



June 10, 2021

President Joe Biden
The White House
1600 Pennsylvania Ave NW
Washington, DC 20500

Dear President Biden,

The Cancer Support Community (CSC), an international nonprofit organization that provides support, education, and hope to cancer patients, survivors, and their loved ones, applauds your continued commitment to advancing cancer research efforts and accelerating cancer discoveries by your bold proposal to create the Advanced Research Projects Agency for Health (ARPA-H). As the largest 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 to ensure that the patient voice is at the center of the national dialogue. We look forward to working with you and your Administration to ensure that ARPA-H includes the patient perspective within its medical, health, and technological initiatives.

Over the last 50 years, we have seen remarkable advancements in cancer research and innovation. We proudly worked as partners with you on the Biden Cancer Initiative (BCI) and the Cancer Moonshot Initiative, and have seen both directly impact advancements in innovation, collaboration, and urgency in the fight against cancer. We are confident that ARPA-H will further accelerate innovative breakthroughs in cancer and other diseases that significantly impact people nationwide and will provide patients with hope for a brighter future.

As you and your Administration structure ARPA-H, we respectfully request that CSC, along with other patient advocacy organizations, be included throughout the creation and implementation of this new agency. It is essential that any new treatments and cures achieved through the transformational research and new technologies of ARPA-H be patient-centered as well as elevate the full patient experience, which goes beyond the physical symptoms or side effects of a disease, therapy, or clinical investigation, to also address the psychosocial concerns, needs, and preferences of cancer patients. Patients' experiences living with, treating, and/or managing their disease provides crucial information not otherwise captured through the clinical process. Passage of the *21st Century Cures Act* and the *Food and Drug Administration Reauthorization Act (FDARA)* amplified the importance of collecting patient experience data. Notable stakeholders such as the Institute of Medicine, the Patient-Center Outcomes Research Institute, and the American College of Surgeons Commission on Cancer recognize psychosocial care as the standard of care in oncology.

We are pleased to see that your proposed fiscal year 2022 budget includes \$6.5 billion for ARPA-H. We urge you to work with Congress to ensure that this new endeavor in no way reduces or redirects funding away from either the National Institutes of Health (NIH) or National Cancer Institute (NCI). NIH and NCI conduct critical basic, translational, and clinical research that help fuel discoveries in cancer prevention, detection, diagnosis, and survivorship. Meaningful and ongoing investment in both agencies is necessary to continue building a cancer research infrastructure for the future. To that end, we believe the budget for ARPA-H should be separate and distinct from that of the NIH and NCI, with the new

agency structured in a way that leverages the incredible existing scientific research programs developed from NIH as well as the private sector.

We appreciate your long-time advocacy and support of people impacted by cancer. As you begin to develop and establish ARPA-H, CSC looks forward to working with you and your Administration to incorporate the patient experience at the outset. Should you have any questions or would like to arrange a time to discuss further, please contact Phylicia L. Woods, Executive Director of the Cancer Policy Institute at the Cancer Support Community at pwoods@cancersupportcommunity.org.

Sincerely,

A handwritten signature in cursive script that reads "Phylicia L. Woods".

Phylicia L. Woods, JD, MSW
Executive Director – Cancer Policy Institute
Cancer Support Community Headquarters