A Plain-Language Tool to Bridge the Health Literacy Gap for People with Inherited Cancer Risk

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INTRODUCTION

Background: Although numbers are improving, patient participation in clinical cancer research remains low.

Issue: Gaps in patient and provider awareness of clinical research opportunities, jargon, and hard-to-navigate study listings contribute to low participation.

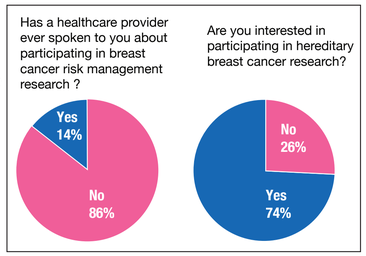
FORCE's Approach: FORCE's "Search and Enroll Tool" is a custom-designed database that curates and disseminates plain-language summaries of clinical research studies enrolling people with inherited mutations.

Conclusion: Users find the tool easy to use, and they are able to understand study eligibility and what is required of participants. Many users subsequently enrolled or intend to enroll in a hereditary cancer research study.

BACKGROUND

Only 7% of adult cancer patients enroll in treatment-related clinical trials, with even lower rates for genetics and quality-of-life studies.[1] Low enrollment in clinical trials leads to early study closures, slower progress and increased costs, with the possibility of poorer outcomes for cancer patients.

People with inherited mutations are interested in participating in hereditary cancer research, but few are being offered the opportunity by their healthcare team. In a 2024 FORCE survey, only 14% of people with inherited risk for breast cancer reported hearing about clinical research options from their healthcare providers, while 74% expressed interest.[2] Similar trends were reported by people at high risk for gynecologic and colorectal cancer.[3]

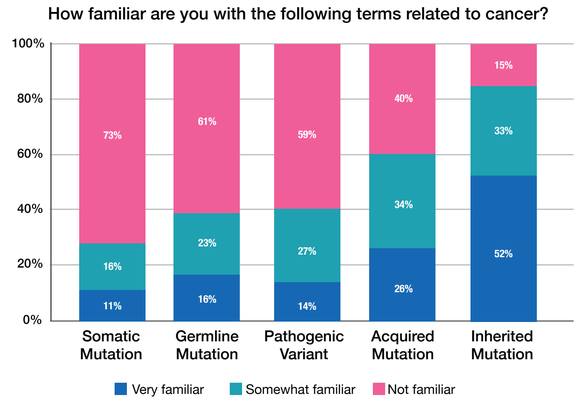


The development of cancer targeted therapies and new approaches to prevention and interception have led to an increase in research studies enrolling people with germline mutations. Dedicated efforts are needed to ensure that the hereditary cancer community is aware of clinical research opportunities.

HEALTH LITERACY IS A BARRIER

In 2020 FORCE surveys, 46% of oncology nurse and 55% of genetic counselors identified research jargon and health literacy as a major barrier to clinical trial referrals.[4,5]

In 2020, FORCE and other advocacy group members of the Consistent Testing Terminology Working Group surveyed patients with or at high risk for cancer about familiarity with terminology frequently used in research and found significant gaps in patient understanding of terms commonly used to in cancer research.[6]



In 2024, FORCE conducted focus groups of 24 women with or at high risk for hereditary breast cancer. Participants reviewed a cancer treatment and prevention study listing on ClinicalTrials.gov. All agreed that the study description was difficult to understand due to complexity and academic jargon and all agreed that Clinicaltrials.gov required a lot of time and practice to find studies relevant to their situation.[7]

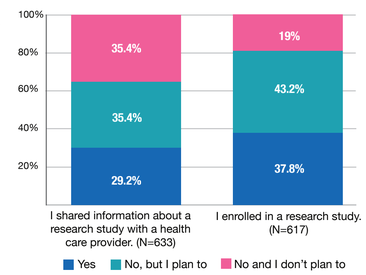
FORCE SEARCH AND ENROLL TOOL

In 2014, FORCE built our "Search and Enroll Tool" to help hereditary cancer patients find, understand, and enroll in relevant studies. The tool consists of a custom database with plain-language summaries of clinical research studies relevant for people with inherited cancer risk. Features include:

- Plain language descriptions of study goals, eligibility, and what will be required of participants.
- Built-in glossary.
- Printer-friendly version of study listings.
- Users can search for featured studies in the FORCE database and on ClinicalTrials.gov. Users can search by study type, cancer type, gene or biomarker, study location or key word.

Study listing features

Of the respondents, almost 38% stated that they had enrolled in a research study and 43% responded that they planned to enroll in a study.



> *I've found studies for myself, my sister and my daughter. It's empowering to help researchers understand hereditary cancers.*
>
> – Program user

> *I appreciate having this information readily available. It's easier to find relevant studies than having to sort through the NIH website.*
>
> – Program user

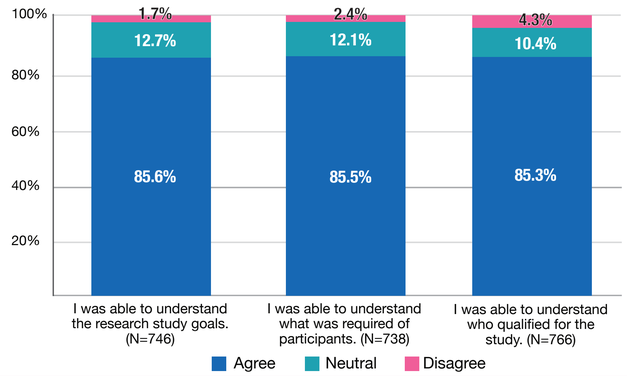
PROGRAM USER FEEDBACK

To evaluate FORCE's Search and Enroll Tool, FORCE has collected program feedback via an online survey since 2019.

Of 808 respondents, 81% indicated they were looking for screening or prevention studies, 58% were looking for studies on genetic counseling, testing or cancer risk, 49% were looking for studies on long-term health outcomes, 40% were looking for treatment studies, and 40% were looking for studies on behavioral health or quality of life.

Key results include:

- 85% were able to understand the study goals.
- 85% were able to understand what was required of participants.
- 85% were able to understand who was eligible for the study.



CONCLUSIONS

People with inherited cancer risk are highly motivated to participate in clinical research—but most are never informed about available studies by their healthcare team.

ClinicalTrials.gov is not patient-friendly and hereditary cancer patients find the site difficult to use and understand.

FORCE's Search and Enroll Tool bridges this gap by offering accessible, accurate, and easy-to-understand listings of studies enrolling hereditary cancer patients.

Results from our focus groups and survey demonstrate that the tool meets a critical need. Users reported high satisfaction, comprehension, and utilization of the tool to enroll in studies.

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