

People with metastatic breast cancer face barriers to finding information and support

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Facing Hereditary Cancer EMPOWERED

FacingOurRisk.org

BACKGROUND

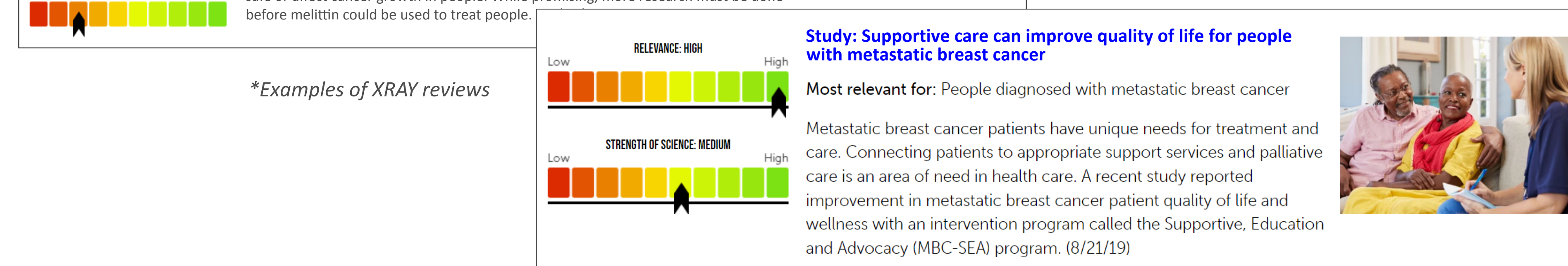
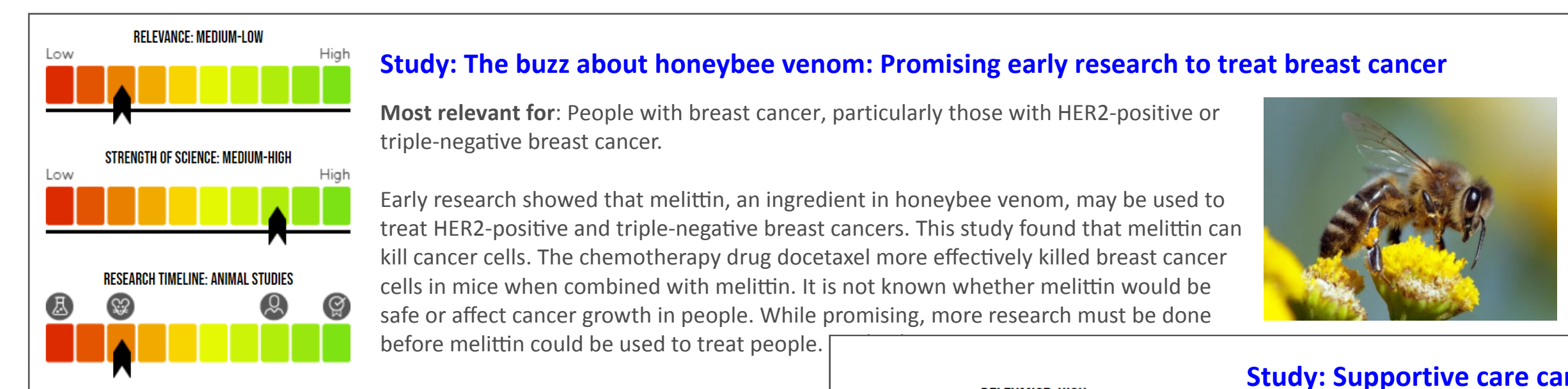
FORCE, a national nonprofit organization developed a health communication tool to help patients assess research relevance, key findings, and the quality of media reporting on cancer to support informed and shared health decision-making. People with metastatic breast cancer are a priority population.

METHODS

FORCE conducted a survey about awareness of and access to breast cancer information and supportive services for people living with metastatic breast cancer. The organization promoted the survey through e-mail and social media, and a network of partner organizations that serve the metastatic breast cancer community, including METAvivor and Susan G. Komen.

The survey invited respondents to volunteer to participate in focus groups and a follow-up survey in order to support efforts to serve this priority population and provide feedback on a FORCE health communication program called eXamining the Relevance of Articles for You (XRAY)*. Participants were asked to read an XRAY review of research before the focus group. The topics covered were:

- FDA approval of a new treatment for mBC
- Research on side effects reported by women with breast cancer on endocrine therapy
- Early research on a protein found in honeybee venom
- Quality of life, palliative and integrative care

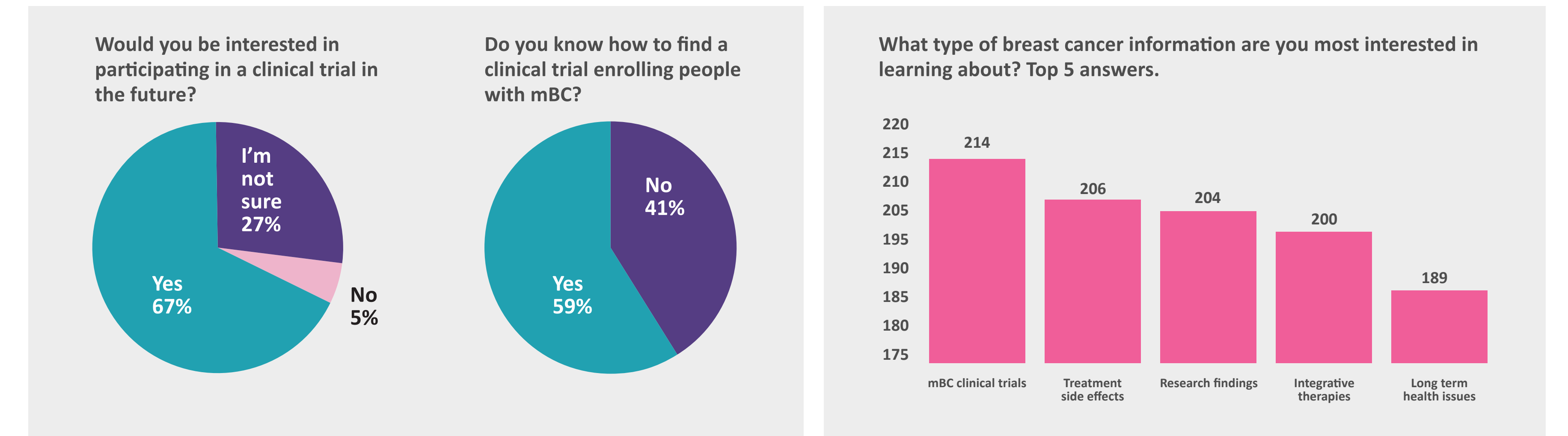


*Examples of XRAY reviews

RESULTS

While interest in clinical trials was high, many users reported that they do not know how to find an appropriate clinical trial. A majority of the 335 respondents were interested in information about clinical trials, treatment side effects, research findings, long-term health issues, diet/exercise, fatigue, and emotional health. Three quarters of the respondents indicated that they had never participated in a clinical trial, 67% indicated they would be interested in participating in the future, and about 40% indicated they did not know how to find a clinical trial recruiting people with metastatic breast cancer.

Approximately one-third of participants were unable to obtain referrals to services they sought. Other barriers to services included lack of insurance coverage, lack of availability, and the COVID-19 public health emergency. Focus group responses indicate that women with mBC find the health communication tool to be useful, and appropriate in language, images, and tone.



Quotes from survey and focus groups

- I need what's KNOWN to work. Not be used like a guinea pig. I still have 2 young children to raise!*
- I live too far from any facility that would run a clinical trial.*
- You're fighting to live every day. You shouldn't have to turn around and fight your insurance company to pay for something. It's like a battle all of the time. I feel bad for the people who don't know they can fight. (They) take that first answer and go away.*

DISCUSSION

Results indicate that women with mBC are interested in finding information about clinical trials and other topics related to treatment side effects and quality of life. FORCE and partners are incorporating these results into the XRAY program by:

- prioritizing topics of highest interest to people with mBC.
- including links to relevant clinical trials.
- adding resources for finding local service providers and paying for care.

1.Akeso Consulting, LLC, Vienna, VA. 2.Facing Our Risk of Cancer Empowered, Tampa, FL. 3.Susan G. Komen, Dallas, TX.

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