The Importance of Diversity in Clinical Trials: A Conversation with RadComp Advisor Ivis Febus-Sampayo



Attention to diversity in clinical trials helps research outcomes become relevant to a wider variety of patients and is a core aspect of patient-centered outcomes research. Diversity in clinical trials means individuals and groups of people from different cultural, educational, socio-economic backgrounds are included in study participation and development.

To help promote diversity in RadComp, the RadComp Stakeholder Advisory Committee (SAC) provides feedback on how the trial is designed and conducted. One partner on SAC is SHARE Cancer Support, a national nonprofit whose mission is "to connect women with the unique support of survivors and peers, creating a community where no one has to face breast, ovarian, uterine or metastatic breast cancer alone."

We asked Ivis Febus-Sampayo, a two-time breast cancer survivor and the Chief Diversity Officer and Senior Director of Public Outreach at SHARE, about her commitment to diversity and inclusion in cancer research:

SHARE has developed several resources to ensure diverse populations can access the cancer care they need. What resources promote diversity and inclusion in clinical trials?

At SHARE, we know the importance of diversity within clinical trials and work on educating our communities about it. We have webinars and Zoom presentations on this topic in English, Spanish and Japanese and have staff involved in national and local committees that deal with clinical trials so that a diverse population is included. One example is our participation in the National Cancer Institute (NCI): Alliance on Clinical Trials in Oncology.

> *"We work with communities by asking them to help us, help them. They are the experts that have lived through the issues they are facing. I truly believe that if we just listen closely and support them, we can do a better job."*

What is culturally competent cancer support?

LatinaSHARE provides materials and support programs in Spanish by trained peer survivors who have been there and can use their experience to help others. We have helplines and support groups. The majority of the staff in these programs came to SHARE, received support, and then eventually became staff members themselves. We understand this culture because we come from this community.

> *"Through our personal experiences, we are able to understand what survivors might be going through with their diagnosis, treatment and survivorship. We've been there and want to make sure no one goes through this alone!"*

What are some of the misconceptions and challenges related to cancer within Hispanic/Latinx communities?

One misconception is that this community does not want to learn about cancer and its signs and symptoms. Our LatinaSHARE Outreach Ambassador Program provides information on risks and symptoms of breast cancer using Spanish materials which are culturally appropriate and sensitive to health literacy (such as SHARE's Novelas, which dispel myths and highlight signs, symptoms and resources). Our trained ambassadors also use their personal experience with breast cancer to break the stigma and let their communities know that there is life after a cancer diagnosis.

Reflecting on your twenty-five year history with SHARE, what accomplishments makes you the most proud?

The influence I have provided to staff, various communities, political members and other community leaders and organizations on the importance of building programming and services that fulfill the needs of diverse audiences.

> *"I believe that everyone affected by breast cancer deserves the chance to get the best access to care, treatment, and support."*

I'm also excited and proud of our comic book style novelas in Spanish and English! We have three on: Early Breast Cancer and Myths, Metastatic Breast Cancer, and Ovarian Cancer. We are working on a fourth one on Genetics and Breast Cancer. These cultural educational tools have been a success. You see, my mother taught me to read Spanish using Spanish novelas and since I was a comic book kid, I figured by combining the two we could provide it as an educational resource, while honoring my mother.

Reflecting on your involvement with RadComp, what are your hopes for the future of patient-centered cancer care?

Wow! Do you have a whole day? My hopes for the future of patient centered cancer care is that ALL services can be provided for everyone dealing with cancer. By truly listening and working with communities we will better understand their needs and help us develop research, interventions, support and educational programs to reach many more patients. I'm so happy to be a part of the RadComp Advisory Committee. They are an amazing, caring group that works diligently to make sure we do the best we can in RadComp.

To learn more about SHARE Cancer Support, visit https://www.sharecancersupport.org/.