COTA

Consumer Attitudes Toward Clinical Trials for Cancer: Overcoming Frustration to Accelerate Innovation

Executive Summary

"Operation Warp Speed" - the successful effort to fast-track creation and adoption of vaccines for COVID-19 - has undoubtedly changed consumer expectations for the life sciences and healthcare industries.

In fact, according to a study sponsored by COTA, Inc., approximately half of all respondents indicated that this specific initiative has made them believe that cancer treatment and drug development processes can and should be faster moving forward.

The study, which surveyed 1,110 Americans who've either had cancer or who've had someone in their immediate family with cancer, found that attitudes specific to cancer care and treatment are swiftly evolving based on lessons learned from the pandemic. Most notably, the study found:

- **Two-thirds of respondents** feel clinical trials for cancer are too slow to produce results
- More than **80% of respondents** familiar with the clinical trial process incorrectly think that clinical trials adequately include real-world data from varied racial, ethnic, and socioeconomic groups
- Approximately **85% of respondents** would agree to share their anonymous data if asked by their doctor
- **86% of respondents** believe oncologists should be actively discussing the value of sharing data as part of patient interactions

Based on these changes in consumer expectations, life sciences leaders and oncology providers need to reimagine how they are innovating, treating, and collaborating with cancer patients and their families moving forward.

What's Impeding Innovation in Cancer Care?

We know that innovation thrives when life science companies, healthcare providers, patients, and family members come together to participate in innovative clinical trials for cancer. These trials often lead to innovative medicines that can extend cancer patients' lives and improve quality of life.

However, many promising clinical trials simply don't get off the ground as quickly as they could, so these life-saving medicines are delayed. Chronically low enrollment rates slow down the rate of success, but what is stopping patients from engaging in the research community?

The answers might be surprising.

While conventional wisdom says that data privacy concerns, lack of education about clinical trials, and fear of experimentation are limiting participation, patients appear more ready to engage than previously thought. Instead, they feel like the clinical trial environment is holding them back, and they are ready to demand changes.

To further explore how patients and their family members view their roles in the clinical trial ecosystem, COTA recently surveyed **1,110 people** who've either had cancer or who've had someone in their immediate family with cancer. We wanted to know how patients perceived current efforts to bring new cancer therapies to market and how they wished to engage with the clinical research community.

Here's what we learned.

Clinical trials aren't moving fast enough for patients and their loved ones

A cure for cancer can't come fast enough. Perhaps unsurprisingly, participants in the survey want access to the latest and greatest treatments quickly, and they are deeply frustrated with how long it takes to develop, test, and approve new therapies.

Two-thirds feel the clinical trial process for developing cancer therapeutics is too slow. About half of patients and family members cited a specific reason for this belief: the success of Operation Warp Speed. The public-private collaboration to develop safe and effective COVID-19 vaccines has skewed their ideas about how quickly medical research happens.

60% of people who have had cancer themselves said COVID-19 demonstrated that cancer treatments should be developed faster.

44% of family members of cancer patients feel that COVID-19 has changed their expectations for the speed of cancer research.

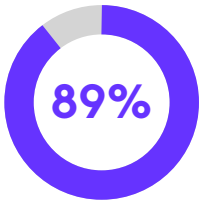
These respondents are correct that medical research can and should move faster than in the past, but they might not be fully aware that the COVID-19 vaccines are actually founded upon decades of previous research about similar viruses. Providers and researchers faced with patient frustration may wish to manage expectation by putting the medical discovery process in context.

"As an oncologist, I have seen firsthand how devastating a cancer diagnosis is for a patient and their family," said **CK Wang, Chief Medical Officer at COTA, Inc.** "It is hard to not look back and question whether some of my patients would have survived had innovations specific to cancer care and treatment been accelerated through highly focused funding, research, technology, and innovative collaborations like those prioritized for the COVID-19 vaccine."

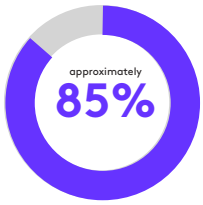
Patients are eager to support clinical trials by sharing their data

Despite—or perhaps because of—concerns that research is too slow, interest in clinical trial participation is high. Approximately 71% of patients and family members regularly research new clinical trial options of their own volition, the survey found.

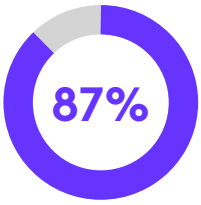
And they are eager to actively participate. 86% of respondents believe oncologists should be actively discussing the value of sharing data with researchers as part of patient interactions, yet less than half reported their oncologist discussed the value of anonymously sharing cancer data. However, COTA's study found that they are ready to donate their anonymized data to enhance cancer research, and they think others should do the same.



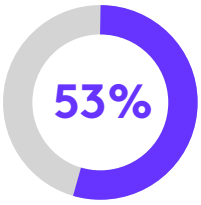
support all cancer patients sharing their health data anonymously for advancing treatment research and discovery.



would agree to share their anonymous data if asked by their doctor.



indicated they wouldn't care if their data had already been anonymously shared.



believe that a cure for cancer would already be available if all cancer patients' data were collected and combined.

Misinformation about representation and diversity in clinical trial data is widespread

A broad desire for participation is good news for providers and clinical trial sponsors looking for diverse, representative data. The vast majority of patients were quick to agree with industry experts that clinical trialsare at their most effective when they include diverse and representative data.

87% of patients and family members believe clinical trials should be required to represent real-world population patterns.

Yet while more than **80% of respondents** who indicated they were familiar with the clinical trial process think that clinical trials already do adequately include data from varied racial, ethnic, and socioeconomic groups, they couldn't be more wrong.

Black or African Americans represent more than 13% of the US population, but they only comprise 5% of clinical trial participants, according to the FDA. People of Hispanic or Latino heritage represent 18% of the population but make up only 1% of clinical trial participants.

These disparities can have significant impacts on the speed with which clinical trials are completed, especially in studies for rare cancers. A lack of diverse, representative data can also lead to questions about the efficacy of therapeutics under review, creating worrisome gaps in knowledge about safety and outcomes.

We must do more to support and cultivate patient interest in donating data, especially in traditionally underserved and underrepresented communities, to ensure we have enough rich, trustworthy, realistic data to develop safe and effective therapies.

Advance Cancer Care and Patient-Provider Collaboration in the Next Decade

Cancer care has markedly improved over the decades, but there is still a great deal of work to do. To maximize the efficacy of cancer clinical trials moving forward, we recommend the following:

Providers

- Discuss the benefits of health data sharing with patients
- Identify ways to remove barriers to clinical trial enrollment to encourage underrepresented populations to participate
- Proactively discuss clinical trials with patients
- Maintain high ethical and privacy standards for health data sharing

Life Sciences

- Expand cross-industry collaborations initiated during COVID-19 and apply them to other disease areas like cancer
- Adopt innovative clinical trial designs to decrease enrollment barriers
- Continue to expand the use of real-world data and real-world evidence to accelerate drug development and make clinical trials more diverse

Patients

- Take an active and informed role in your own cancer care and treatment
- Approve the sharing of your anonymized health data for research use
- Inquire into the availability of clinical trials

Regulators

- Continue to work with stakeholders to accelerate clinical trial innovations
- Safely remove regulatory barriers when possible to increase participation in clinical trials
- Demand that clinical trials are representative of real world patient populations

Survey methodology

The survey was conducted by PureSpectrum, an independent market research platform that gathers insights via online, nonprobability samples collected from panels in the PureSpectrum Marketplace. For more information on PureSpectrum's methodology, visit purespectrum.com.