



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

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Dear Dr. Rashid:

The undersigned organizations, representing cancer patients, physicians and researchers, appreciate the opportunity to comment on the Centers for Disease Control and Prevention (CDC) Health Protection Research Guide, 2006-2015. We applaud CDC for developing a comprehensive ten-year blueprint for health protection research, including public health research and prevention research, through a process that allowed input from a wide range of stakeholders. We recommend revisions of the plan to strengthen the research agenda related to cancer and propose strategies for setting priorities among the research initiatives that are identified in the plan.

**Implementation of the Plan**

We understand that the Research Agenda Steering Subworkgroup and the CDC Excellence in Science Committee served as external and internal advisory panels, respectively, during the development of the Research Guide. These panels should remain in place as oversight bodies as the research identified in the plan is undertaken, to ensure that the fundamental goals of the plan are honored.

The membership of the Research Agenda Steering Subworkgroup should be expanded to include consumers as the ultimate beneficiaries of the public health and prevention research outlined in the plan. Thus, we recommend the inclusion of several patient advocates in the Subworkgroup. Such representatives can provide the point of view of the consumer and can also offer advice about the investment of private foundations in prevention and public health research. For example, our group of 31 cancer nonprofits

includes organizations that make a significant investment in research, including prevention research, and have impressive experience as research funders and administrators. They would provide valuable insights to CDC as it implements the recommendations in the Research Guide. We strongly recommend that representatives of patient advocacy organizations and research foundations be named to the Subworkgroup.

### **Funding of Research Identified in the Plan**

We understand that the Research Guide identifies research opportunities for CDC and for private sector research funders. Although there is no budget attached to the Research Guide, the research initiatives outlined in the document appear to outstrip the available public and private resources for public health and prevention research. As a result, it will be necessary to set priorities among the initiatives in the plan. We recommend that advice regarding priority-setting be sought from the external and internal advisory groups. In addition, CDC should obtain guidance regarding implementation of the Research Guide priorities from patient advocate and consumer stakeholders.

### **Cancer Survivorship Research**

The Research Guide recommends that CDC, “Develop and evaluate strategies that enable families, employers, and communities to control and prevent the burden of chronic diseases and to reduce the preventable physical and emotional adverse health effects associated with these diseases and conditions.” We strongly urge that this recommendation be revised to include a special emphasis on strategies to reduce the burden of cancer. There is a rapidly developing body of knowledge regarding strategies that will help cancer survivors deal with the late and long-term effects, including potentially serious effects, of cancer and its treatment. CDC should invest in this area of research and should ensure that the results of this research are reflected in its cancer control programs.

### **Collaboration with Other Federal Agencies**

We endorse the inclusion of several research recommendations that have special relevance to cancer, and we propose that these research efforts be undertaken in collaboration with the National Cancer Institute (NCI) and other appropriate federal agencies. A cooperative and multi-institutional research effort is the most efficient use of federal resources. Among the topics that are appropriate for a cooperative research effort, including some that are already a special focus for NCI, are:

- Research to “[d]evelop improved methods to determine, measure, monitor, treat, and/or prevent chronic diseases attributable to infectious agents in general and specific populations.” NCI currently invests in research investigating the links

between infectious agents, including hepatitis B virus (HBV), human papillomavirus (HPV), *Helicobacter pylori* (*H. pylori*), and Epstein Barr virus (EBV), and development of cancer, and any CDC effort should be complementary and consistent with the NCI program.

- Research to “establish the major environmental causes of disease and disability, and identify related risk factors.” CDC research in this area should not unnecessarily duplicate but should be coordinated with the efforts of NCI and the National Institute of Environmental Health Sciences (NIEHS), which have been leaders in examining the environmental links to cancer.
- Investigation of strategies to eliminate premature death, illness and disability in disadvantaged populations. We suggest that the study of underserved and disadvantaged populations include a special focus on cancer survivors and be consistent with research that is currently undertaken by NCI-supported investigators.
- Development of strategies to prevent disease. The CDC has a strong history of involvement in tobacco cessation efforts and is therefore the appropriate agency to provide leadership on research related to smoking cessation. CDC collaboration with the private sector and NCI in the development of smoking cessation interventions, including pharmacological interventions, is appropriate.

### **Screening and Early Detection Research**

There is great promise in the development and utilization of new cancer screening and early detection tools, but there may also be challenges to the implementation of technologies that may be developed. We urge CDC to include as part of its research agenda a wide range of research, including behavioral, economic and health systems research, to ensure optimal acceptance and utilization of screening and early detection technologies. These research efforts would be consistent with CDC goals of reducing the burden of chronic diseases and enhancing access to quality health care, including preventive services.

### **Electronic Health Records**

The Research Guide proposes that CDC “[e]xplore practices and strategies for using electronic and personal health records for public health.” The Department of Health and Human Services (HHS) is making a substantial investment in the development of interoperable electronic health records, and any parallel effort by CDC should be coordinated with the broad and aggressive HHS program. An appropriate area of focus for CDC research would be the development of electronic records systems that would

serve cancer survivors, who need access to cancer care summaries and follow-up plans to aid in tracking and addressing the long-term effects of cancer and its treatment.

**Immunization Services Delivery Research**

We commend CDC for highlighting research on immunization services delivery as a priority in the Guide. The plan suggests that research is necessary to identify strategies for delivery of new vaccines, including the Herpes zoster vaccine, which may be of special benefit to the elderly. We recommend that the research plan be expanded to include an investigation of a cervical cancer prevention strategy for delivery of the human papillomavirus vaccine to young adults as well as to those populations traditionally served by the childhood immunization program. CDC should evaluate a number of different approaches to delivery of this vaccine, including coordination with the current breast and cervical cancer screening program.

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We commend CDC for the lengthy and open process it embraced to develop its Research Guide, and we look forward to continued discussion with CDC regarding the plan and its implementation.

Sincerely,

**Cancer Leadership Council**

American Society of Clinical Oncology  
C3: Colorectal Cancer Coalition  
Cancer Research and Prevention Foundation  
The Children's Cause for Cancer Advocacy  
Fertile Hope  
International Myeloma Foundation  
Lance Armstrong Foundation  
The Leukemia & Lymphoma Society  
Lymphoma Research Foundation  
Multiple Myeloma Research Foundation  
National Coalition for Cancer Survivorship

National Prostate Cancer Coalition  
North American Brain Tumor Coalition  
Ovarian Cancer National Alliance  
Pancreatic Cancer Action Network  
Sarcoma Foundation of America  
The Susan G. Komen Breast Cancer  
Foundation  
Us TOO International Prostate Cancer  
Education and Support Network  
Y-ME National Breast Cancer Organization

cc: Julie Gerberding, MD, MPH  
Eddie Reed, MD