

CANCER LEADERSHIP COUNCIL

A PATIENT-CENTERED FORUM OF NATIONAL ADVOCACY ORGANIZATIONS
ADDRESSING PUBLIC POLICY ISSUES IN CANCER

July 30, 2020

Norman E. "Ned" Sharpless, MD
Director
National Cancer Institute
9000 Rockville Pike
Bethesda, MD 20892

RE: NOT-CA-20-080, Request for Information (RFI): Seeking Stakeholder Input on Scientific Gaps and Research Needs Related to Delivery of Cancer-Related Care via Telehealth

Dear Dr. Sharpless:

The undersigned organizations of the Cancer Leadership Council represent cancer patients, providers, researchers, and caregivers. We appreciate the opportunity to offer advice about research needs and scientific gaps related to cancer care delivered by telehealth. All of us have been on a challenging journey during the current coronavirus Public Health Emergency (PHE), learning how to deliver and receive care by telehealth and preparing for a future of quality telehealth after the pandemic.

We identify below some opportunities for research on cancer care through telehealth.

Identifying Patient and Provider Preferences Regarding Services That Can Be Delivered by Telehealth

The clinicians and patients we represent embraced the option for providing and receiving cancer care through telehealth safely and timely during the COVID pandemic. Although many practices saw their telehealth visits increase dramatically early in the pandemic, some have shifted visits back to the provider office. However, the volume of telehealth visits remains above pre-pandemic levels.

Since the pandemic emergence, health care professionals and patients have been identifying the types of visits and range of cancer care services that can be delivered successfully through telehealth. Many of our organizations are soliciting input regarding clinician and patient preferences, through formal and informal means. We would like to share our findings with you and your team at the National Cancer Institute (NCI) and strongly encourage that our survey be continued and expanded with NCI support. Real world experience with telehealth during the pandemic must be collected and analyzed.

Researching Strategies to Enhance Access Rather Than Worsen Disparities

The waiver of telehealth requirements permits the delivery and reimbursement of services by audio only. Although this flexibility has ensured access to telehealth services for those who face limits in their devices, software, or wireless connection, it is an inadequate solution. We encourage research that analyzes the limits on access to the technology necessary for video telehealth among both patients and clinicians because recent experience suggests that technology issues are contributing to disparities in access.

Research should also address potential solutions and the overall extent of disparities in accessing telehealth, whether related to technology or other barriers.

Researching Options to Enhance Coordination of Care Through Telehealth

Cancer patients receiving telehealth services have identified coordination of care as a serious challenge. The challenges include ensuring timely access to previous laboratory or imaging reports at the time of a telehealth visit, scheduling services so that results are available at the time of the telehealth visit, and ensuring access to medical records so that patient and clinician can rely on the same information during a telehealth visit. We urge research on the problems and potential solutions for coordinating care and exploring whether medical record interoperability and improved patient portals can enhance care coordination.

Patients who have had telehealth visits have identified the need for preparation to ensure a successful visit. Preparing includes tips about the technology platform their oncologist is using, reminders about access to health information on a patient portal or elsewhere, and reminders about the start and stop time of a telehealth visit. Patients have suggested a checklist or updating their personal and medical information to maximize visit productivity. We recommend that research address patient preparation for telehealth visits, as a part of the research on coordination of care through telehealth.

Researching the Technological and Practice Obstacles to Receiving Second Opinions

Cancer patients have said that they see great promise in access to second opinions through telehealth visits. Research should explore professional licensing and other issues required to make second opinions and consultations readily available through telehealth. Engaging policymakers will ensure their input on licensing issues so that second opinions can be readily offered across state borders.

Additional Issues for Study

Several other issues have been identified by providers and patients as topics for additional research, including:

- Optimal means for training health care professionals in telehealth services, including the communication and caring skills which patients indicate are necessary for quality visits.
- Provider burnout, which is a problem among those caring for COVID-19 patients as well as cancer care clinicians who are adjusting and adapting to new means of providing care and maintaining high quality of care during the pandemic.
- The advantages and disadvantages of telehealth for a first visit with a new provider (other than a consultation or second opinion telehealth visit).
- Strategies for ensuring protection of patient privacy, considering the wide range of telehealth platforms in use.
- The potential use of telehealth visits in clinical trials, in the pandemic and beyond.
- Maximizing the role of caregivers to ease the delivery of telehealth services and assist in coordination of care related to telehealth visits.

We appreciate the opportunity to offer advice regarding telehealth topics appropriate for research.

Sincerely,

Cancer Leadership Council

American Society for Radiation Oncology
CancerCare
Children's Cancer Cause
Fight Colorectal Cancer
International Myeloma Foundation
LUNgevity Foundation
Lymphoma Research Foundation
National Coalition for Cancer Survivorship
Ovarian Cancer Research Alliance
Prevent Cancer Foundation
Susan G. Komen