There are more than 100 kinds of cancer, each with a distinct pathology and a unique blend of hereditary and environmental triggers. People facing a cancer diagnosis often face decisions over several treatment options and little consensus on what will work best given their individual circumstances and preferences. Cancer can place severe physical, emotional, and financial burdens on patients and their families.

PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

1.69 MILLION people in the United States were diagnosed with cancer in 2016

$87.8 BILLION is estimated to be the direct medical costs for cancer in the United States in 2011

Source: Centers for Disease Control and Prevention

Research Addressing Questions That Matter

PCORI funds comparative clinical effectiveness research (CER) to determine which healthcare options work best for which patients, based on their needs and preferences. CER produces evidence that helps people make better-informed healthcare choices.

Patient-Centered Information for Decision Making in Localized Prostate Cancer

This study analyzed quality of life changes over three years among prostate cancer patients who received either radical prostatectomy (surgery), external beam radiotherapy (radiation), or those who pursued active surveillance. It found that those who had either surgery or radiation reported more adverse effects. However, quality of life levels evened out among all patients after three years. More information may be found at www.pcori.org/Penson007.

North Carolina Prostate Cancer Comparative Effectiveness & Survivorship Study

This project examined outcomes after two years among a racially diverse group of men with localized prostate cancer who underwent either surgery, radiation, or active surveillance. It found that men who chose either surgery or radiation reported more side effects than those who chose active surveillance. It also found that quality of life levels and adverse effects were similar after 24 months, regardless of the strategy chosen. Further details are at www.pcori.org/Chen008.
Building Capacity for Patient-Centered Research

PCORI is investing in people and infrastructure to support high-quality patient-centered research for years to come. **PCORnet, the National Patient-Centered Clinical Research Network**, will enable us to learn from the data and experiences of more than 145 million Americans. It is building capacity for research and other studies by supporting patient-driven networks and helping them connect with researchers who are studying similar topics, including cancer.

For example, one patient-powered network, **ABOUT PPRN**, will provide a critical resource for studies of hereditary cancer. It is enrolling people with a family or personal history of cancer who have undergone genetic testing for inherited mutations in genes such as BRCA, PALB2, and PTEN, which are associated with a high risk for specific cancers.

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**As of September 2017, PCORI has awarded $285 MILLION TO FUND 77 comparative clinical effectiveness research studies related to cancer**

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**BY THE NUMBERS**

**Most Studied Cancer Types**

- Breast: 22
- Colorectal: 12
- Lung: 12
- Prostate: 9
- Cervical: 8
- Blood: 5
- Head and Neck: 4

**Areas of Care Addressed**

- Prevention: 4
- Screening: 12
- Diagnosis: 10
- Treatment: 2
- Survivorship: 51

**Most Studied Populations of Interest**

- Racial/Ethnic Minorities: 51
- Older Adults: 32
- Women: 29
- Low Income: 25
- Urban: 15
- Rural: 10
- Low Literacy/ Numeracy: 9
- Individuals with Multiple Chronic Conditions: 9

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The **ABOUT PPRN** has enrolled 8,000 patients in its registry and continues to grow. It will enable faster, more accurate research on hereditary cancer. ABOUT has formed partnerships with:

- Black Women’s Health Imperative
- Ovarian Cancer Research Fund Alliance
- Sharsheret
- Young Survival Coalition

**UPDATED SEPTEMBER 2017 | RESEARCH DONE DIFFERENTLY®**