### American BRCA Outcomes and Utilization of Testing: A Participant-Powered Research Network

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PCORI funded the development of PCORnet®, the National Patient-Centered Clinical Research Network, to make it easier and more efficient to conduct research. PCORnet is made up of Partner Networks that harness the power of large amounts of health data and patient partnerships.

Patient-Powered Research Networks (PPRNs) are networks operated and governed by patients, families, caregivers, and community members in close collaboration with clinical researchers, with the goal of shaping and conducting research to better serve their communities and improve their health outcomes. Several PPRNs, including American BRCA Outcomes and Utilization of Testing (ABOUT), participated as Partner Networks in PCORnet.

PCORI funded ABOUT's participation in PCORnet from 2015 to 2019. This report outlines the ABOUT network's achievements in building its research infrastructure capacity to

1. Create ways to involve patients, families, and caregivers in decision making about the network

2. Create a way to collect and share data reported by patients for research

3. Involve patients, caregivers, families, and communities in the research process, including recruiting people to participate in research studies

4. Lead or join in research studies that focus on the community's priorities

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<tr>
<th>Title</th>
<th>American BRCA Outcomes and Utilization of Testing (ABOUT) Network</th>
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<tbody>
<tr>
<td>Network design</td>
<td>Patient-Powered Research Network (PPRN)</td>
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| Lead partners | University of South Florida  
Facing Our Risk of Cancer Empowered (FORCE) |
| Other partners | Ovarian Cancer Research Alliance  
Sharsheret  
Young Survival Coalition |
| Participants | 12,981 |
| Area(s) of focus | Hereditary breast, ovarian, pancreatic, and prostate cancers, and melanoma |

**Network at a glance**

ABOUT is a PPRN that includes people affected by hereditary breast, ovarian, and related cancers. Hereditary cancers are caused by a mutation, or a change in a gene, that is present at birth. Mutations in BRCA genes can cause breast, ovarian, and related cancers such as pancreatic and prostate cancer and melanoma.

ABOUT is led by the University of South Florida and Facing Our Risk of Cancer Empowered, or FORCE, an advocacy group for individuals and families affected by hereditary breast, ovarian, and related cancers. To help conduct research, the network gathered information from advocacy groups, health insurers, and cancer treatment centers about people diagnosed...
with these cancers, people with a family history of these cancers, and people with the genetic mutations that cause these cancers. People also provided information themselves through ABOUT's secure website. The network includes 12,981 individuals affected by hereditary breast, ovarian, and related cancers.

**How does the network operate?**

The Executive and Steering Committees lead the network. Patients make up the majority of the Executive Committee, which also includes researchers and key staff from the University of South Florida and FORCE. The Steering Committee is made up of the Executive Committee as well as patients who received special training from FORCE and representatives from each advocacy partner. Two work groups include patients, researchers, doctors, and patient advocates. These work groups help shape and conduct research, determine the best ways to communicate with network participants, and encourage patient participation.

The goal of ABOUT research is to help people with hereditary cancers or an inherited mutation make informed medical decisions to improve their health and well-being. The network developed several tools to increase patient involvement in all stages of research. The primary tool was the GAP (Generate-Assess-Prioritize) 360 process. This process began when people affected by hereditary breast, ovarian, and related cancers generated medical research questions and submitted them through a portal on the network website, an email to a member of the Executive Committee, or a volunteer advocate. Then the Steering and Executive Committees, with feedback from the work groups,

- Assessed and prioritized the research questions
- Submitted research proposals
- Designed and performed studies and analyzed information
- Published research in formats for both the public and professionals

Other ways to increase patient involvement included a search tool that connected patients with research studies enrolling people affected by hereditary cancers and a process that matched trained volunteer research advocates with researchers seeking patient input.

**How did the network involve patients and other partners?**

Patients hold a majority of positions in the network. Cancer survivors, people who have a gene mutation, and representatives from patient organizations served on the Steering Committee. They also participated on committees that reviewed research ideas, planned and carried out research, and communicated with members of the network.

ABOUT worked with FORCE to develop a course that prepared patients to be involved in the network. Online and in-person sessions covered

- Breast and ovarian cancer
- Genetics
- Statistics
- Research study design
- Patient-centered research
- Medical ethics
- Government regulations for research
Who is in the network?

Population (as of 03/31/19)

Race/ethnicity
- 64% white
- 3% black
- 2% Asian
- 2% mixed race
- 29% no information
- 4% Hispanic

Sex
- 72% female
- 1% male
- 27% no information

Age
- 26% 18–44 years
- 41% 45–64 years
- 4% 65 or older
- 29% no information

The ABOUT network had 12,981 participants as of March 31, 2019. Information about patients for use in research studies came from patients themselves, health insurance companies, cancer treatment centers, patient advocacy groups, and genetic testing. Patients gave their consent before this information was provided.

While a Partner Network in PCORnet, the ABOUT network participated in 13 research studies.

How does the network support future research?
ABOUT is working with other PCORnet networks to identify opportunities for research on hereditary breast, ovarian, and related cancers.

To learn more about this network, visit www.pcori.org/RI-Sutphen013.

Glossary
Patient-Powered Research Networks (PPRN): PPRNs are operated and governed by patient groups and their partners and are focused on particular conditions or populations.

PCORnet: PCORnet is a network of networks that brings together patients, clinicians, researchers, and healthcare systems to share information and participate in research.