


Talking to Adult Family Members About Cancer Risk: Results from the ABOUT Network

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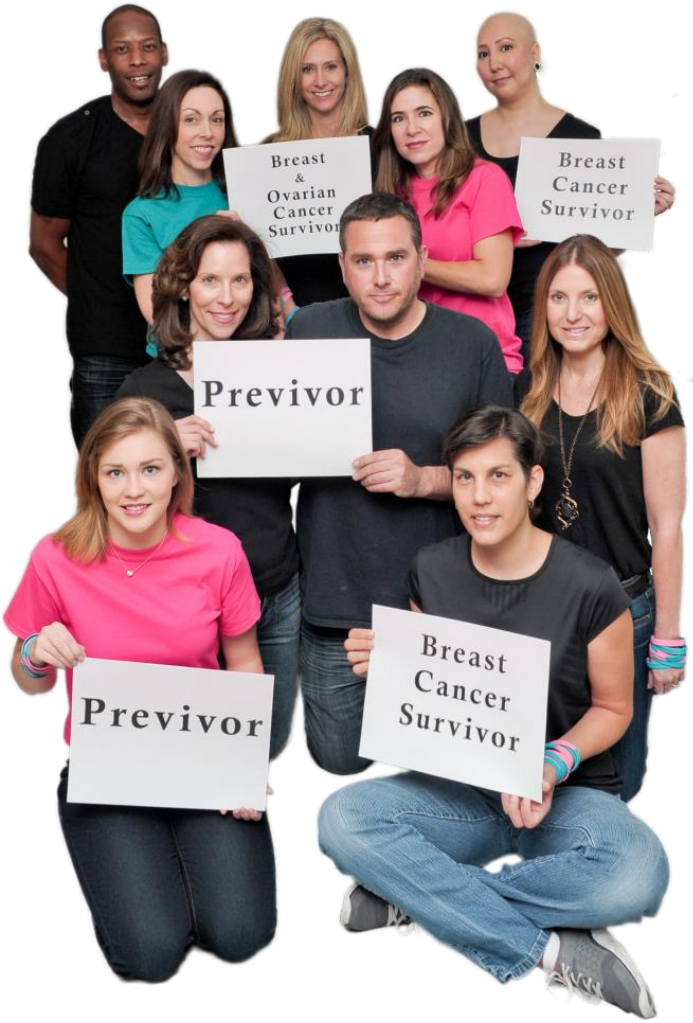

Mission Statement

Improve the lives
of individuals and families
affected by hereditary breast,
ovarian and related cancers

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FORCE: Facing Our Risk of Cancer Empowered

- Established in 1999 as an education and support organization for women affected by hereditary breast and ovarian cancer
- Over 50 outreach groups around the U.S. and international affiliates
- Programs include outreach, education and support for *individuals and families* affected by HBOC—survivors, previvors, family members, caretakers, etc.
- A leader in legislative, regulatory and research advocacy on behalf of the high risk cancer community
- The most comprehensive repository of expert-reviewed information on hereditary breast and ovarian cancer

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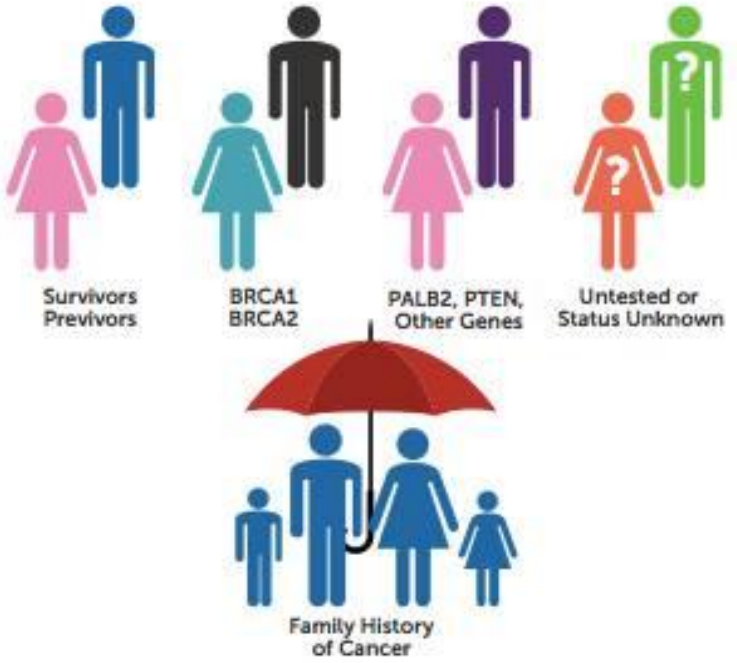
FORCE serves all people affected by HBOC



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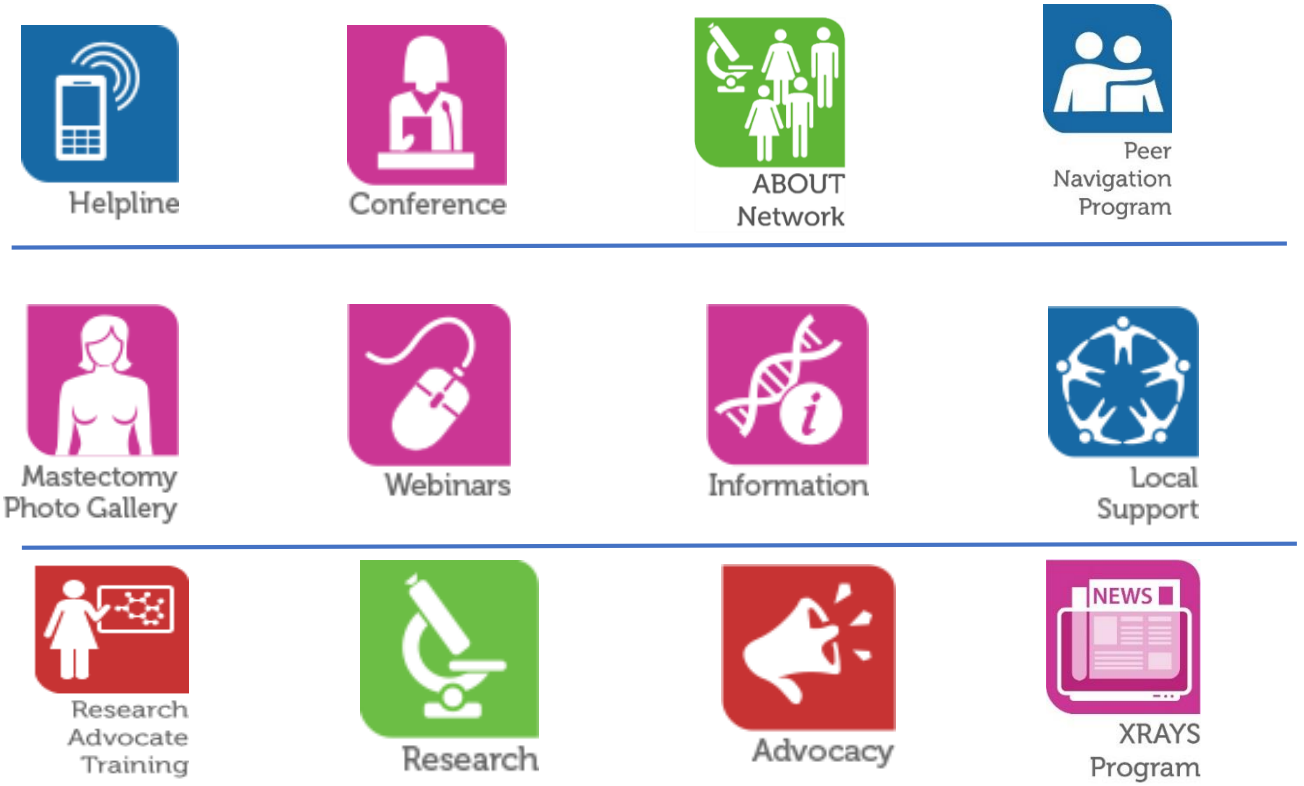
FORCE empowers patients through our programs



ABOUT Patient-Powered Research Network

- ABOUT is a research registry developed and governed by and for the HBOC community
- Result of 10 year collaboration between FORCE and University of South Florida
- Enrolled 8000 participants from HBOC community
- Current partners include Michigan Department of Health and Human Services and several advocacy groups

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USF
UNIVERSITY OF SOUTH FLORIDA

Black Women's Health Imperative

OVARIAN CANCER RESEARCH FUND

SHARSHERET

Ovarian Cancer National Alliance
We Work To Save Women's Lives

YSC Young Survival Coalition

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ABOUT Patient-powered Research Network

- ABOUT research is designed and conducted by people from within the HBOC community
- Research team belongs to the community we are studying
- We meet people out in the community to turn their real-world experiences and questions into relevant and scientifically rigorous research
- One of PCORnet's 20 patient-powered, condition-focused research networks

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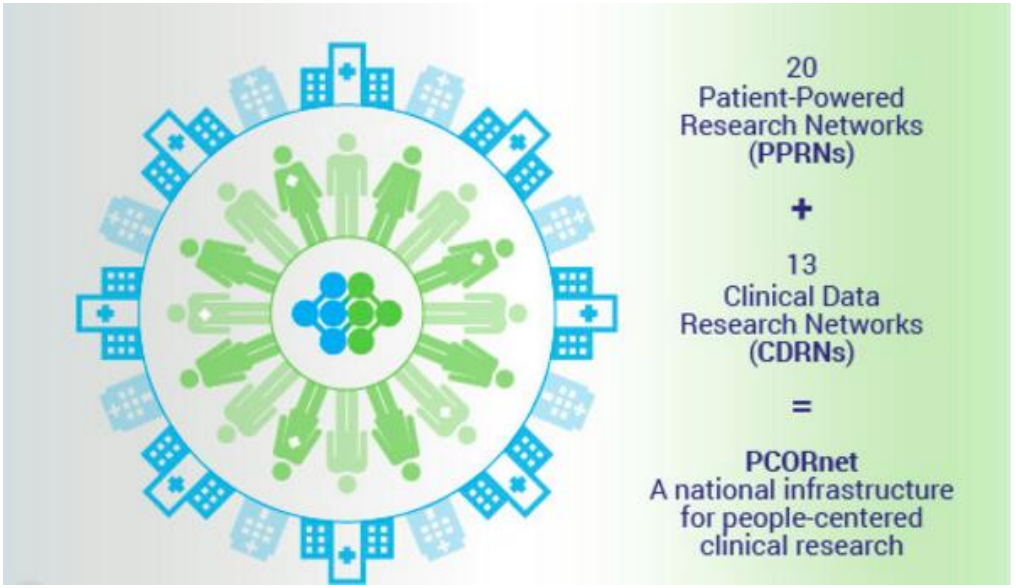
What is PCORnet?

- Research Network

  Conducting

  Patient-Centered Research

- Used in Research:
  - Patients
  - Researchers
  - Hospitals
  - Health Plans
  - Data



What Consumers Bring to the Table

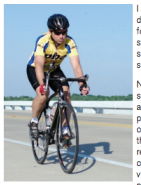
- Understand the gaps and barriers to care because they have lived them
- Bring a sense of relevance and urgency
- Low tolerance for bureaucracy, duplication, wasted efforts and politics

Voices of FORCE

In each issue, we'll invite a FORCE member to share an insightful perspective, a valuable experience, or a touching story to help others who are dealing with issues of hereditary breast and ovarian cancer

Participating in Pancreatic Cancer Clinical Trials

by David Dessert



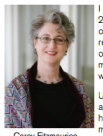
David Dessert

I am a pancreatic cancer survivor with a BRCA2 deleterious mutation. Although chemotherapy followed by surgery were effective for me, statistics for pancreatic cancer are grim, showing a 75% cancer recurrence rate after surgery.

No reliable pancreatic cancer treatments exist, so I researched clinical trials—every treatment available today is thanks to previous cancer patients who went through clinical trials. My oncologists informed me only about trials at their own hospitals. Expanding my options, I reviewed all pancreatic-specific trials, focusing on PARP inhibitors, platinum-based treatments, vaccines, and others. I found research papers about my specific BRCA2 mutation and contacted the authors to volunteer my participation in research. I felt that I was more likely to get results by bringing my list of 8-10 specific trial summaries to my 20-minute appointment with my busy oncologist.

Fighting Breast and Ovarian Cancer Through Research:

by Carey Fitzmaurice



Carey Fitzmaurice
Credit: Jen Farello Photograph

I was diagnosed with Stage IIIC ovarian cancer in 2006 at the age of 37. I completed my initial course of chemotherapy and enjoyed almost a year of remission. When the cancer returned, my gynecological oncologist thought that Avastin showed promise to help me. I did not hesitate to enroll in the trial using it since that was the only way to get this drug.

Unfortunately, I was diagnosed with Stage 2b breast cancer after only a few months on the trial, so I had to stop and have surgery for that. Knowing I was positive for a BRCA mutation, I tried to schedule a prophylactic mastectomy but the ovarian cancer treatment made that difficult.

The second trial I joined was for PARP inhibitors. Participants were BRCA+ with recurrent ovarian cancer. I participated for 15 months and it worked very well. I hope that PARP inhibitors can be brought to market soon.

While on both trials I felt as if I was getting the red carpet treatment. True, there were more blood draws and other tests, but fewer lines to wait in while getting them! Trial participants have a research nurse to call on for any questions and all aspects of care are integrated.

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What are Patient Roles in About?

- Identify Important Research Gaps
- Help Prioritize Research Questions
- Participate in the Design and Conduct of Research Proposals
- Participate, as Partners, in Network Decision-Making
- Enroll in the Registry and Participate in Research Studies for which They Qualify

How ABOUT Develops Research Questions

- Solicit community's input, guidance, and engagement at every step
- Generate and refine the important patient questions that are highest priority into answerable research questions using our Generator And Percolator (GAP) Process
  - Input
    - Inquiries from community to helpline, message boards, outreach groups
    - Engagement surveys

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What the HBOC Community Tells Us

"I am at high risk & have been advised to remove my ovaries by age 35. That's not ok with this unmarried woman with no kids...& it shouldn't have to be."

"I'm 45 and had ooph 2 years ago. I've gotten conflicting opinions from my doctors on hormones. Most recommended that we wait and see how things were going."

"I'm 38. My mom died of ovarian cancer. My BSO is next week. My gyn-onc told me:

'There are increased risks of heart disease and osteoporosis from premature menopause.'

I'm at risk for these diseases. Should I wait until closer to menopause? It's a horrible, hard thing; there is substantial risk no matter what I do."

"I am 19 years old, and recently been tested positive for the BRCA2 gene. For the first couple months I was okay. Then I had a doctor discussing the prophylactic surgeries I would eventually need to undergo, where he then proceeded to pinch my cheek and tell me, 'There won't be much of you left, but you're handling it well.'"

"I am at my wits end....just diagnosed with BRCA2 positive and 52. Dr. is pushing for double mastectomy, which really scares me."

"There is a lot of conflicting information on what is appropriate for prostate screening, ie. is PSA necessary or meaningful for men with mutations?"

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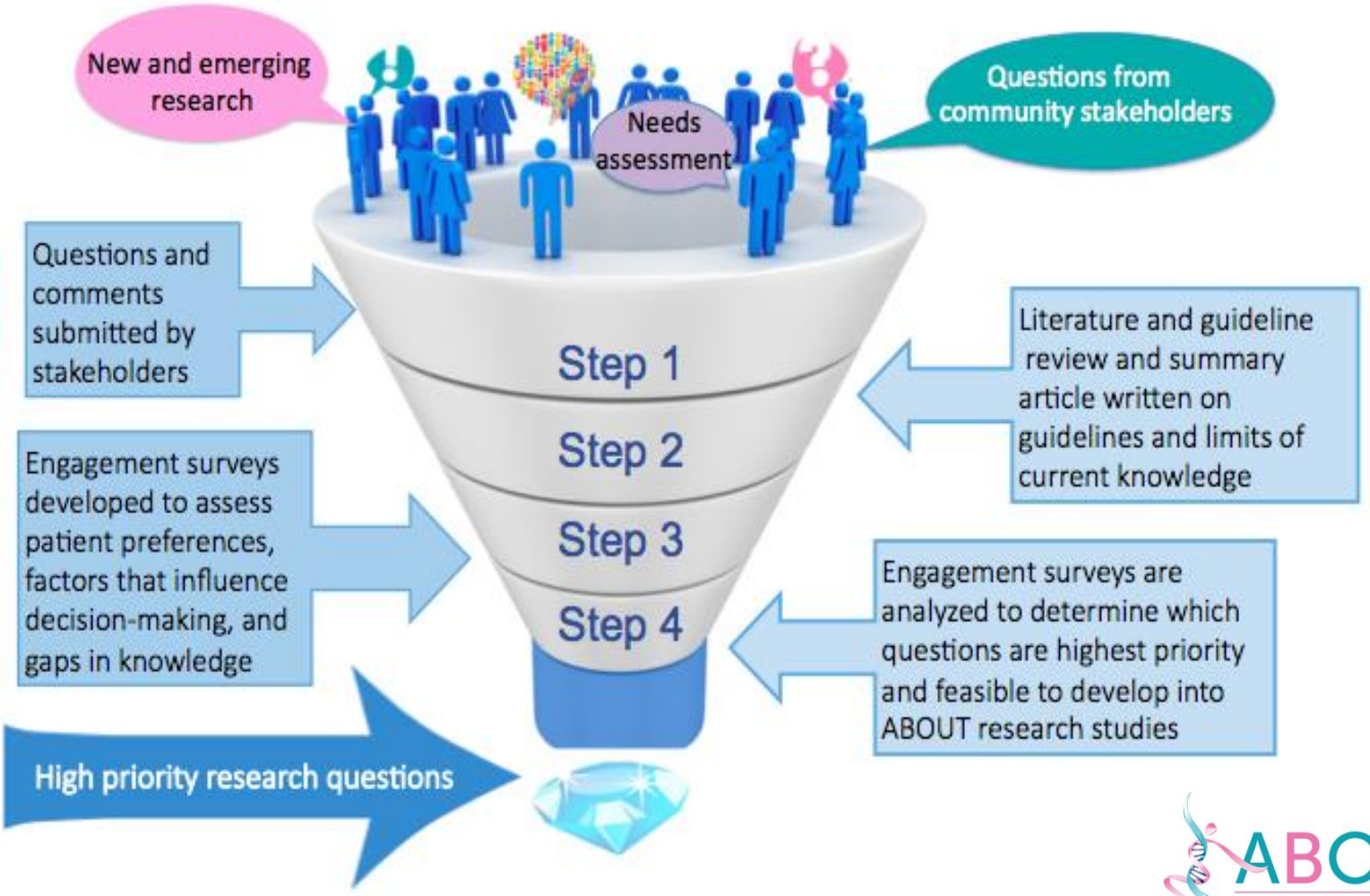
Original GAP Tools



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GAP 360 Process

Generate
- Constituent questions, emerging research, gaps
- Formulate into research question or hypothesis

Assess
- Literature review/Advisory board consulted
- Article written
- Engagement survey deployed

Prioritize
- Steering Committee (SC) and Research Work Group (RWG) scoring on priorities
- Executive Committee (EC) and Research Team (RT) score feasibility
- Results compiled and reported back to SC, RWG, EC and RT
- Recommendations for next steps

Plan (Studies that are promoted)
- Study design considerations: size, length, eligibility, resources, partnerships and collaborations
- Potential funding sources identified

Proposal (Studies that are promoted)
- Study team assembled
- Objectives, aims, milestones, and timeline developed.
- Proposal written and submitted

Perform
- Study team performs research according to proposal

Publish
- Draft technical and lay articles
- Publish through open access
- Disseminate through FORCE, ABOUT and partner channels

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Assess: Engagement Surveys

- Provide a rapid, real-world setting snapshot of HBOC community and:
  - factors that influence medical decision-making
  - variability in recommendations and care
  - patient reported outcomes and preferences
  - patient understanding of prevailing knowledge on health and outcomes
- Allows us to rapidly incorporate knowledge into research study design

- How Do Women Decide Whether Or Not To Remove Their Uterus During BSO?
- How Women Manage Menopause Symptoms After Risk-reducing Removal of Ovaries and Fallopian Tubes
- Decision Making on the Use of Hormones After Risk-reducing Removal of Ovaries and Fallopian Tubes
- Decision Making and Experiences with Risk-reducing Mastectomy
- **Your Experiences Talking to Family Members About the Inherited Mutation in Your Family: Results from the ABOUT Network Family Communication Survey**

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GAP 360

- 3 high-priority questions have been promoted to planning phase
  1. What are the differences in outcomes for women with BRCA mutations who choose hysterectomy vs. no hysterectomy during RRSO?
  2. Are people with BRCA mutations more sensitive to cardiac-damaging effects of chemotherapy than people without mutations?
  3. Can patient-generated interventions improve the uptake of cascade genetic testing through relatives?

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Engagement Survey: Family Communication

- Disseminated through ABOUT Network Partners
- 365 respondents
  - 98% Female
  - 1% Male
  - 1% prefer not to answer
- 350 respondents had undergone genetic testing

Family Communication Survey: Genetic Test Results

- 47% have a BRCA1 mutation
- 41% have a BRCA2 mutation
- 5% were negative for BRCA1 or BRCA2 mutations and have not had further testing
- 4% were told they had a variant of uncertain significance (VUS) in one or more genes that increase cancer risk
- Remaining 3% had mutations in one of the following: PALB2, ATM, RAD50, BARD1, CHEK2, PTEN, or APC

How did you find out about the mutation in your family?

- 48% were the first in their family to undergo genetic testing
- 15% said their mother was the first
- 12% said their sister was the first
- 10% said an aunt was first
- 8% said a female cousin was first
- 2% said their grandmother was first
- 1% said their father was first
- Other responses include niece, uncle, and son

Comments on the first to test

"(Female cousin) *At age 28, lived out of state. Our family 'heard' she was positive, but that is where the info ended until my sister was diagnosed with breast cancer, underwent bilateral mastectomy, cancer was discovered in the opposite breast as well during pathology and her doctor did the genetic testing too."*

"I lost a cousin to ovarian cancer in the 1990s. In the early 2000s, her younger half-sister was diagnosed with ovarian cancer. Their mom was my dad's sister, and she died of breast cancer. The second one with ovarian tested BRCA positive around 2005 and told all our cousins about it. My then-gynecologist said I didn't need to worry because it was on my dad's side of the family."

Who told you about the mutation in your family?

- 28% mother
- 21% sister
- 13% female cousin
- 11% an aunt
- 8% father
- 2% daughter
- 2% niece
- 1% grandmother

"I went to genetic counseling with my sister."

"I was already diagnosed w/breast cancer. A cousin calling to wish me luck w/my mastectomy casually mentioned the fact that many people in our family carry the BRCA2 gene."

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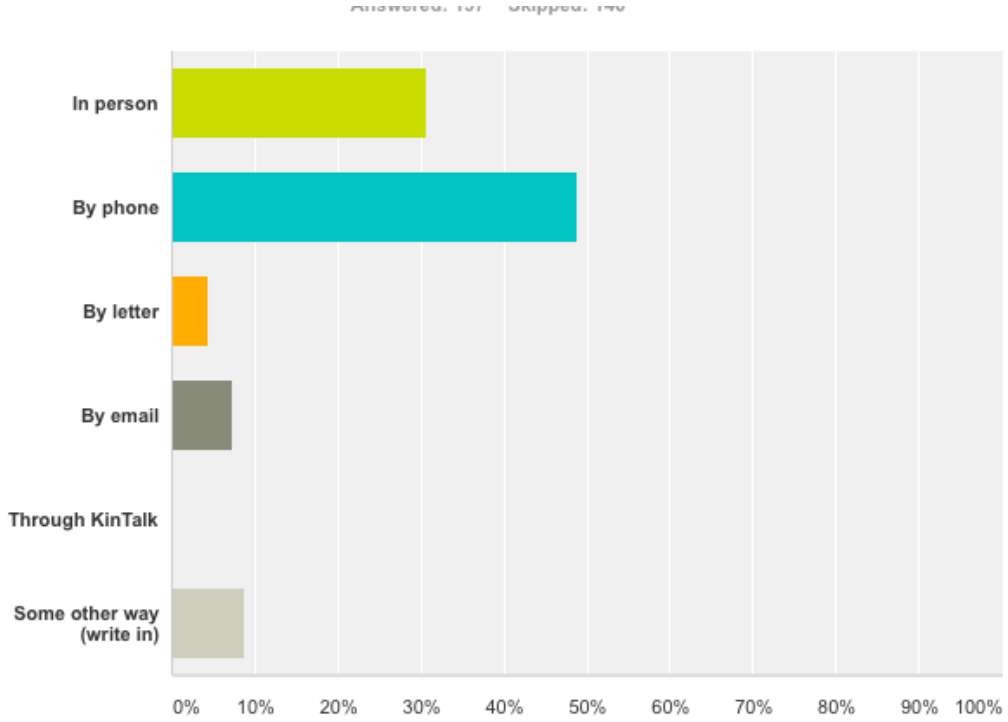
How were you told about the mutation in the family?



Other responses include attending the Appointment with their family member, text message, and Facebook messenger:

" Through a Facebook message to my sister. After my mother died from brca-caused breast cancer, my father estranged my sister and I from my mother's family. So we had no contact with them until my cousin found my sister through Facebook."

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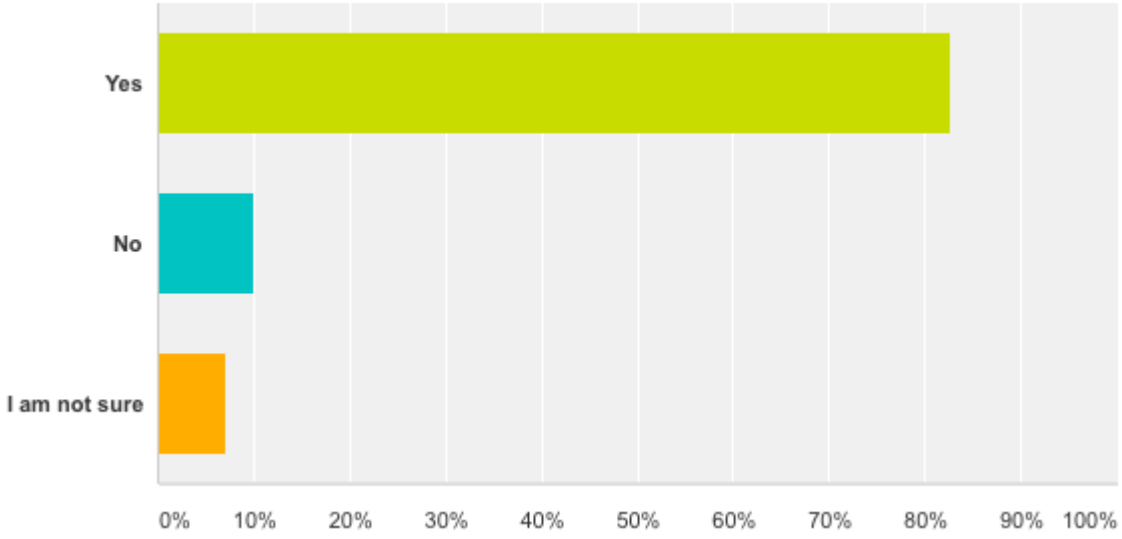
Were you satisfied with the way you were told about the mutation in your family?



"I knew we were high risk for cancer"

"When there are family issues, problems with communication occur."

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Most respondents shared the information with multiple family members

- 18% of respondents shared results with 6 or more male relatives while 36% said they shared with 6 or more female relatives
- 35% of respondents report sharing results with 3-5 male relatives while 37% of respondents report sharing results with 3-5 female relatives
- **10% of respondents said they did not share their test results with any male relatives** while only 3% report not sharing test results with any female relatives.

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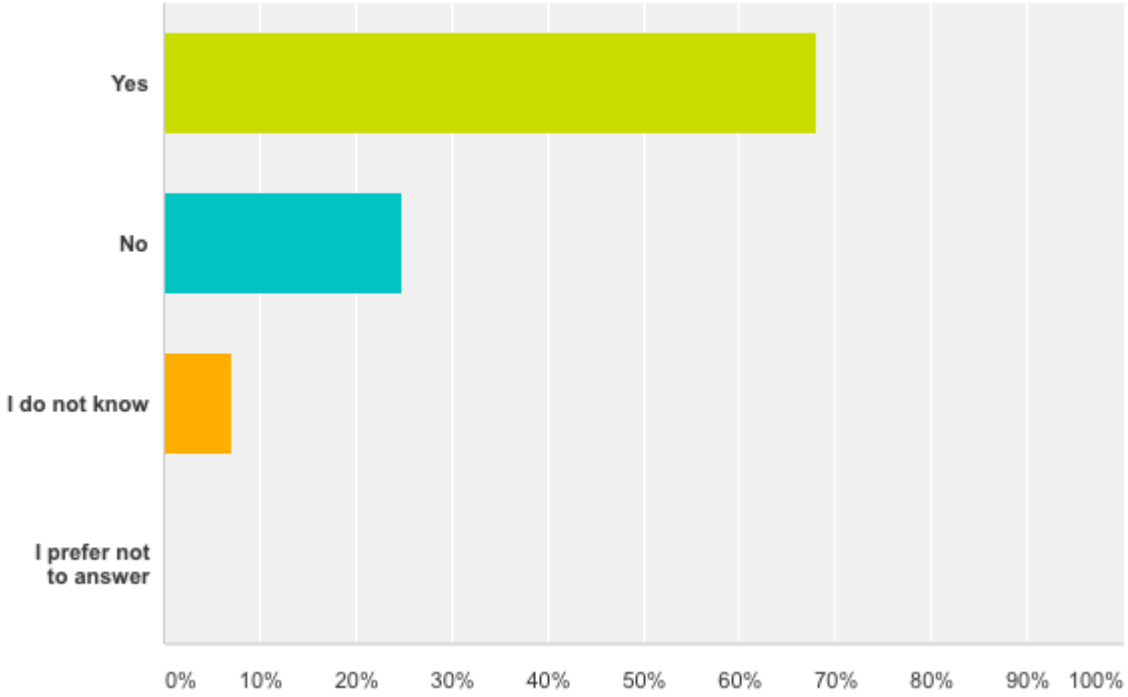
Have any of the blood relatives you shared genetic information with undergone testing?



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More female relatives have undergone testing than male relatives

- Only 2% of respondents said more than 6 male relatives had undergone testing, while 10% of respondents said more than 6 female relatives had undergone testing
- **41% of respondents said none of their male relatives had undergone testing** while only 4% of respondents said none of their female relatives had undergone testing

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Comments on family members testing

"Many cousins also tested after we were able to determine which side of the family the mutation came from. I only informed my parents. They then shared the news."

"Fairly recent so allowing time for siblings to share with their children either at the time of my surgery, or their testing. Plan to follow up in a few months with my nieces and nephews."

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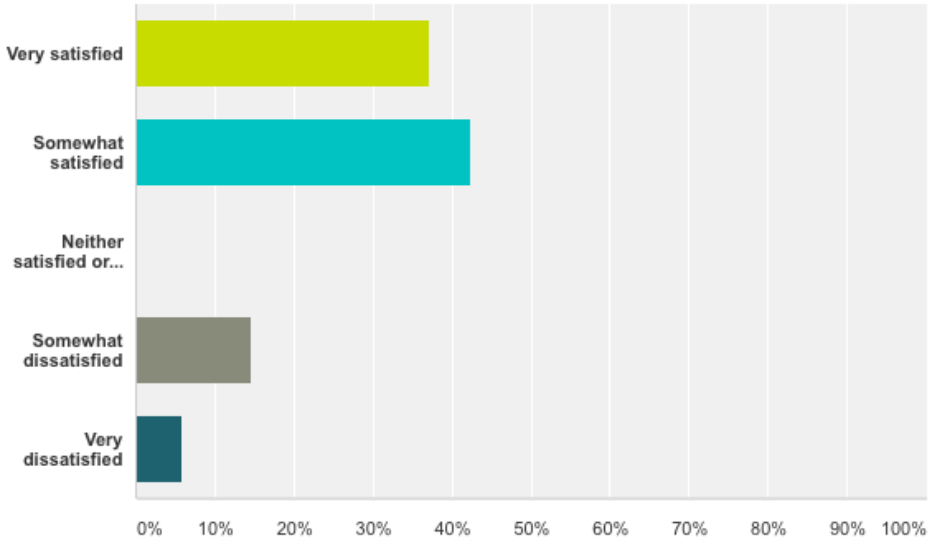
How satisfied are you with your experiences sharing genetic information with family?



"Most of them didn't care or show concern in following up with their doctors. They assume they won't get cancer like me."

"Having the test with a positive mutation helped catch my ovarian cancer early. Because it saved my life I am a big advocate for testing so I discuss the subject with family, friends and complete strangers."

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What resources were you given to share information with family?

- Template letter for family members- 18%
- Brochure or other printed material- 29%
- Material from the laboratory that did the genetic test- 32%
- Information about organizations that serve people with hereditary cancer- 32%
- Other resources- 8% (including inviting family members to the appointment, planning for communicating with family members, and recommendations from a book)

What types of resources would help you share genetic information with family?

- Print information (65%)
- Internet information (66%)
- Webinars (21%)
- Sample letter to family members (45%)
- Resources to help locate family members (17%)
- Resources to help my family member find a genetics expert (39%)

Comments on resources

"At my post-testing genetic counseling visit, we took time to talk about what type of information to convey to family members, what resources to give them, and my health care providers said I could share their contact details with my family members."

" This is a difficult issue since some doctors do not understand the need to be tested… we need to educate PCPs about this so they can inform our family members about the importance of being tested when they inquire about it….:

About half (48%) have not informed one or more relatives- we asked why.

- Not in contact with blood relatives (50%)
- Relative is under age 18 (33%)
- Honoring the wishes of the blood relative's parent or other close family member (18%)
- Did not think the relative would want to know (12%)
- Did not think to contact some family members (11%)
- Did not think it was their place to tell that relative (11%)
- Lack of resources to share the information (10%)
- Desire to keep the results private (8%)

Comments on not sharing information

"I'm good on what to share and how.. It's just hard figuring out which ones to share with so I'm not alarming a huge amount of people for no good reason."

"I've been too busy with my current cancer treatment, but plan to talk with my aunt and cousins at an upcoming family reunion."

"My mother was the main communicator in our family, and she passed away from breast cancer in 2003. I have maintained a minimal level of contact with her relatives. It is challenging to know how best to tell someone about my results, and very weird to think about talking about my ovaries and my breasts with my uncles..."

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Conclusions

- Most of our respondents (81%) are satisfied with how they were told about the mutation in their family
- Most shared the information with one or more blood relatives.
- Information was shared with more often with female relatives. 96% report at least one female relative has undergone testing
- 10% of respondents reported not sharing genetic information with any men in their family and 42% report that none of the men in their family have undergone testing

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Conclusions

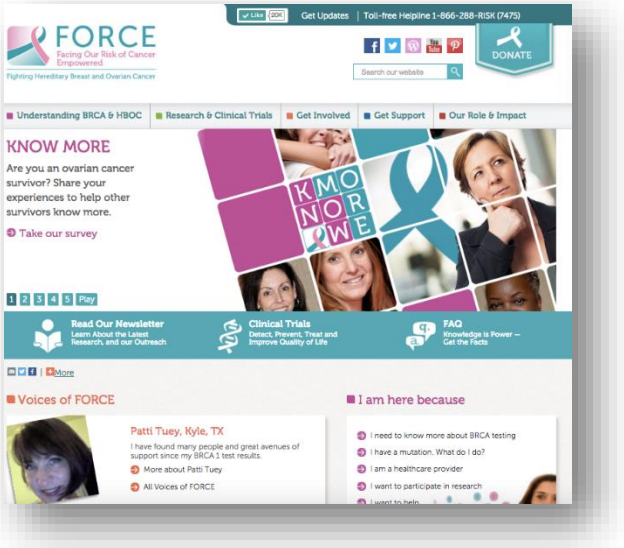
- Patients need resources for sharing information including print and Internet sources, sample letters to families, and resources on locating family members.
- About half of respondents have not shared their genetic information with one or more blood relative

Next steps

- Look at opportunities to develop and test patient-generated materials for sharing genetic information with family members

We hope you take home:

- There is value in engaging consumers in research beyond just studying them as subjects
- Consumers bring real world experience that cannot be harnessed any other way
- ABOUT is looking for collaborators to help us move forward on research studies for top priority questions



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Thank You!

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