



Advocates for Collaborative Education

Many Voices. One Mission.

2025 Impact Report

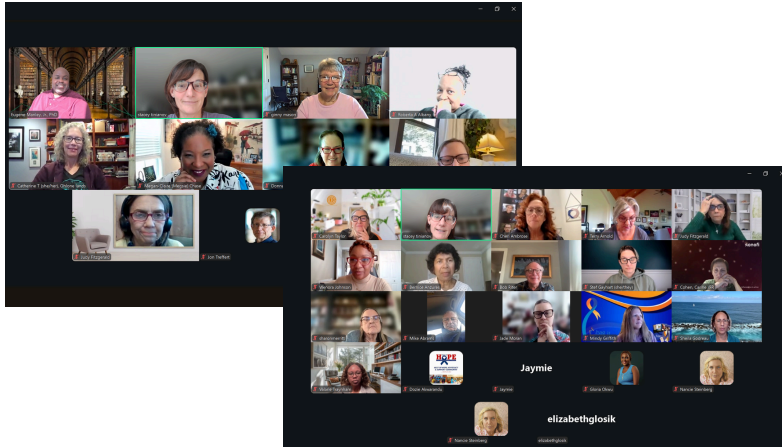
Advocates for Collaborative Education is the only pan-cancer advocacy organization uniting patient, research, and policy advocates through pan-cancer collaborations, advocate education, and the sharing of leading practices.

CONNECTION

200+ Advocates
22+ Cancer types
30 US states & territories
6 Countries



EDUCATION



LEARNING WITH AND FROM EACH OTHER

38 Member-Only Sessions
8 New Member Orientations
12 Member Newsletters

"[ACE] connects me with other advocates & helps define current unmet needs & future directions that need to be addressed. We learn from, and support one another."

~ Janice Cowden, member since 2020

ADVOCATE-LED RESEARCH

More Than a Diagnosis (MTAD) QoL Survey

Co-created QoL survey, measuring what matters to people living with and beyond a cancer diagnosis

Status: *n=515*; presented at SABCS, ASCO Quality, MASCC

Advocacy Expertise & Compensation Survey

Mapping advocate expertise and compensation gaps; laying the groundwork for ethical, compensated engagement

Status: *n = 159*; Survey closed; data analysis ongoing

Screening to Survivorship - An SDM Toolkit

Co-creation of toolkit supporting shared-decision making (SDM) from screening to survivorship to connect care conversations with patient priorities

Status: Co-creation with core team

SEEING THE PERSON THROUGH THE FOREST PLOT: A CO-CREATED QUALITY-OF-LIFE SURVEY

Stacey Tzouros, MPH¹, Kelly Shaughan, MD², Malinda Bachini³, Marisa Horn⁴, Terri Gonzalez⁵, Laura Carling, MD⁶
¹Advocates for Collaborative Education, ²METN/MDCC, ³Cholangiocarcinoma Foundation, ⁴International Advocacy Action Network, ⁵NAS Kikars, ⁶Surviving Breast Cancer

Background: While clinical research traditionally uses measures of health-related quality of life (HRQL) to assess patient outcomes, few studies have examined the impact of patient-reported outcomes (PROs) on patient quality of life (QoL). This study aims to explore the impact of patient-reported outcomes on QoL in a diverse population of cancer survivors.

Methods: A cross-sectional survey was conducted by people with lived experience in chronic illness, including cancer survivors, and researchers. The survey was designed to explore the impact of patient-reported outcomes on QoL in a diverse population of cancer survivors.

Results: The survey identified the substantial effects of cancer treatment on an individual's QoL, as an area of research that remains largely unexplored in relation to the experience of patients, caregivers, and the broader community. The top three effects identified were consistent across respondents with metastatic and non-metastatic disease. Additionally, the research highlights cancer-causing job effects, especially related to caregiver burden, which is a significant area for future research.

Conclusions: This study identifies the substantial effects of cancer treatment on an individual's QoL, as an area of research that remains largely unexplored in relation to the experience of patients, caregivers, and the broader community. The top three effects identified were consistent across respondents with metastatic and non-metastatic disease. Additionally, the research highlights cancer-causing job effects, especially related to caregiver burden, which is a significant area for future research.

WHAT'S NEXT

With your continued support, the Advocate Collaborative plans to expand our advocate-led research and our advocate-focused educational programming.

If you are interested in learning more about ways to partner with us, please contact

admin@advocatecollaborative.org

