# Results of a Training Workshop for Genetic Counseling Students on Improving Patient Research Literacy and Engagement in Clinical Research

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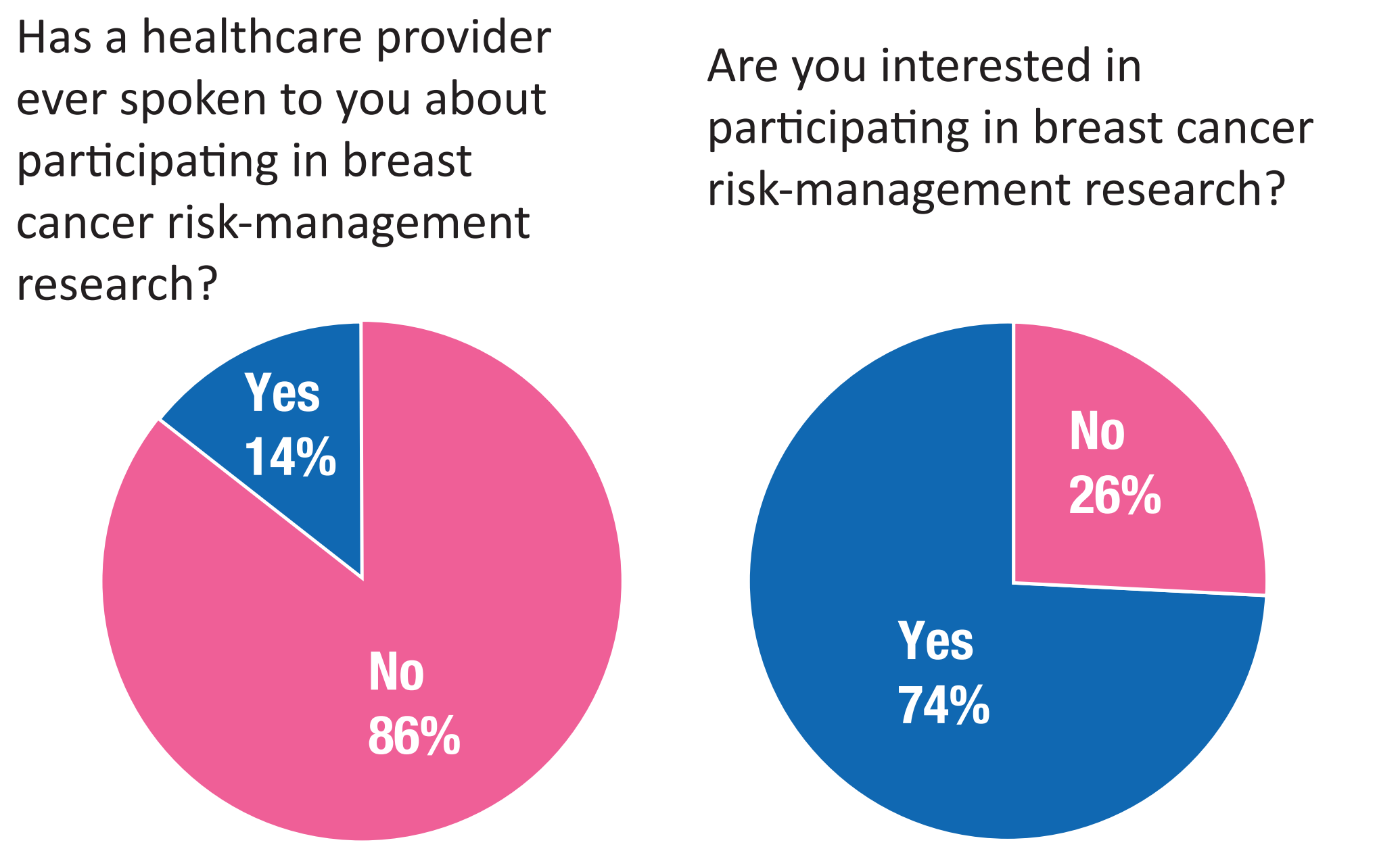
Facing Hereditary Cancer EMPOWERED

## BACKGROUND

The development of new targeted agents and approaches to prevent, intercept or treat cancer have led to an increase in research studies enrolling people with germline mutations linked to inherited cancer risk. However, referral of patients with, or at high risk for hereditary cancer remains low. In a 2024 FORCE survey, only 14% of respondents at high risk for breast cancer were told by providers about clinical research opportunities, while 74% expressed interest (see Figure 1)[1].

Figure 1. Survey results from people at high risk for breast cancer.



Has a healthcare provider ever spoken to you about participating in breast cancer risk-management research?

Are you interested in participating in breast cancer risk-management research?

## INCREASING GENETIC COUNSELOR REFERRAL TO CLINICAL RESEARCH

In a FORCE survey of genetic counselors, most indicated that they never referred young breast cancer survivors (63%) or metastatic breast cancer patients (69%) to clinical trials and 55% identified research jargon and health literacy as barriers to clinical trial referrals[2].

The authors developed a training for genetic counseling students outlining barriers to progress in hereditary cancer research with the following features to support genetic counselor referral of patients to clinical research studies (see Figure 2):

- Outlines barriers to progress in hereditary cancer research.
- Format includes a presentation, activities and small group discussions.
- Includes content on health literacy and social determinants that act as facilitators or barriers to research participation
- Provides strategies to improve students' communication skills to help patients find and enroll in clinical research.
- Introduces resources, including FORCE's Search and Enroll Tool[3], a custom-designed research matching tool to connect hereditary cancer patients with plain-language descriptions of relevant clinical research opportunities.

## METHODS

Between March 10, 2022 and April 16, 2025 FORCE conducted 17 training workshops for genetic counselor training programs, which lasted between 60 to 120 minutes depending on the program's schedule. A total of 256 students attended the trainings and 113 completed evaluation surveys. In parallel, 3 genetic counseling training program course directors participated in post-training interviews about the workshop.

## RESULTS

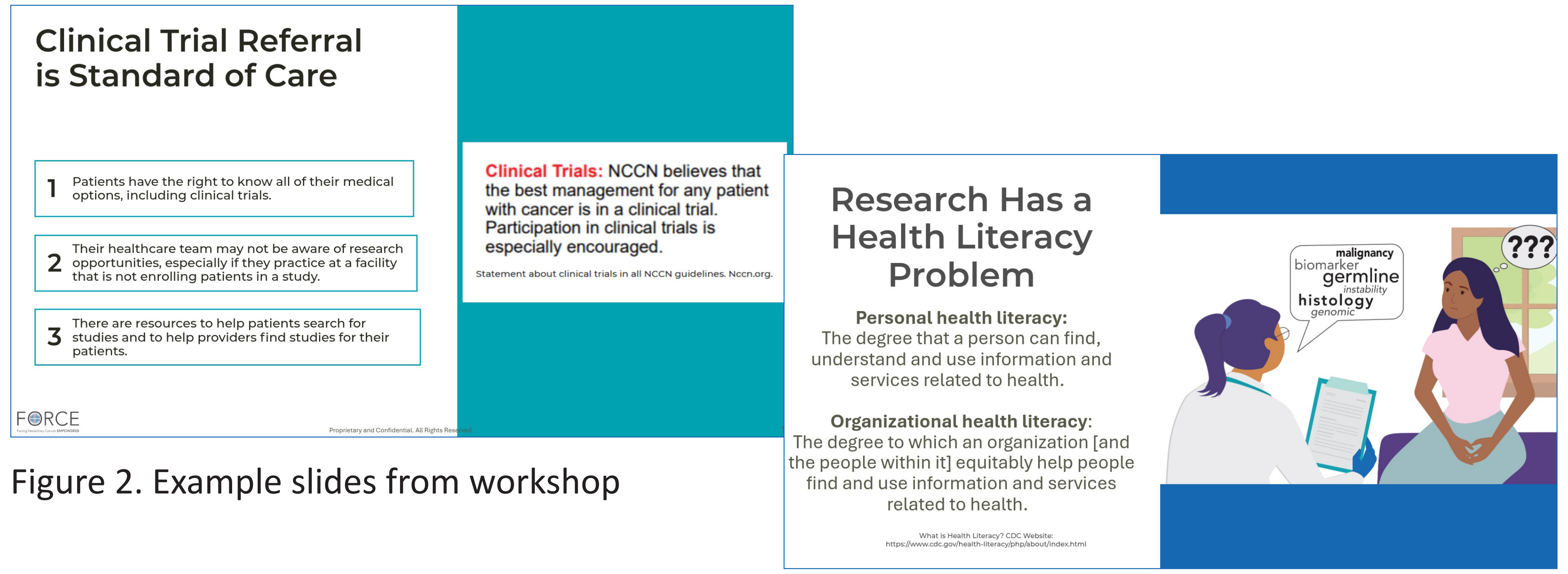
Students' survey responses indicate that the training achieved its objectives and that students planned to apply what they had learned in practice, including using FORCE's Search and Enroll Tool to find studies enrolling hereditary cancer patients. Open-ended responses emphasized that students appreciated the availability of a tool that provides plain language summaries of clinical research studies and that prioritizes studies enrolling people with germline mutations. Students reported that experiential learning activities were valuable. See Table 1.

Program course directors agreed that the training was appropriate to integrate into their curricula. One program had already integrated the workshop into their curriculum, with plans to continue. One program director said that the training reinforces the current curriculum and integrating it will reduce teaching burden. Course directors agreed that the training helps students to understand the importance of seeking research that their patients can participate in, and that the training effectively teaches students how to find this information and present it to patients in easy-to-understand terms. Interviewees said that the experiential aspects of the training using clinicaltrials.gov were especially helpful. The training provides students with tools for having constructive conversations in clinical settings and during outreach efforts that are typically part of genetic counselor responsibilities. One interviewee noted the value of the training emphasizing the importance of representativeness in research and of not assuming lack of participation is due to lack of interest.

Students and directors recommended retaining the content, flow and presentation approach, activities and discussions, appealing graphics, and emphasis on the practical implications of material presented. Suggestions for improving the training included: dividing the training into modules, minimizing potential for self-consciousness about making mistakes, providing clear explanations about how implementing recommended practices could improve health communication, offering descriptions of how students could apply the information in their future practice, and ensuring adequate time for discussion.

Table 1. Genetic counseling students post-workshop responses

| Question | Number who agreed or strongly agreed (Total #) | % |
|---|---|---|
| After the presentation I had a stronger understanding of the challenges of enrolling patients in cancer research. | 109 (113) | 96.4 |
| After the presentation, I had a stronger understanding of how social determinants of health affect research participation. | 106 (113) | 93.8 |
| After the presentation, I had a stronger understanding of how to find research studies for specific patient populations. | 109 (112) | 97.3 |
| The presentation will help me better communicate directly with people about research opportunities. | 109 (113) | 96.4 |
| The presentation provided me with useful tools to help me find and refer patients to clinical research studies. | 110 (112) | 98.2 |
| The presentation made me more likely to refer patients to clinical research studies. | 102 (113) | 90.3 |
| I plan to use FORCE's Search and Enroll Tool to find studies enrolling patients with inherited mutations. | 106 (112) | 94.6 |
| The presentation met the stated objectives. | 109 (111) | 98.2 |



Clinical Trial Referral is Standard of Care

1 Patients have the right to know all of their medical options, including clinical trials.

2 Their healthcare team may not be aware of research opportunities, especially if they practice at a facility that is not enrolling patients in a study.

3 There are resources to help patients search for studies and to help providers find studies for their patients.

**Clinical Trials:** NCCN believes that the best management for any patient with cancer is in a clinical trial. Participation in clinical trials is especially encouraged.

Statement about clinical trials in all NCCN guidelines. Nccn.org.

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Research Has a Health Literacy Problem

**Personal health literacy:** The degree that a person can find, understand and use information and services related to health.

**Organizational health literacy:** The degree to which an organization [and the people within it] equitably help people find and use information and services related to health.

What is Health Literacy? CDC Website: https://www.cdc.gov/health-literacy/php/about/index.html

Figure 2. Example slides from workshop

> *"I really enjoyed becoming familiar with FORCE and learning how barriers can affect patients' ability to find research."*

> *"I found the breakout groups extremely beneficial for engaging with the material. It allowed us to investigate a little bit on our own and then share with the group - I think this will help me commit this to long term memory."*

Student quotes from survey

## DISCUSSION

Both students and faculty found training on overcoming barriers to patient research participation to be informative, relevant, and engaging. Genetic counseling training programs could benefit from training on this critical topic that may not be offered elsewhere in their curricula. In addition to learning information and skills related to finding and communicating with patients about hereditary cancer research, students and faculty agreed that FORCE's Search and Enroll Tool is useful for matching patients to relevant clinical research opportunities.

1. "Results from FORCE's 2024 Survey Highlighting the Needs of People at High Risk for Breast Cancer." FORCE blog, October 2024.
2. Clark E, Bonini K, et. al. Experiences of Genetic Counselors in Referring Young and Metastatic Breast Cancer Patients to Support Services: A Needs Assessment. Patient Education and Counseling Volume 116, November 2023.
3. FORCE Search and Enroll Tool: https://www.facingourrisk.org/research.

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