

Background

Fewer than 5% of cancer clinical trial enrollees are Latino and Hispanic, although they comprise 11% of the U.S. population (Fashoyin-Aje LA; et al, 2018). Barriers to cancer clinical trials participation among Latinos and Hispanics include: language and cultural differences; low health literacy; lack of information about clinical trials; and lack of opportunity for involving family in medical decisions (Quinn GP, 2014). Use of culturally sensitive approaches to enhance ethnic minorities' participation is important for advancing cancer care and eliminating health disparities. The Cancer Support Community (CSC) provides evidence-based educational materials that are written from perspectives of patients and caregivers. With the impact of low clinical trials participation among Hispanics in mind, CSC culturally adapted its clinical trials educational materials, Frankly Speaking about Cancer (FSAC): Clinical Trials photo-narrative and booklet, to make information about cancer clinical trials more accessible to Hispanics affected by cancer.

Research Questions

- Do the photo-narrative and booklet make it easy for native Spanish speakers to understand clinical trials?
- Do the photo-narrative and booklet help Spanish speakers consider participation in a clinical trial?
- Do the photo-narrative and booklet reflect understanding of diverse Hispanic cultures?
- At what stage of patient-clinician communication should the photo-narrative and booklet be provided to patients and families?
- How could the material better address the impact of cultural beliefs on understanding of cancer research and clinical trials participation?

Methods

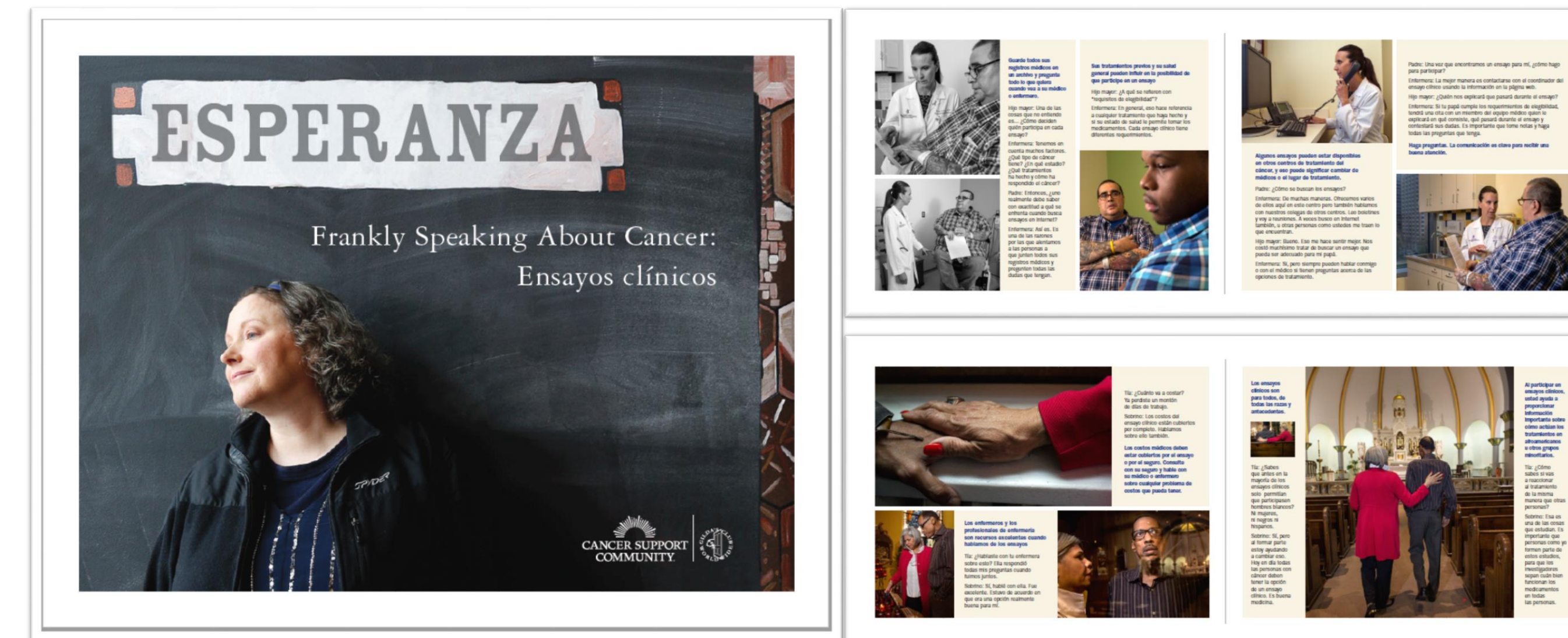
- 3 Focus groups were conducted in Spanish with a total of 33 adult Spanish-speaking participants (25 female) in Miami (N=10), New York (N=11) and Phoenix (N=12).
- Each group reviewed and discussed CSC's educational materials about clinical trials, Frankly Speaking about Cancer: Clinical Trials photo narrative and booklet. Participants were asked to give feedback about: ease of understanding; utility for decision-making about clinical trials participation; applicability to Hispanic culture; reactions to photos; and preferred time to receive the information.
- The discussions were transcribed; thematic content was categorized and coded, and frequencies of categories were tabulated.
- Double data entry was performed independently by the authors to ensure data accuracy. To assess intra- and inter-observer reliability, responses from each reviewer were cross-tabulated to enable the calculation of agreement and the kappa statistic. The kappa statistic was categorized as minimal (0-.39), weak (.40-.59), moderate (.60-.79), strong (.80-.90), almost perfect (>.90). The mean kappa statistics was 0.91.

Participant Characteristics

GENDER		AGE		PLACE OF ORIGIN	
Males	25%	29 - 39	3%	Central America	53%
Females	75%	40 - 59	50%	Caribbean	31%
		60 - 79	41%	South America	16%

- Nearly 93% of focus groups participants had never participated in a clinical trial and almost 90% reported having very low understanding of clinical trials.

FSAC: Clinical Trials Photo Narrative



Findings:

1. Ease of Understanding

- Aside from a few words, 97% of participants reported the photo narrative was very easy to understand and would help them consider clinical trials.

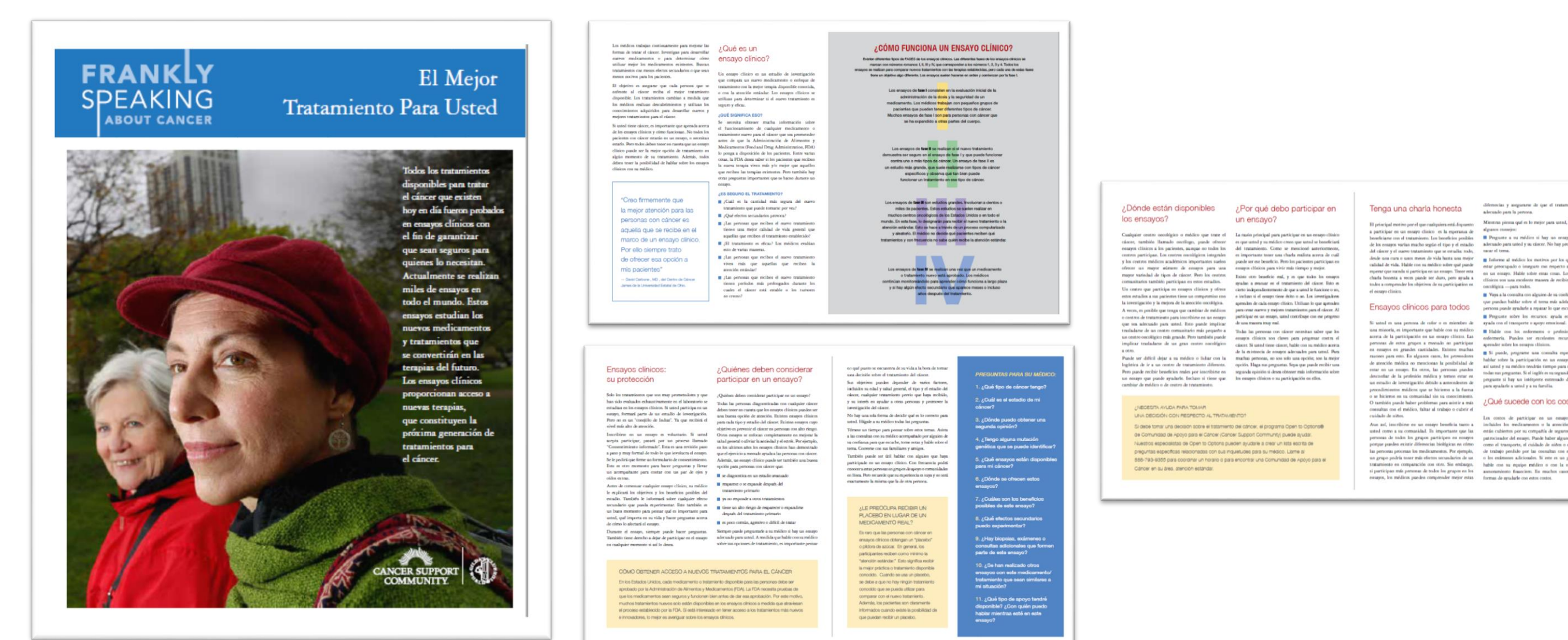
2. Reflection of Hispanic Culture

- 98% of participants reported that the images reflected the importance of family (immediate and extended), the central role of religion in times of need, and the role of friendship. All these themes were identified as congruent with Hispanic cultural values.
- Several participants reported wanting photographs of more diverse people or people of color.

3. Timing for receiving the photo narrative

- The preferred timing (70%) for receiving the photo narrative was anytime after patient visited an oncology office but NOT on the day of diagnosis as many said that they would not have been able to process that information on that day.
- Photo narrative was also seen as a good information for family members

FSAC: Clinical Trials Booklet



Findings:

1. Ease of Understanding

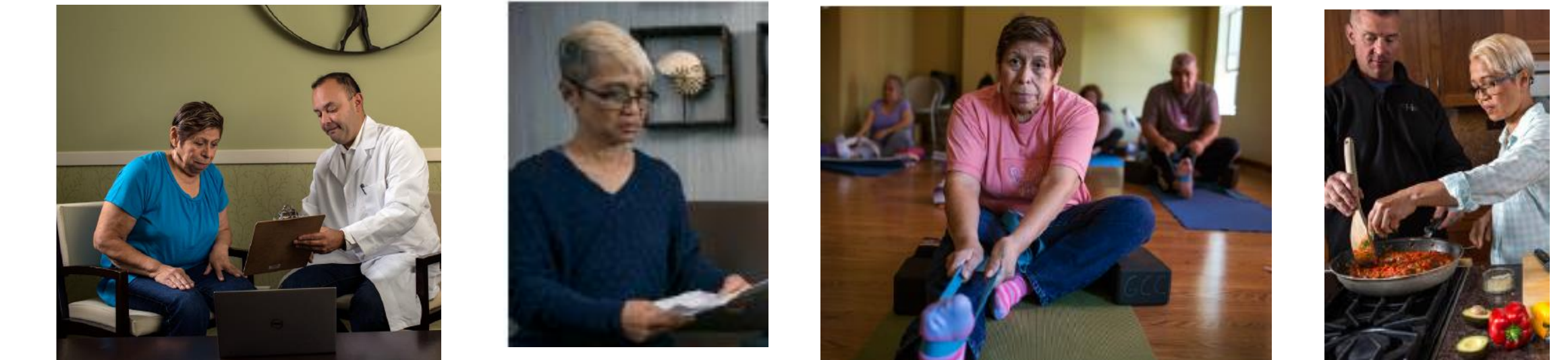
- 91% of participants reported that the booklet provides clear information about what clinical trials are and what participation in a clinical trial entails.
- The booklet (along with the photo narrative) was preferred for those participants actively considering a clinical trial.

2. Timing for receiving the booklet

- 90% of participants reported that the booklet offers deeper information to Hispanic cancer patients to learn about clinical trials as a treatment option.
- The preferred timing (90%) to receive the booklet was on the day of treatment planning ALONG with the photo narrative.

Implementation

- We implemented the feedback received by focus groups participants and updated the photo narrative to ensure that the material is culturally appropriate, and accessible to Hispanic in the US.
- The implementation process included adding photographs of more diverse people:



- In addition to CSC's current distribution utilizing our multi-channel network and those of our partners and funders, CSC is working to increase our reach by partnering with cancer centers, patient advocacy organizations, and other organizations that serve minority and underserved populations.
- We would also like to make nurses and patient navigators aware of this tool to help Hispanic cancer patients and caregivers improve their communication with health care providers.

Summary

- Hispanic cancer survivors are very receptive to the use of the FSAC: Clinical Trials and booklet for purposes of patient education.
- The photo narrative may enhance broad knowledge about:
 - ✓ how medical treatment advances take place;
 - ✓ the importance of being an informed consumer of medical treatment; and
 - ✓ the importance of participating in clinical trials.
- All participants expressed understanding the mistrust Hispanics have for clinical trials. Most participants indicated that the photo narrative and booklet may helped them understand and trust the clinical research more.
- The photo narrative format appears to be a useful tool for helping Hispanics learn more about cancer clinical trials and by addressing certain existing barriers to cancer clinical trials participation – particularly language and cultural differences and lack of information about clinical trials.
- Providing the booklet with the photo narrative may helps to inform Hispanic cancer patients with more specifics about considering cancer clinical trials as a treatment option.

Conclusions

Findings suggest that CSC's educational materials about cancer clinical trials in Spanish may help address existing barriers to cancer clinical trials participation among Hispanic cancer patients and caregivers. These materials can lead to fruitful conversations among Hispanic cancer patients, family members, and clinicians about clinical trials as viable treatment options.

References

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