CANCER LEADERSHIP COUNCIL

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

CANCER LEADERSHIP COUNCIL
PRINCIPLES FOR THE ADVANCED RESEARCH PROJECTS AGENCY FOR HEALTH (ARPA-H)

The member organizations of the Cancer Leadership Council are dedicated to researching and developing lifesaving cancer therapies; delivering quality cancer care; providing support services and educational services to cancer survivors from diagnosis and across the continuum of care as well as to individuals, families, and communities with elevated cancer risk; supporting research and programs to improve cancer prevention and early detection efforts; and ensuring equitable access to quality cancer care. We recommend principles for the Advanced Research Projects Agency for Health, or ARPA-H, to ensure that the new entity produces meaningful benefits for people with cancer, strengthens and complements ongoing cancer research efforts, advances quality cancer care for all, and reduces health care disparities.

- The new entity should not replicate the work of academic researchers supported by private research foundations and the National Institutes of Health (NIH) or the work of pharmaceutical or biotechnology companies engaged in research and development. The entity should collaborate with those partners and a wide range of government agencies. ARPA-H should focus on projects that would not be undertaken by other research entities or industry partners.

- ARPA-H should be guided by a culture of risk-taking that accepts failure. Fostering this culture will require a leader who has a broad range of research and development expertise and experience managing collaborative ventures. The ARPA-H leader should be given significant independence to achieve this culture of innovation. Congress should consider making the ARPA-H Director a Presidential appointee not requiring Senate confirmation (comparable to the National Cancer Institute Director position) to provide the leader adequate authority and independence.

- The new research entity should employ criteria for selecting projects that can be used efficiently and that do not have the limitations of some peer review programs, including the length of the review process. However, the standards for selection of projects, the metrics for success, and the standards for continuing or terminating projects must be transparent and publicly disseminated. ARPA-H should report routinely and publicly on funded projects and their status.

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- ARPA-H should support "use-driven" research, or research that is directed at solving a practical and specific problem. This research might be directed at developing a specific product or treatment, and it might also involve creating platforms, capabilities, and resources that can be used across a range of products and across many diseases.

- The use-driven research of the new entity should include efforts to develop new and improved tools for cancer screening, risk management for genetic predisposition to cancer, and early detection, especially important in the wake of the disruptive impact of the coronavirus pandemic on screening and early detection.

- ARPA-H leaders and managers should evaluate all the new agency's projects and initiatives for their potential to address health disparities. The new research agency should include use-driven research efforts that are specifically directed toward improving the diversity of clinical trials enrollees and enhancing the diversity of the research workforce and clinical care workforce.

- Improving cancer treatment should be one goal of the new research entity, and those efforts should focus not only on development of new drugs and therapies but also on strategies to improve the delivery of care and ensure equitable access to quality care. Projects to improve cancer treatment should include the development of interventions and systems of care that reduce immediate and late and long-term side effects of therapies to enhance the quality of life of cancer survivors from diagnosis through treatment and survivorship. The side effects of cancer and cancer treatment for which better interventions should be developed include but are not limited to nausea and vomiting, fatigue, mental health challenges, hair loss, sexual dysfunction, cachexia, and financial toxicity.

- The new research entity should direct special attention to diseases where there is unmet medical need, which may relate to the limited incidence of the disease, lack of basic scientific understanding of the disease, modest private sector investment in the disease, or other factors.

- The new entity should invest in cancer prevention as a means of reducing disparities in access to screening, care, disease burden, and health care costs. These efforts should include attention to the genetic predisposition to elevated cancer risk and disproportionate disease burden due to social determinants of health such as education, environmental and neighborhood factors, economic stability, health and health care, and social and community contexts.

- The work of ARPA-H should be informed by a permanent advisory council including patients, patient advocacy organizations, health care professionals, researchers, industry representatives, third-party payers, health policy experts, and other stakeholders. This panel should be utilized early to provide advice about possible projects. Although these stakeholders will be able to advise about all types of projects,

their advice may be especially important regarding projects to improve health care delivery, enhance equitable access to care, and strengthen resources for clinical research. The participation of patients and patient advocacy organizations in the advisory council is of paramount importance.

- Congress should consider how intellectual property issues that may arise in connection with ARPA-H projects will be addressed. Congress should also consider how Americans will be ensured access to the products developed through ARPA-H projects.

- ARPA-H should be generously funded so that promising projects can be awarded support without delay or without funding adjustments that might affect project success. ARPA-H funding must not be provided at the expense of NIH or other federal public health agencies and programs important to cancer patients and survivors.

- NIH funding should be increased at the same time ARPA-H is launched, to boost the percentage of approved grants that can be funded and to ensure that NIH can be a strong partner to ARPA-H through aggressive funding of basic, translational, and clinical research.

These principles of the **Cancer Leadership Council** are endorsed by the following member organizations:

Academy of Oncology Nurse & Patient Navigators
American Society for Radiation Oncology
Association for Clinical Oncology
Association of Oncology Social Work
Cancer*Care*
Cancer Support Community
Children's Cancer Cause
Family Reach
Fight Colorectal Cancer
Hematology/Oncology Pharmacy Association
International Myeloma Foundation
LUNGevity Foundation
Lymphoma Research Foundation
National Coalition for Cancer Survivorship
Ovarian Cancer Research Alliance
Prevent Cancer Foundation
Susan G. Komen

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