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

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FORCE
Facing Hereditary Cancer EMPOWERED

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] In a FORCE survey, only 14% of people at high risk for breast cancer reported hearing about clinical research opportunities from their healthcare providers, while 74% expressed interest (see Figure 1)[2].

In FORCE surveys, 46% of oncology nurses and 55% of genetic counselors reported research jargon and health literacy as barriers to clinical trial referral.[3-4]

FORCE, as part of the "Consistent Testing Terminology Working Group" identified major gaps in patient understanding of commonly-used cancer research terms (see Figure 2)[5].

In focus groups, women at high risk for breast cancer found study listing on ClinicalTrials.gov difficult to understand due to the complexity and jargon and noted that the site required a lot of practice to use.[6]

Dedicated efforts are needed to ensure that the hereditary cancer community is aware of clinical research opportunities.

Fig. 1: Survey results of people at high risk for breast cancer

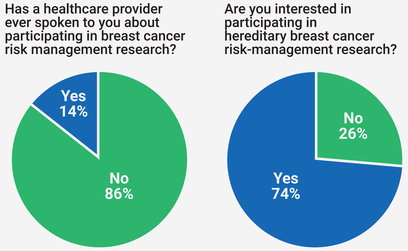
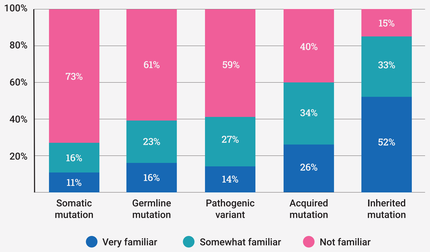


Fig. 2: A majority of patients are not familiar with commonly-used research terms

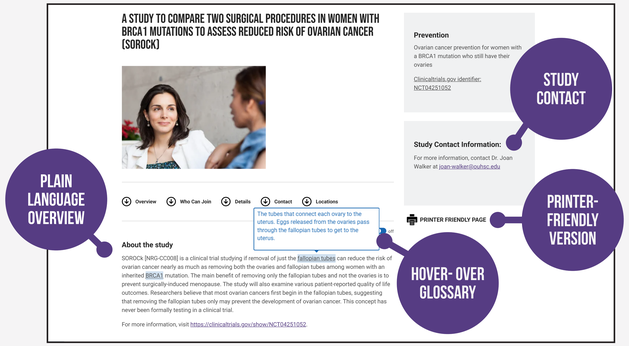


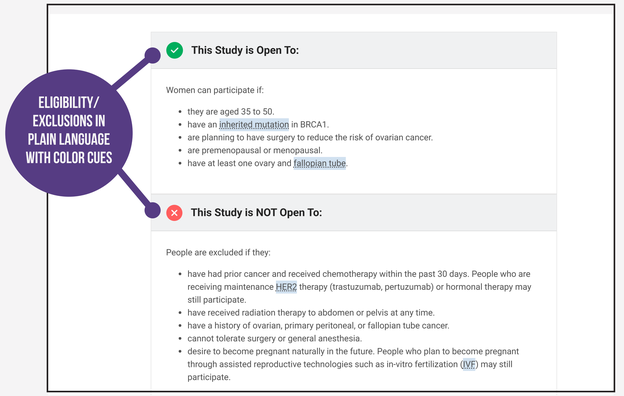
METHODS

In 2014, FORCE built a 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 research studies relevant for people with inherited cancer risk. Users can search for studies listed in the FORCE database as well as on ClinicalTrials.gov by study type, cancer type, gene or biomarker, study location and key word. FORCE evaluated the tool through focus groups and a user survey. Focus group participants were asked to compare the ClinicalTrials.gov listing with the FORCE plain-language version of the same study.

SEARCH AND ENROLL TOOL FEATURES

- Custom database of curated studies enrolling people with inherited cancer risk.
- Title, details and eligibility in plain language.
- People can search by study type, cancer type, gene, biomarker and keyword.
- Embedded glossary defines scientific terms.





RESULTS

Focus group participants agreed that the FORCE listing was clearer and easier to understand than ClinicalTrials.gov.

Search and Enroll Tool user survey results show that 36% enrolled, and 43% planned to enroll in a research study (see Figure 3). Other key survey findings are listed below (see Table 1).

Fig. 3: Research participation among respondents

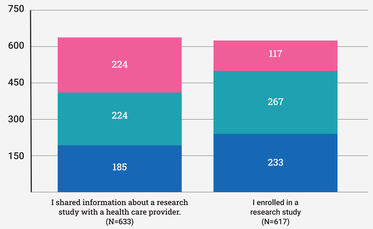


Table 1: Key results of user surveys

Program User Feedback	Agree	Neutral	Disagree
I found a study that interest me	72%	19%	9%
I found a study for which I was eligible	53%	23.5%	23.5%
I found a study for which a friend or relative was eligible	45%	32%	23%
I understood the study goals	85%	13%	2%
I was able to understand what was required of participants	86%	12%	2%
I was able to understand who was eligible	86%	10%	4%

> *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

CONCLUSIONS

Many people with inherited cancer risk are highly motivated to participate in clinical research-but most are never informed about 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. Participants reported high user satisfaction, comprehension, and intension to utilize the tool to enroll in future studies.

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