



Measuring What Really Matters: Advocacy-Led Co-Creation and Accrual of a Pan-Cancer QoL Survey

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Background

Existing validated measurement tools and rubrics for examining patient quality-of-life (QoL) are typically designed and administered by non-patients and frequently without patient or patient advocate input. A 2023 survey across oncology community stakeholders listed patient QoL the highest priority, however, patients were not the majority respondents¹.

Implementing co-creation methods in research including quality of QoL research, may provide vital input to improve accrual, retention, and research value. In addition, creating measurement tools that better reflect actual patient careabouts may help to guide more relevant supportive care therapies.

Advocates for Collaborative Education (ACE), a global coalition of patient, community, research, and policy advocates, used co-creation methodology with patients, survivors, and metaversors to Design, Develop, and Deploy a survey to define and quantify QoL impacts and supportive care needs across a large sample of individuals with a diagnosis or history of cancer.

Objectives

Leverage best practices of co-creation to design, develop, and deploy an electronic, anonymous, pan-cancer survey on the impacts of cancer treatment on quality-of-life to:

- Gain a greater understanding of the impact of cancer treatments and treatment side effects on the QoL of individuals;
- Gather information on what matters most to individuals in terms of supportive care for addressing QoL impacts;
- Provide valuable data for research and clinical care in improving the well-being of individuals with cancer.

Methods and Materials

With a defined primary objective to “gain insight into challenges faced by individuals with a history or diagnosis of cancer and how these challenges impact their life and quality of life,” a co-creation team of individuals with lived experience in early stage or metastatic cancers was established.

Methods and Materials

Members of the co-creation team represented specific cancer communities and also brought unique demographic and cancer stage and status perspectives. All members of the co-creation team had a lived experience with cancer, cancer treatment, and patient advocacy

Methods and Materials

DESIGN

In the Design phase, co-creation team members were interviewed and engaged in discussions on side effect measurement and impact. They were asked a variety of questions, including what side effects they believed were most impactful to QoL, what elements they felt were missing in conversations around QoL, and how accurately they felt QoL was measured in the clinical setting.

DEVELOP

In the Develop phase, affinity mapping was performed on information provided and survey questions were developed based on priorities articulated in the interviews with the co-creation team. Survey questions were then vetted with the co-creation team to ensure their thoughts were accurately represented. Using a no-cost, user friendly platform, the questions were inserted into an online anonymous survey form.

DEPLOY

In the Deploy phase, co-creation team members, other advocate members of the ACE community, and aligned advocacy groups, shared the link to the online, anonymous survey form. These advocacy alliances were key to recruiting a broad audience via electronic distribution and social media platforms.

NOTE: In order to maintain anonymity necessary for IRB exemption, but to respect the valuable time of respondents, compensation was offered in an indirect manner. Individuals, upon completion of the 15-20 minute survey were invited to choose from a list of 501c3s (all members of the Advocate Collaborative) as the beneficiary of financial compensation for their time.

Patients, care partners, and community members have contextual knowledge which is not only relevant to the design and development of processes, products, and services but also, through the process of co-creation, these individuals tend to become further involved, motivated, and influenced by the very element they are co-creating.²

Results

Efforts resulted in the co-creation of a six-section, 93 question, IRB-exempt survey. The co-creation team identified 17 treatment-related side effects that were incorporated into the survey. Survey questions asked respondents about perceived severity of side effects, how well informed they felt about possibilities of experiencing these side effects, access to supportive care, side effects of supportive care therapies, and personal preferences for receiving cancer-related information. A unique measurement scale was shaped by the co-creation team to be more reflective of side effect impact on QoL.

In five weeks, the survey accrued over 500 responses across over fifteen (15) cancer types, stages (0 - IV), ages, statuses, and racial groups.

Cancer Type	Respondents # / % (n =515)	Race	Respondents # / % (n = 515)
Prostate	7 / 1.4	Caucasian / white	398 / 77.1
Pancreatic	8 / 1.6	Black / African-American	53 / 10.3
Leukemia/Lymphoma	10 / 2	Asian American / Pacific Islander	38 / 7.4
Gynecological	10 / 2	Mixed Race	18 / 3.5
Other*	27 / 5.2	Native American	0 / 0
Colorectal	37 / 7.2	Prefer Not to Answer	8 / 1.6
Lung	82 / 16		
Breast	334 / 64.9		

* includes Bladder, Brain, Rare, Liver, Skin, Stomach/Esophageal, Thyroid cancers

Table 1. Respondent Breakdown by Cancer Type and Race

Conclusions

Co-creation methods were used in the **Design** phase to identify side effect experiences in cancer treatment and validate what matters most to individuals with cancer; in the **Develop** phase to validate a pan-cancer survey examining what mattered to the audience of interest; and in the **Deploy** phase to rapidly accrue a large and diverse set of responses through advocacy partnerships. **Co-creation also identified layers of side effect management challenges that cannot be reflected in current rubrics for QoL measurement.**

Unlike current QoL rubrics, this study-created survey examined many of the underlying challenges to maintaining QoL while on, and following, treatment. While co-creation may seem daunting, this study provides a template for effective, quality partnerships between study teams, advocates, and advocacy groups for implementing co-creation methods in the cancer setting.

Additional Research

Subsets of the data for the survey has been presented at SABCS23 and ASCO24 but the full body of data is yet to be published. ACE is leveraging similar co-creation methods to create abstracts and proposals that patients, clinical care, and research find valuable to modifying the status quo including stratification based on cancer type, stage, and treatment status.

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