COMMUNITY CONVERSATIONS ABOUT CANCER

Simmons Cancer Center
Community Outreach,
Engagement, & Equity

UTSouthwestern

January 2020 - July 2021

17 listening sessions • 140 participants • in person • online • adults and youth caring community members • across DFW Metroplex • diverse races and ethnicities various faiths • students • LGBTQIA+ • American Cancer Society • seniors • clerg

HERE'S WHAT YOU SAID

Describing The Cancer Experience

- "Horrible"
- "Devastating"
- "Nothing prepared me for that"
- "It amplifies your stresses"
- "You wonder what you're going to pay for this"

Factors in Choosing A Cancer Hospital

- Trust "Honest and sincere communication" builds trust and confidence
- Quality Research and specialized care are a plus; all UTSW sites should match the quality of main campus
- Affordability Must know "insurance plans accepted" and "financial support available" up front
- Convenience Prefer "one-stop medical care" with oncologists, specialists, primary care physician, and labs "in the same vicinity"

Key Needs in Cancer Care

- Patient navigation Need a range of help, from making an appointment and using MyChart to comprehending billing and understanding the path ahead
- Support groups Offer in convenient neighborhood locations, rural areas; include caregivers and children; be culturally sensitive and inclusive; host groups in Spanish

A Message to Providers

- Look up from your laptops, spend a few extra minutes with seniors
- Be clear, honest, and transparent
- Don't be afraid to use the "c word"
- Speak in "layman's terms"
- Communicate with all my doctors, and "be on the same page" about treatment, across care team members
- Welcome spiritual leaders into treatment conversations
- Place follow-up calls to allow questions after a visit
- Seek understanding of the LGBTQIA+ life experience

Barriers to Good Health

Be sensitive to, or help us address:

- Lack of access to resources transportation, babysitters, healthy groceries, insurance, a gym membership
- Fear of "speaking up," "being judged," revealing cancer status, serious impact of illness
- Shame and stigma, cultural taboos about lacking resources, needing to ask for help, appearing vulnerable as a male, discussing family cancer history
- Lack of awareness about the connection between your health and "what you eat," what to ask the doctor, where to find free screenings and other resources, what insurance will cover

Promoting Cancer Awareness and Clinical Trial Participation

Reach us through...

- Social media (all age groups)
- "Short" TikToks and Reddits, Instagram and Snapchat (youth)

With these messengers...

- Relatable influencers who "look like me" and "speak my language"
- Mainstream media "champions" from individual communities
- Muslim spiritual leaders
- Patients with positive testimonials about screenings and clinical trials

Tell us...

- "Knowledge is power"
- You can reduce your cancer risks through lifestyle changes
- "It's ok to be vulnerable" and "open up" about your family cancer history

Show us...

- Healthy behaviors that look fun, "like alcohol ads do"
- Where to find resources if uninsured or undocumented
- The immediate, serious dangers of smoking or eating the wrong foods

Don't forget to...

- Use words that everyone can understand
- Own up to historical missteps

Suggestions for Outreach

- Partner with schools and colleges, sororities and fraternities, African American churches and other faithbased organizations, non-profits that promote health or help the underserved, neighborhood grocery stores
- Promote screenings, pass out literature, create cancer resources for congregations, host cancer experts, demonstrate healthy cooking with "tried and true" cultural recipes

THANK YOU TO OUR COMMUNITY

We are grateful to you, DFW community. Your voices and your spirit of collaboration will help foster better health for everyone. We also thank our Community Advisory Board for gathering community members together for online conversations during the COVID pandemic. For news on how we're responding to your needs, please visit Cancer Care Community Outreach (utswmed.org)

