancer." Previvors are people living with an inherited mutation who have never been diagnosed with cancer.

The term includes people with an inherited mutation, a family history of cancer, or some other factor that increases their risk for cancer.

Previvors have medical options to manage their cancer risks. These include:

- enhanced screening to find cancer early and at its most treatable stage.
- medications, lifestyle changes and other approaches to lowering cancer risk.
- surgery to remove organs at high risk before cancer develops.
- clinical research studies that are testing new ways to manage risk.

Genes linked to hereditary cancer risk

Check out our list of genes to learn more about the risks and recommendations for previvors in each selected gene.


[Information by gene](#)

Cancer risks and management guidelines vary by gene, therefore, it's important to know which mutation you have. A genetics expert can help you understand more about your

What's behind the definition of previvor?

FORCE coined the term in 2000 in response to a challenge by a FORCE member who posted, "I need a label!"

Prior to our coining the term, the medical community referred to previvors as "unaffected carriers," a designation many people found dismissive. The term previvor unites a community of important stakeholders to advocate for more research, resources and policy protections.



PREVIVOR DAY 10.2.24



National Hereditary Cancer Week

9.29.24 – 10.5.24



Young Previvors Support Group



BRCA1 Breast Cancer Prevention Study

Denosumab for Breast Cancer Risk Reduction in Women With an Inherited BRCA1 Mutation (The Breast Cancer Prevention Study)

Clinicaltrials.gov identifier:
[NCT04711109](https://clinicaltrials.gov/ct2/show/study/NCT04711109)

Prevention

Prevention study enrolling women ages 25-55 with a BRCA1 mutation

[More info](#)

Emotional Support from Peers

- 77% found it hard to emotionally prepare for mastectomy.
- 66% found it hard to emotionally recover from mastectomy.
- 67% found it hard to emotionally prepare for oophorectomy surgery (RRSO).
- 51% found it hard to emotionally recover from RRSO surgery.



- Virtual Meetings
- 1-to-1 Peer Navigation
- Private Facebook Group
- Message Boards
- Helpline



Click on one of the Support Groups below to learn more about that group.

General Virtual Support Group	American Sign Language (ASL) Virtual Support Group
ATM, CHEK2, PALB2 & Other Mutations Virtual Support Group	Grupo Virtual de Apoyo en Español
LGBTQIA+ Virtual Support Group	Men's Virtual Support Group
Parents or Caregivers Virtual Support Group	People of Color Virtual Support Group
Lynch Syndrome Virtual Support Group	Young Previvors Virtual Support Group
Previvors Virtual Support Group	Survivors Virtual Support Group

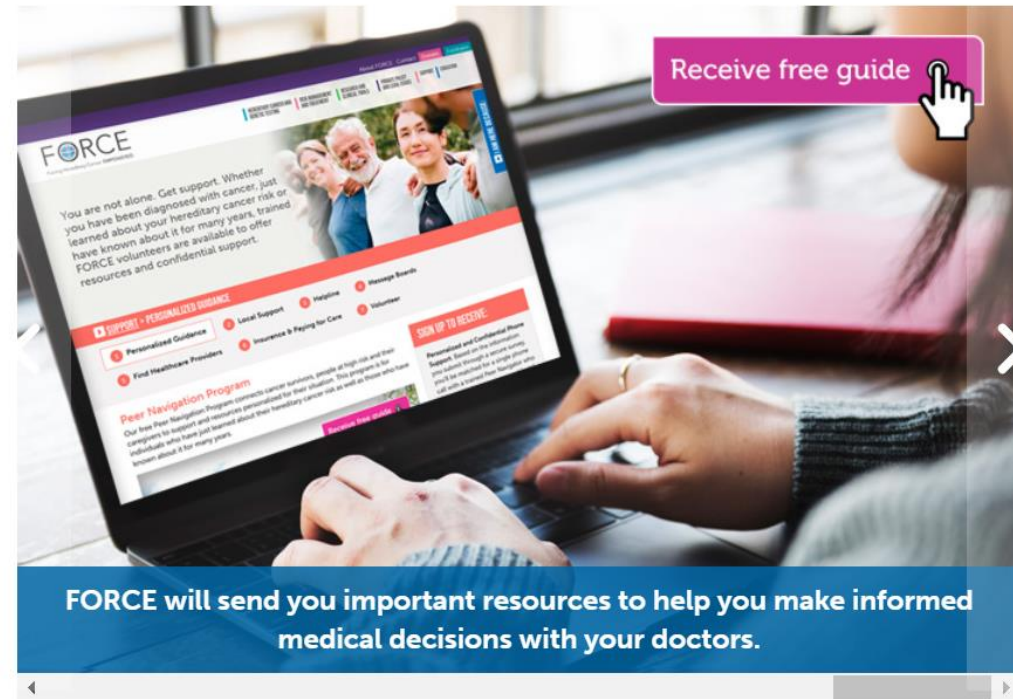
1-on-1 Navigation from Peers

Many respondents needed navigation assistance:

- 55% needed help related to genetic testing.
- 54% needed help related to caregiving.
- 49% needed help related to breast cancer risk management.
- 47% needed help related to gynecologic cancer risk management.

Get Matched for 1:1 Support

Our free Peer Navigation Program connects cancer survivors, people at high risk and their caregivers to support and resources personalized for their situation. This program is for individuals who have just learned about their hereditary cancer risk as well as those who have known about it for many years.



Navigation to Healthcare Expertise and Services

- 40% of respondents found it hard to find a facility that offers fertility preservation.
- 22% of respondents found it hard to find a facility with expertise in managing high-risk patients.

FIND HEALTHCARE PROVIDERS

Find the experts you need
Depending on your situation, you may benefit by speaking with the following experts.

Breast Care
Breast experts are healthcare professionals who focus on breast health and breast cancer screening, prevention and treatment.
[Find Experts](#)

Breast Reconstruction
Breast reconstruction experts are plastic surgeons with training in rebuilding breasts after mastectomy.
[Find Experts](#)

Dermatologists
Dermatologists are doctors who focuses on conditions of the skin, including cancer.
[Find Experts](#)

Fertility Experts
Fertility experts can assist with family planning challenges due to cancer prevention, treatment or an inherited cancer syndrome.
[Find Experts](#)

Gastroenterologists
Gastroenterologists are doctors who focus on conditions of the gastrointestinal tract, including the stomach, colon and pancreas.
[Find Experts](#)

Genetics
Genetics experts have training in the genetic causes of diseases and conditions.
[Find Experts](#)

Search for Experts
Which Experts Do You Need:
Choose

Tips for finding experts
Knowledgeable experts
When choosing experts or specialists, ask the following questions.

- Do they have experience managing people with your mutation or condition?
- Do they have the right equipment and protocols for your situation?
- Ask for referrals from trusted doctors, friends and family who understand or share your situation.

In- or out-of-network
Some specialists may not be part of your health plan's network, meaning you may have to pay more for care. If your health plan has no in-network experts with the training you need, contact them to learn next steps. If they deny coverage for expert care, ask your doctor's office staff to help you appeal their decision.

Primary care doctors
Your primary care doctor can help. Some health plans need prior approval or a referral from a primary care doctor.

<https://bit.ly/force-find-experts>

Our Community is Interested in Participating in Research

- 88% are interested in participating in clinical trials.
- 88% have never been told about studies by their healthcare team.
- 59% do not know how to find a study relevant to their situation.

[Research & Clinical Trials](#) > Featured Research


Our Featured Research Page lists cancer prevention, treatment and quality of life studies enrolling people with or at high risk for hereditary cancers. Sign up for our community newsletter to stay up-to-date on the latest hereditary cancer research.

[Quick Search](#) [In-Depth Search](#) [View All](#)

[How to Use Our Search and Enroll Tool](#) [Additional Help](#)

[Sign Up Now](#)

Featured Research




Study of a New Investigational Inhibitor to Treat People with Advanced Solid Tumors

Clinicaltrials.gov identifier: [NCT05932862](#)

Treatment
Treatment study for people with advanced solid tumors


[More info](#)



Social Support and Coping Strategies Among LGBTQIA+ Cancer Patients

Surveys, Registries, Interviews
This study explores how different levels of support systems influence coping strategies among LGBTQIA+ cancer patients

[More info](#)




PROMISE

PROMISE Registry: A Prostate Cancer Registry of Outcomes and Germline Mutations for Improved Survival and Treatment Effectiveness

Clinicaltrials.gov identifier: [NCT04995198](#)

Surveys, Registries, Interviews
A screening registry for people diagnosed with prostate cancer

[More info](#)



BRCA-P

BRCA1 Breast Cancer Prevention Study

Denosumab for Breast Cancer Risk Reduction in Women With an Inherited BRCA1 Mutation (The Breast Cancer Prevention Study)

Clinicaltrials.gov identifier: [NCT04711109](#)

Prevention
Prevention study enrolling women ages 25-55 with a BRCA1 mutation

[More info](#)



<https://bit.ly/force-research>

Research Search and Enroll Tool

Custom database of studies enrolling people with inherited mutations.

- Study listings written in plain language
- Includes studies on:
 - Treatment
 - Detection, prevention, interception, risk
 - Quality of life
 - Surveys and registries

Printer Friendly Page

BRCA-P

BRCA1 Breast Cancer Prevention Study

Denosumab for Breast Cancer Risk Reduction in Women With an Inherited BRCA1 Mutation (The Breast Cancer Prevention Study)

Clinicaltrials.gov identifier:
[NCT04711109](#)

Prevention
Prevention study enrolling women ages 25-55 with a BRCA1 mutation

Study Contact Information:
For additional information, please contact:
Judy E. Garber, MD, MPH: (617) 632-5961 or by email: judy_garber@dfci.harvard.edu

THIS STUDY IS OPEN TO:

You may be eligible to participate in the BRCA-P Study if you:

- Are a woman who has a confirmed BRCA1 gene mutation (variant)
- Are 25 to 55 years old Do NOT have a history of breast or ovarian cancer
- Are not pregnant or breastfeeding
- Have not had a mastectomy (removal of breast(s) by surgery)

We encourage women of all racial and ethnic groups to participate in this study so that it fully represents all populations affected by BRCA1 mutations.

THIS STUDY IS NOT OPEN TO:

The study is not open to people assigned at birth as male.

The study is not open to women:

- who have had a prior bilateral mastectomy.
- who have a history of breast or ovarian cancer (including fallopian and peritoneal cancer).

State Laws on Insurance Coverage for Breast Screenings

Information about state laws related to insurance coverage for care.

- 23% of respondents had difficulty paying for guideline-recommended breast screening.

State Laws

At the federal level, the [Affordable Care Act](#) requires coverage of certain cancer screenings at no cost to the patient. These screenings are appropriate for people at average risk of cancer. Additional cancer screenings are typically recommended for people with an inherited genetic mutation that increases their cancer risk. Many states have laws requiring coverage of these "supplemental" screenings and other health services for individuals at increased risk of cancer.

Click below to learn about your state's breast screening law(s). In the coming months, we will add information about laws for other high-risk cancer screenings.

[Glossary of Terms](#)

Alabama +

Alaska +

Arizona

Arkansas

California

Breast Screening

No state law. This state follows the federal breast cancer screening law:

- Coverage of annual breast cancer screening mammograms (including tomosynthesis/mammograms) with no copay, deductible, or coinsurance starting at age 40
 - Mammograms before age 40 and screening with other technologies such as MRI or ultrasound are not covered by federal law and cost-sharing applies
- Includes most individual and group health plans
- Women only

[Take Action Now](#)

[Become an Advocate](#)

[2024 Policy Priorities](#)

[Federal Policy](#)

[Advocacy Archive](#)

Interested in current legislative efforts?
Visit the Public Policy section of our website for information about

Kentucky

Breast Screening

- Currently follows the federal breast cancer screening law

Effective January 1, 2025

- Follows National Comprehensive Cancer Network (NCCN) guidelines
 - Coverage of supplemental/high-risk screening and diagnostic imaging with no copay, deductible, or coinsurance
- Includes most individual and group health plans, and Medicaid
- Gender-neutral

Note: Coverage with no cost-sharing applies to in-network providers and facilities only. Unless explicitly stated, these laws may not apply to Medicaid, Medicare, self-funded, high-deductible, catastrophic, ERISA, federal, or small employer health plans.

Disclaimer: FORCE does its best to reflect information about current laws that benefit the hereditary cancer community. The information provided may not be comprehensive and is not a guarantee of coverage. Contact your health plan or [state insurance commission](#) for additional information.

Don't have a known genetic mutation but have dense breasts? Visit [DenseBreast-info.org](#) for the latest on state and federal laws related to breast density notification and screening.



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Appeal Letters and Financial Resources

Providing sample appeal letters and links to programs and partners that offer financial assistance.

- 54% of respondents needed financial support.
- 73% of respondents found it hard to pay for fertility preservation.

Our sample letters help you appeal insurance denials

FORCE has created sample appeal letters for a variety of screening and preventive services as well as treatments needed by members of our community. Simply click on the link to download the letter template in a Microsoft Word file.

It is important that you personalize the letter to include details about your unique circumstances and include supporting documentation such as genetic test results, doctor's notes, etc. to make a solid case for approval. You should also ask your healthcare provider (surgeon, oncologist, etc.) to submit an insurance appeal on your behalf or to write a letter of medical necessity which you can include with your written appeal.

Need help with an appeal for a service or situation not listed? [Email Us](#) for assistance.

Genetic Services

- [BRCA counseling and/or testing](#) - women
- [BRCA counseling and/or testing](#) - men

Cancer Screening

- [Breast screening MRI](#) - women with BRCA mutation
- [Breast screening MRI](#) - women with mutation other than BRCA
- [Breast screening MRI](#) - women with 20% or higher risk (no known mutation)
- [Colonoscopy](#) - people with Lynch syndrome
- [Mammogram](#) - women with BRCA mutation
- [Mammogram](#) - women at increased risk of breast cancer (no genetic testing or no genetic mutation)

Find resources to help pay for care

FORCE does not provide financial assistance. However, we are happy to share these national resources.

Genetic Services

Low-cost or no-cost genetic testing is available from many labs and organizations.

[Find Resources](#)

Screening

Some organizations offer financial assistance for specific cancer screenings, such as mammograms and colonoscopies.

[Find Resources](#)

Risk-Reducing Surgeries

Limited assistance is available to offset the out-of-pocket costs of risk-reducing surgeries.

[Find Resources](#)

Fertility Preservation

Financial assistance for fertility services may be available to individuals undergoing cancer treatment or hereditary cancer risk-reducing surgery.

[Find Resources](#)



Solving Insurance and Healthcare Access Issues | since 1996

Patient Advocate Foundation

Established in 1996, Patient Advocate Foundation is a national 501(c)(3) non-profit organization which provides case management services and financial aid to Americans with chronic, life-threatening, and debilitating diseases.

Partnership Program

Working with partners to increase access to information, inclusive care and resources.

Through our partnership program, we work together with other organizations to advocate for greater awareness, broader access to care, and better treatment and prevention options for all those who are impacted by hereditary cancer.

- You can view or search for partners below.
- If you are interested in becoming a partner, you can read more about our program and [apply here](#).

Find a Partner

Search for a Partner by Areas of Focus (Multiple checkboxes allowed.)

AND - OR

And = Both (or more) of your selections must be relevant to this partner. This will narrow your results significantly.

Or = Any of your selections must be relevant to this partner. This will provide a larger number of results.

- | | |
|--|--|
| <input type="checkbox"/> Breast cancer | <input type="checkbox"/> Race, ethnicity, sexual orientation |
| <input type="checkbox"/> Gastrointestinal cancer (colorectal, gastric, pancreatic) | <input type="checkbox"/> Financial support or navigation |
| <input type="checkbox"/> Gynecologic cancer (endometrial, fallopian tube, ovarian) | <input type="checkbox"/> Genetics |
| <input type="checkbox"/> Melanoma | <input type="checkbox"/> Behavioral health or wellness |
| <input type="checkbox"/> Urogenital cancer (bladder, kidney, prostate) | <input type="checkbox"/> Clinical services |
| <input type="checkbox"/> Other cancers | <input type="checkbox"/> Research |
| <input type="checkbox"/> Hereditary cancer | <input type="checkbox"/> Health Equity |
| | <input type="checkbox"/> All Cancers |

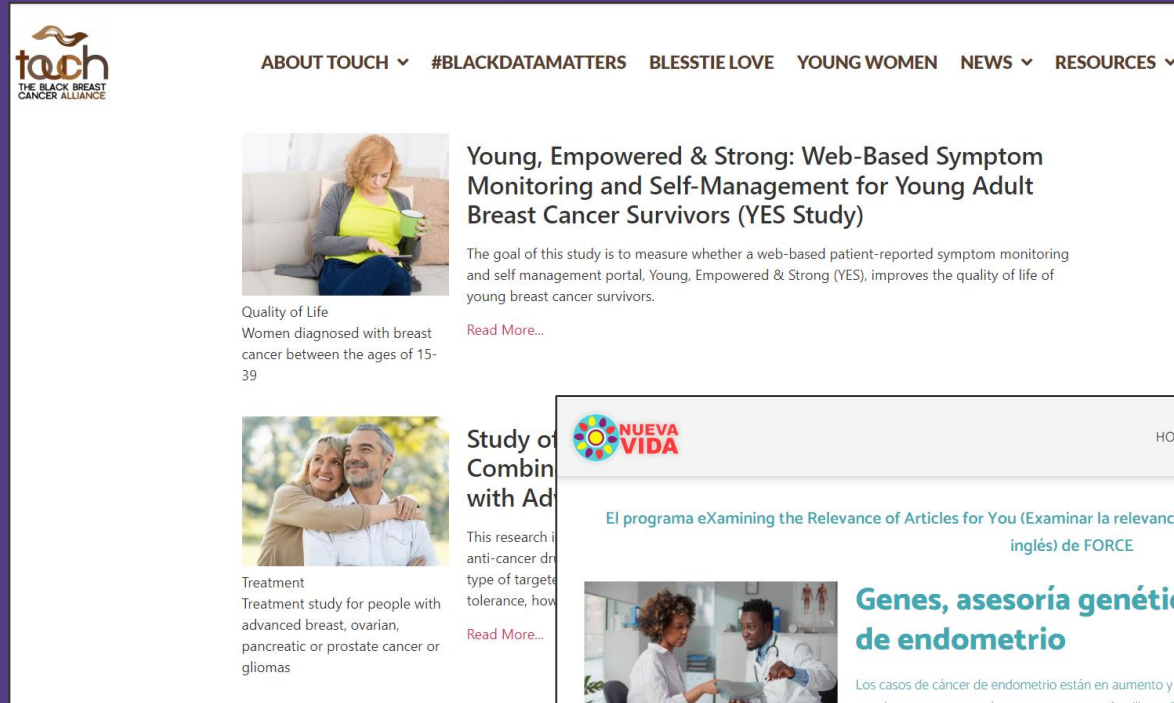


All Partners

- | | | |
|--|---|--|
| ▶ ABCD: After Breast Cancer Diagnosis | ▶ GI Cancers Alliance | ▶ Patient Advocate Foundation |
| ▶ Academy of Oncology Nurse and Patient Navigators | ▶ HIS Breast Cancer Awareness | ▶ Patient Empowerment Network (PEN) |
| ▶ AIM at Melanoma | ▶ Hope for Stomach Cancer | ▶ Pink Fund |
| ▶ AliveAndKickn | ▶ Hospital Oncológico Dr. Isaac González Martínez | ▶ Pink Ribbon Moms |
| ▶ AnCan | ▶ Hospitales HIMA•San Pablo | ▶ Prevent Cancer Foundation |
| ▶ Bag It | ▶ JScreen | ▶ Project Life |
| ▶ Basser Center for BRCA | ▶ Keepers of the Flame Foundation, Inc. | ▶ Prostate Conditions Education Council |
| ▶ Bay Area Cancer Connections | ▶ Know Your Lemons Foundation | ▶ PTEN Hamartoma Tumor Syndrome Foundation |
| ▶ Black Health Matters | ▶ Let's Win Pancreatic Cancer | ▶ SHARE Cancer Support |
| ▶ Bloom Syndrome Association | ▶ Living Beyond Breast Cancer | ▶ Sharsheret: The Jewish Breast & Ovarian Cancer Community |
| ▶ Breast Cancer Resource Center | ▶ Male Breast Cancer Global Alliance | ▶ Surviving Breast Cancer |
| ▶ Breast Cancer Support Services of Berks County | ▶ Male Breast Cancer Happens | ▶ Susan G. Komen |
| ▶ Breastcancer.org | ▶ Malecare | ▶ The Beautiful Gate Cancer Support and Resource Center |
| ▶ BreastReconstruction.org | ▶ Mayberry Memorial | ▶ The Chrysalis Initiative |
| ▶ Byrd Cancer Education and Advocacy Foundation | ▶ Metastatic Breast Cancer Alliance | ▶ The Clarity Foundation |
| ▶ Cancer Support Community | ▶ Metavivor Research and Support, Inc. | ▶ The Missing Pink Breast Cancer Alliance |
| ▶ CCARE Lynch Syndrome | ▶ National Alliance for Hispanic Health | ▶ The Raymond Foundation |
| ▶ Cierra Sisters | ▶ National Association of Chronic Disease Directors | ▶ Tigerlily Foundation |
| ▶ Colon Cancer Coalition | ▶ National Coalition for Cancer Survivorship | ▶ Touch, The Black Breast Cancer Alliance |
| | ▶ National LGBT Cancer Network | |

Partners Share Syndicated Content

Partners help disseminate XRAY articles and research studies using syndicated content.



The screenshot shows the TOUCH website header with navigation links: ABOUT TOUCH, #BLACKDATAMATTERS, BLESSTIE LOVE, YOUNG WOMEN, NEWS, and RESOURCES. The main content area features two articles:

- Young, Empowered & Strong: Web-Based Symptom Monitoring and Self-Management for Young Adult Breast Cancer Survivors (YES Study)**
The goal of this study is to measure whether a web-based patient-reported symptom monitoring and self management portal, Young, Empowered & Strong (YES), improves the quality of life of young breast cancer survivors.
[Read More...](#)
- Quality of Life**
Women diagnosed with breast cancer between the ages of 15-39
- Study of Combining with Ad**
This research i anti-cancer dr type of target tolerance, how
[Read More...](#)
- Treatment**
Treatment study for people with advanced breast, ovarian, pancreatic or prostate cancer or gliomas



The screenshot shows the NUEVA VIDA website header with navigation links: HOME, ABOUT, SERVICES, RESEARCH, CONTACT, and a DONATE button. The main content area features two articles:

- El programa eXamining the Relevance of Articles for You (Examinar la relevancia de artículos para usted o XRAY, por sus siglas en inglés) de FORCE**
- Genes, asesoría genética y desigualdades en el cáncer de endometrio**
Los casos de cáncer de endometrio están en aumento y es un tipo de cáncer hereditario. La asesoría genética tiene ventajas tanto para las personas con cáncer como para sus familiares. Sin embargo, las mujeres negras con cáncer de endometrio, por lo general, presentan resultados peores que las mujeres blancas. Las mujeres negras con cáncer de endometrio que dan positivo para una mutación hereditaria tienen menos probabilidades de poder consultar a un asesor genético. Es por estas desigualdades que las mujeres negras se beneficiarían al tener un mejor acceso y ser canalizadas con especialistas en asesoría genética. (Publicado el 14/12/23)
[Leer más](#)
- La inmunoterapia mejora los resultados del tratamiento contra el cáncer de endometrio avanzado**
El tratamiento estándar contra el cáncer de endometrio avanzado puede cambiar en un futuro cercano. En un estudio se descubrió que las personas con cáncer de endometrio avanzado o recurrente que recibieron inmunoterapia con quimioterapia presentaron mejores resultados que las personas que sólo recibieron quimioterapia. (Publicado el 4/12/23)
[Leer más](#)

Partner Collaborations

Working with partners to increase access to information, inclusive care and resources.

August 12, 2024

WHY GENDER MATTERS IN BREAST CANCER CARE

A new survey of healthcare providers, policy, and advocacy organizations conducted by [FORCE](#) and [Living Beyond Breast Cancer](#) in partnership with the [National LGBT+ Cancer Network](#) identified improving gender and sexual orientation inclusivity as a priority in providing competent care.

Every patient should have high-quality health care that meets their needs. Many health issues are related to gender or are impacted by gender—everything from cancer screenings, drug prescriptions, and health recommendations for diet or heart health to the impact of hormonal status on treatment plans [\(1-8\)](#).

Clear communication between patient and provider is needed to ensure appropriate care. Healthcare is best when patients can effectively talk and be heard by their provider and feel safe disclosing relevant details that may impact their situation [\(9-11\)](#). Unfortunately, we know that many people, especially LGBTQIA+ people, don't have access to high-quality care or feel safe disclosing relevant details with their providers [\(12-14\)](#). Guidance for providers on best practices for cancer care for gender-diverse patients is sparse but emerging [\(15-19\)](#).



<https://bit.ly/force-gender-matters>

Partner Collaborations

Working with partners to increase access to information, inclusive care and resources.

WHAT YOUR GRANDPARENTS DIDN'T KNOW ABOUT CANCER COULD SAVE YOUR LIFE!



Do you know your family health history? Does your family talk about the topic? Let's break the cycle of silence! Join FORCE and the National Pan-Hellenic Council for a free workshop about cancer genetics and how this information could protect your family.

Wednesday, September 18 at 9:00 PM ET

Join FORCE and the National Pan-Hellenic Council for a free lifesaving workshop!

Register now:
bit.ly/nphc-force-workshop



Juanita Rogers, MS, CHES
FORCE Vice President of Health Education and Communication



Verinda Hobbs
FORCE Partnership Strategy Manager
Cancer Previvor



Angela Trepanier, CGC
Genetic Counselor
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FORCE Board President
Colorectal and Endometrial Cancer Survivor



Junius Nottingham, Jr.
CEO of J-NOTT-GTT Corp.
Colorectal Cancer Survivor
FORCE Volunteer

<https://bit.ly/nphc-force-workshop>

Stay in Touch!

Website: FacingOurRisk.org
Helpline: 866-288-RISK
Email: info@FacingOurRisk.org
Get Social: [FacingOurRisk](#)

