CANCER SUPPORT
COMMUNITY
COMMUNITY IS STRONGER THAN CANCER

March 25, 2022

Norman E. Sharpless, M.D.
Director
National Cancer Institute
9609 Medical Center Drive
Rockville, MD 20850

VIA Electronic Submission: ncidccpsprioritiesrfi@mail.nih.gov

Re: Request for Information (RFI): Priorities for Cancer Control and Population Sciences at NCI
Notice Number: NOT-CA-22-053

Dear Director Sharpless,

The Cancer Support Community (CSC), an international nonprofit organization that provides support, education, and hope to cancer patients, survivors, and their loved ones, appreciates the opportunity to comment on the National Cancer Institute's (NCI) Request for Information (RFI) on Priorities for Cancer Control and Population Sciences at NCI (Priorities).

As the largest direct provider of social and emotional support services for people impacted by cancer, CSC has a unique understanding of the cancer patient experience. In addition to our direct services, our Research and Training Institute and Cancer Policy Institute are industry leaders in advancing the evidence base and promoting patient-centered public policies. We believe the information below will assist the Division of Cancer Control and Population Sciences (DCCPS) to reduce the risk, incidence, morbidity, and deaths from cancer and enhance the quality of life for cancer survivors and others affected by cancer.

**Patient Experience Data**

One common thread that cuts across all three categories addressed in the RFI is the untapped role and benefit of patient experience data. Passage of the 21st Century Cures Act in 2016 and the Food and Drug Administration Reauthorization Act (FDARA) in 2017 heightened the importance of collecting "patient experience data" (PED) that includes both the physical *and* psychosocial impacts of a condition, therapy, or clinical investigation.

PED provides meaningful information that can be used to better inform cancer prevention, drug development, care and treatment, and survivorship by capturing patients' experiences, perspectives, needs, and priorities related to important issues. These include the symptoms and natural history of a condition, the impact a condition has on an individual's functioning and quality of life, experiences with treatment, patients' input on which outcomes are important to them, and their preferences for treatment (21st Century Cures, 2016).

Understanding a patient's social and emotional well-being is so fundamental to care that it is a required patient-centered standard in the accreditation process for the Commission on Cancer. Further, in oncology, the Institute of Medicine concluded "it is not possible to deliver good quality cancer care without using existing approaches, tools, and resources to address patients' psychosocial health needs" (IOM, 2008). For drug developers, tracking patient experience and offering interventions throughout a clinical trial could very likely improve outcomes and may also allow for more efficient trials by improving patients' compliance and retention in trials. Collecting and considering PED in survivorship can provide valuable insights on patients' quality of life including possible long or late onset adverse consequences of treatment (Jacobsen & Jim, 2011).

Developing and implementing methodologies to ensure the consistent capture, consideration, and use of PED across the cancer continuum will facilitate the realization of a patient-centered health care system and accelerate progress by expanding not just the volume of information available to draw upon when advising on prevention, developing therapies, treating patients, or providing survivorship care, but also the *type of information* revealed. This enhanced knowledge base will generate measurable and meaningful quality data that can be used to maximize benefits to patients, providers, and drug developers. The PED generated could help provide a greater understanding of known challenges, identify new challenges, and help facilitate solutions to better control cancer. For example, PED could reveal healthy behaviors that reduce cancer risks and/or improve treatment outcomes, provide a greater understanding of how social determinants of health impact cancer, link environmental factors to cancer, create new clinical trial designs to meet the unique unmet needs of underserved populations, and anticipate psychosocial needs and have resources already in place to proactively address them.

## Digital Health Technologies

The development, availability, and use of digital health technologies is providing new methods to help ensure PED is consistently collected, considered, used, and, most importantly, communicated back to patients and providers. While innovative technologies such as wearable devices are evolving and can enhance both the ability to capture PED and the expanse of the information collected, it is important to address the barriers that prevent people from using existing technologies such as computers, tablets, smartphones, as well as the broadband services necessary for their use.

The COVID-19 pandemic has highlighted the importance of access to telehealth and tele-mental health services for patients, especially those living with cancer. But in order for all people to have access to telehealth and tele-mental health services, we need to ensure people from traditionally underserved communities, people in rural areas, people with disabilities, and those unfamiliar with technology have consistent and affordable access to the technology essential to receive that care. Policies that make permanent the flexibilities for telehealth and tele-mental health services are one part of the solution but ensuring equitable access to technologies readily employed in health care delivery will bolster the capture, consideration, and use of PED from communities whose information has, to date, typically been excluded but is essential to improving cancer control.

## Cancer Screenings

Cancer screenings are another integral component to cancer control. At the onset of the pandemic, cancer screenings plummeted, with screening for cancers of the breast, colon, and cervix down between 86% and 94% in March of 2020 alone (Mast & Munoz, 2020). While one study showed that by July 2020 the number of tests was recovering, approaching pre–COVID-19 levels (McBain et al., 2021), there is broad concern that these delayed or missed screenings will result in some cancer cases being diagnosed at a later stage increasing the likelihood of a poorer prognosis. NCI predicted that over the next decade we will see almost 10,000 excess deaths from breast and colorectal cancer alone because of pandemic-related delays in cancer screening and treatment (Sharpless, 2020). It is critical to develop and implement a comprehensive plan that reinforces the importance of timely and appropriate cancer screenings, supports the development of effective cancer screening methods that are less susceptible to public health emergency (PHE) interruptions (e.g. appropriate use of fecal immunochemical test (FIT) to screen for colorectal cancer), and establishes policies and practices (including better coordination of care) to minimize the delay in cancer screenings and diagnoses both in and out of PHEs. The collection, consideration, and use of PED across the care continuum in coordination with equitable access to all levels of health technologies, and the leveraging of telehealth and tele-mental health services, can help identify and alert patients that are due and/or past due for a cancer screening and the resources to assist them in obtaining that screening.

**Conclusion**

The Cancer Support Community appreciates the opportunity to share these comments in response to NCI's RFI on priorities for cancer control. We look forward to working with NCI and all stakeholders to improve cancer prevention, treatment, care, and survivorship by ensuring patients' experiences and the meaningful data arising from those experiences are consistently collected, considered, and used to control cancer through better and more equitable methods of prevention, treatment, and care. Should you have any questions or like to discuss these comments in more detail, please reach out to Kim Czubaruk at kczubaruk@cancersupportcommunity.org.

Sincerely,

Kim Czubaruk

Kim Czubaruk, Esq.
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## References

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