

Development, Implementation, and Evaluation of the eXamining Relevance of Articles to Young Survivors (XRAYS) Program to Summarize Recent Research Findings for Young Breast Cancer Survivors: Progress and Findings from the First Year

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Breast Cancer and Risk in Young Women

Breast cancer is the leading cause of cancer-related death, and the second leading cause of all deaths among women ages 20 to 39 years. Approximately one in 14 women with breast cancer is diagnosed before age 40. Breast cancer accounts for 40 percent of all cancers in this age group (Anders, 2009). Research suggests that emotional and social functioning after a breast cancer diagnosis is inversely proportional to age at the time of diagnosis (Anders, 2009). Risk factors for breast cancer vary between younger and older women. Potential long-term effects of breast cancer therapies, such as early menopause, fertility impairment, lowered bone density, and risk of second malignancies are of special relevance to younger breast cancer survivors. Cancer treatment and its after effects can lead to concerns about decreased productivity at home and work (Freedman & Partridge, 2013).

YBCS Needs for Reliable, Accurate Information

As research on the long-term effects of breast cancer therapy emerges, there is a corresponding need for resources that summarize evidence quality and relevance of findings to the specific needs of young breast cancer survivors. Because Internet and mainstream news sources often do not discuss breast cancer research in terms of implications for women from different age groups, and because reporting often involves priorities and processes that result in news that can be challenging for patients and survivors to interpret, YBCS need additional resources to interpret news on breast cancer-related research and how it affects health-related decisions.

Young women frequently seek health information through the Internet and mainstream media, but often find it does not address their particular concerns, that it is difficult to evaluate or interpret, or misleading. Often the media misses or omits the nuance to a research report. Constrained by deadlines or space to present contextual information, health articles in the media can appear to contradict one another, causing confusion in those they intend to inform. The Internet and social media allow stories to get continuous exposure and consideration without caveats regarding evidence quality or interpretation. YBCS need a trustworthy, reliable resource on new and emerging research, and standards by which they can measure its personal and clinical relevance.

XRAYS Responding to YBCS Health Information Needs

Because reliable, valid, clear information is critical for young women with breast cancer to make decisions that are best for their health, access to this information has become a high priority for policy makers, including the Centers for Disease Control and Prevention (CDC).

Facing Our Risk of Cancer Empowered (FORCE), is a support and advocacy organization with more than 15 years of experience collaborating with researchers and clinicians to provide accurate and clear health information to people with or at-risk for hereditary breast and ovarian cancer. Based on ongoing monitoring of its constituents' needs, FORCE proposed to develop eXamining the Relevance of Articles for Young Survivors (XRAYS). The Centers for Disease Control and Prevention (CDC) awarded a 5-year grant to develop and test XRAYS in order to:

- Identify the media sources most frequently used by YBCS and the critical times in treatment and survivorship when YBCS seek new information
- Develop procedures to evaluate and score research and reporting on breast cancer in terms of accuracy, relevance, and utility to YBCS
- Develop engaging and clear rating scales of research and media reporting
- Monitor news media reports related to breast cancer research and create reviews that explain and assess new and emerging research to YBCS in attractive and accessible formats.
- Develop and test an expanded media response team and social media program to disseminate the rated research reviews through FORCE and its network of partners.
- Contract with an independent evaluator to conduct process and outcome evaluations.

Year 1 process evaluation questions include:

- Did implementation proceed as planned?
- What were barriers and facilitators to implementation?

Year 1 planning and needs assessment questions include:

- Does the targeted community find XRAYS to be useful and relevant?
- How can FORCE increase the utility and relevance of XRAYS?
- How can FORCE and its partners best reach all targeted XRAYS audiences?

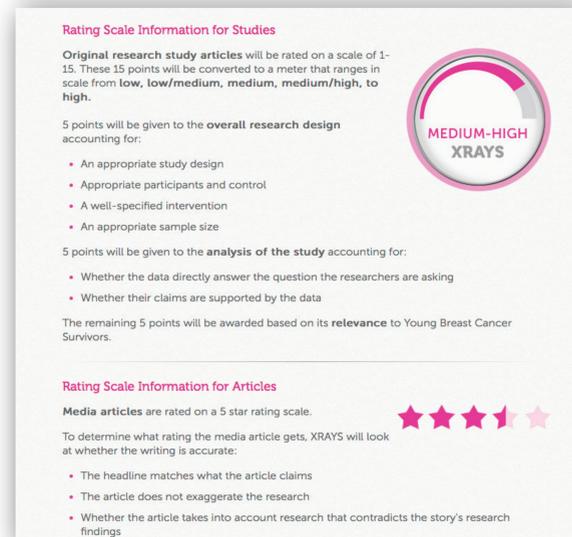
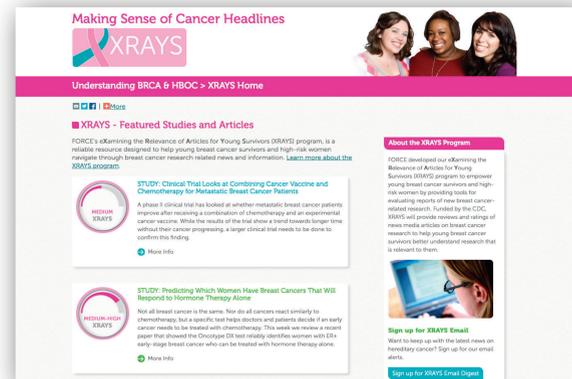
Methods

During Year 1 the independent evaluator conducted key informant interviews with the FORCE program manager, research associate, communications director, and partnership coordinator regarding program planning and implementation. The evaluator also observed two advisory committee meetings, and conducted key informant interviews and focus groups regarding preliminary XRAYS materials.

Results

FORCE accomplished all key implementation goals for Year 1, including:

- Identifying, recruiting, and developing formal agreements with a network of partners that serve diverse YBCS
- Identifying and recruiting an advisory committee that offers expertise on breast cancer and hereditary breast cancer in YBCS, media reporting, and effective dissemination
- Recruiting staff and vendors to develop a scoring system, website, and outreach plan
- Developing an initial scoring system of evidence and media reporting quality and soliciting feedback from target audience members and FORCE's scientific advisory board
- Conducting a media utilization survey of more than 1,000 constituents of FORCE and its partners.



FORCE identified the following as key facilitators to implementation:

- FORCE's years of experience serving the target community and assessing their needs for services
- FORCE's existing network of partners and experts with investment in meeting the health information needs of YBCS
- A collaborative approach to partnerships that ensured they would have input at all phases of program planning and development, and that their constituents needs would be considered throughout program implementation
- A web development vendor with a clear understanding of program goals and objectives, and with strong investment in supporting program success
- A research associate with expertise in scientific methods who is able to work full-time on developing a scoring system and identifying reports to review for XRAYS
- CDC support for long-term planning.

FORCE staff reported that there were no barriers to planning and implementation during the first year of the program.

After conducting a literature review on existing evidence scoring systems, FORCE developed a preliminary scoring system and reporting format. The communications director recruited four FORCE constituents to participate in interviews to discuss an initial study and media reporting review. All interviewees agreed that XRAYS would be an important and practical resource. They also made recommendations for improving utility, including:

- Add an introduction that explains the XRAYS program and purpose.
- Add an explanation of how research and relevance are scored.
- Add explanations of technical terms, especially statistical terms.
- Make the materials more concise. Text is repetitive at times.
- Explain why the research presented is relevant to YBCS and previvors.
- Describe the study sample more; make it clearer to whom results apply.
- Make the article summary simpler and easier to understand. It is only slightly easier to interpret than the news article.
- Add information about how research findings can be applied to health decisions. It was not clear how results could inform clinical or preventive health decisions.

In response to interview results, the FORCE team developed an introduction to XRAYS, brief explanations of the research and relevance scores, and "Study at a Glance" and "What Does this Mean?" sections for the study summary. A glossary of technical terms is currently under development.

The evaluator then conducted four focus groups with 29 women to collect additional feedback. Again, all participants said XRAYS would be a useful resource. They also recommended:

- A shorter, simpler format
- Less medical and scientific jargon
- Subheadings for the study summary
- Clarification of the difference between rating research quality and media reporting quality
- Adding information about reviewers
- Adding information about researchers' qualification
- Adding a searchable index

FORCE referred to these recommendations to revise the XRAYS reporting format and content for the live web site. The independent evaluator then conducted five additional interviews with potential users, who were directed to the live web site. All participants said XRAYS was a resource they would use. Strengths of XRAYS include:

- A credible source is helping to assess the quality of research evidence, which is difficult for lay people.
- Reviews first present a brief summary that allows the reader to assess personal relevance and whether it is worthwhile to read more detailed information.
- Reviews indicate which journalistic reports are most accurate and relevant to YBCS.
- Reviews indicate how findings are relevant to health-related decisions
- The explanations of the review and scoring process are clear and indicate that XRAYS is a credible resource.

Suggestions for further improvement include:

- Present a more detailed description of the program's purpose on the home page
- Present explanations of the review and scoring process in a more easily accessible manner
- Indicate why research studies and media supports did not earn full points for quality

Conclusions

By continuously developing partnerships with diverse stakeholders, FORCE has been able to implement XRAYS as planned during Year 1. XRAYS is a practical resource that addresses a critical information need for YBCS. FORCE has maintained its commitment to ongoing soliciting of constituent input, and has effectively responded to input to create a better quality resource.

Next Steps

During Year 2, FORCE will:

- Analyze media utilization data to assess how best to reach target audiences
- Collaborate with partners to develop strategy for effective outreach to diverse audiences
- Continue to collect and respond to audience feedback on XRAYS
- Begin to assess whether XRAYS is an improvement over media reporting on research relevant to YBCS.

References

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