Re: Request for Information (RFI): Seeking Stakeholder Input on Scientific Gaps and Research Needs Related to Delivery of Cancer-related Care via Telehealth

Dear Dr. Jensen,

I am pleased to submit these comments on behalf of the Association for Clinical Oncology (ASCO) in response to the RFI mentioned above. ASCO is committed to continued research and analysis of telehealth and its role in oncology and appreciates that the NCI shares this priority.

ASCO is a national organization representing nearly 45,000 physicians and other professionals specializing in cancer treatment, diagnosis, and prevention. We are also dedicated to conducting research that leads to improved patient outcomes, and we are committed to ensuring that evidence-based practices for the prevention, diagnosis, and treatment of cancer are available to all Americans.

The Association thanks NCI for including in the list of research topics “understanding of the role of costs, insurance, and payer policies on receipt of telehealth services.” The NCI is creating an important opportunity to generate evidence on whether and how these financial factors influence telehealth adoption.

Telehealth can play an important role in cancer care delivery and ASCO is committed to supporting appropriate continued use of telehealth in the post-pandemic future. Complex factors affect both the continued uptake of telehealth and the goal of providing a sustainable, equitable, and evidence-based approach to using telehealth for cancer care. ASCO recently released an interim position statement, Telemedicine in Cancer Care, outlining areas to address the immediate telemedicine needs emerging during COVID-19. Our input on the NCI’s RFI is grounded in this statement. As the NCI considers the scientific gaps and research needs related to cancer care via telehealth, we suggest the following important areas for consideration:

I. Role of telehealth in addressing issues of equity and access to clinical trials (CTs).

Addressing disparities in cancer care, including in CT enrollment, has long been a priority for ASCO. Patient’s face significant barriers in accessing CTs that include but are not limited to clinicians or practices that do not participate in clinical trials, bias in patients to approach, narrow eligibility criteria, comorbidities, socioeconomic status, and geography. NCI and the Food and Drug Administration’s timely response to COVID-19 enabled patients to continue CT participation through telehealth. This experience provides an excellent opportunity to understand how well-designed telehealth could enable sites to provide enhanced access to CTs and improve CT diversity.

II. Best practices for telehealth and quality assessment. Research is needed to determine the efficacy of emerging telemedicine models to deliver high quality cancer
care. Further research on safety, efficacy, treatment adherence, clinical care, and cost effectiveness will inform an evidence-based approach to this transformation. Having robust measures to assess the impact on patient outcomes and care processes with special attention to the financial impact will be necessary. Our members have reported an increased uptake of telemedicine encounters and there is growing interest in establishing metrics for assessment of telemedicine encounters. ASCO’s CancerLinQ, PracticeNET, and COVID-19 Registry are compiling real-world data on the impact of COVID-19 on various aspects of telemedicine cancer care. For example, there is little data currently available on best practices for a telemedicine visit, conducting physical examinations, and optimal follow-up mechanisms after an initial telemedicine encounter. Research is also needed regarding the optimal approaches to include patients’ caregivers in a telemedicine visit and to assess how well information is transmitted and assimilated by patients and caregivers.

III. Optimal methods to collect and assess patient-reported outcomes (PROs) and clinician views. Surveys are a common method for assessing PROs and clinician views, but inadequacies in both the conduct and reporting of surveys are common. Better understanding of which telemedicine models work best to capture PROs is needed. A number of validated telemedicine survey instruments existed prior to the pandemic (e.g. Telemedicine Satisfaction Questionnaire, The Telemedicine Satisfaction and Usefulness Questionnaire”). Many of these use “satisfaction” as a process outcome measure for which there is widespread criticism, as it lacks conceptual and theoretical clarity. We urge the NCI to support research into the development of more robust PRO assessments and quality measures within the context of telemedicine.

IV. Addressing the digital divide. The potential advantages of and flexibilities available via telehealth will not be fully realized without addressing the digital divide. Despite general availability and widespread use of internet services, many individuals in the U.S. lack broadband access and/or personal devices or they are not proficient in the use of health information technology (HIT). This “digital divide” has led to inequities in effective use of telemedicine for patients, caregivers, and clinicians. Some of these constituencies may be uncomfortable with the technology and may not understand ways to ensure HIT privacy and security and facilitate information sharing policies. Individual differences in digital literacy (competency and technical skills needed to operate digital devices and understand their functionality) can widen health disparities. Approximately half of American adults exhibit low health literacy and consequently struggle to find and use health information. These inequities are especially prominent among individuals living in rural communities, individuals with lower socio-economic status, and older adults. Compounding the challenges, older adults experience the majority of cancer diagnoses, make up the majority of cancer survivors and deaths, and are the fastest growing segment of the US population. Researching effective methods to address these disparities in the context of the digital divide will be critical not only to realizing the promise of telemedicine for patients with cancer, but to providing equitable access to care for all patients, everywhere. The COVID-19 pandemic necessitated overnight adoption of platforms and technologies that had rarely been used in cancer care. Examining how access to technology and reliability of connectivity impact disparities in care will be an important focus of research.

We thank you for the opportunity to comment on the Request for Information (RFI): Seeking Stakeholder Input on Scientific Gaps and Research Needs Related to Delivery of Cancer-related Care via Telehealth. Please contact Allyn Moushey (Allyn.Moushey@asco.org) or Shimere Sherwood (Shimere.Sherwood@asco.org) with any questions or for further information.

Sincerely,

Monica Bertagnolli, MD, FACS, FASCO
Chair of the Board
Association for Clinical Oncology