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May 20, 2015

Linda Porter, Ph.D. NINDS/NIH 31 Center Drive Room 8A31 Bethesda, MD 20892

Re: Call for Comments on Proposed National Pain Strategy

Dear Dr. Porter:

The American Cancer Society Cancer Action Network (ACS CAN) commends the Interagency Pain Research Coordinating Committee (IPRCC), and the associated working groups, for their efforts in creating the draft National Pain Strategy (Strategy). The alleviation of pain is critically important to adult and pediatric cancer patients, and we are pleased to offer comments on the draft Strategy. Given the significance of a national Strategy toward reducing the burden of pain in the U.S., we recommend that, before finalizing the Strategy, the Administration actively foster additional dialog around the proposals by convening a public stakeholder meeting.

Our specific comments and recommendations are organized according to the six components of the national Strategy.

### **Population Research**

ACS CAN supports the collection of additional data on pain prevalence in the U.S. There is a clear need for a coordinated effort that includes resources to address the gap in population-level research. However, if the data gathered are going to be used to provide solutions to the problem of inadequate pain treatment, then prevalence alone will not be sufficient to guide improvements. We suggest that surveys used to conduct population research also gather data on the status of access by individuals to effective pain treatment, and further query respondents about any barriers they experience that prevent adequate diagnosis and treatment.

As part of the data collection, socioeconomic and demographic information should also be captured in order to identify disparities in pain prevalence and treatment among different subgroups. It

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should be noted that surveys and other forms of data collection should include a mechanism for assessing pain in children, as this population group may not directly respond to such surveys, but nonetheless have been identified by the Institute of Medicine as an important subgroup affected by undertreated pain.

# Prevention and Care

The primary goal of the Strategy is the reduction of pain in the U.S. through prevention, and the provision of safe and effective pain relief. Given this goal, we are concerned that one of the primary objectives is to perform a cost-benefit analysis of interventions. Evaluating the overall effectiveness of interventions should be the primary focus, and when effective interventions are identified they should be implemented. Assessing cost — which may vary by location and scale of interventions — rather than effectiveness, risks discouraging the adoption of proven interventions that show impact on pain. Therefore we suggest only assessing costs when comparing two equally efficacious interventions against another.

#### Disparities

Unacceptable disparities exist in pain prevalence as well as patient access to effective pain treatments. We applied the Strategy's focus on eliminating disparities. In order to successfully address pain disparities specific actions have to be integrated into every component of the broader Strategy. For instance, as previously mentioned, the data collection envisioned under *Population Health* should include information about racial, ethnic and socioeconomic status; the *Professional Education and Training* component should include education on cultural competencies; and the use of tailored messages and delivery channels should be emphasized as part of the *Public Education and Communication* component.

In general, we have concerns that some of the strategies envisioned in this component focus on narrow sub-issues and processes rather than broader issues driving disparities. For example, objective two is focused on access to high-quality pain services for vulnerable groups, but there seems to be a strong reliance on providing web-based access to information and resources in order to satisfy this objective. Many of the groups suffering disproportionately from untreated pain may not have access to web-based information due to linguistic, literacy, technological or economic hurdles. Even for individuals who could access such information, there may be far greater hurdles than a lack of information that prevent appropriate access to pain treatment, such as a lack of providers and facilities, or a lack of insurance or ability to pay for treatment. We recommend the

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objectives regarding disparities be more broadly defined, and metrics used to measure progress be more oriented to actual outcomes desired, e.g. the level of disparities.

## Service Delivery and Reimbursement

As the Strategy notes, care models and reimbursement can significantly impact the delivery of high quality care that can prevent and treat pain. We agree that more integrated care delivery models have great potential to improve patient care; however, such models must include patient quality of life performance metrics – including availability and use of palliative care - to ensure that pain control is an outcome that is valued. It is also important to note that integrated models only impact individuals who have access. Unfortunately large sections of the U.S. population still do not have access to health insurance. The groups most likely to be uninsured are also typically the groups most likely to be disproportionately affected by pain, and poor pain treatment. Additional strategies are required to comprehensively reach the entire population.

Further, as much as the Strategy calls for evaluation of care models or therapies, we believe that it is equally important to actively evaluate the impact of public policies on pain management in order to optimize our public health approach to pain.

#### **Professional Education and Training**

We agree that better health care professional training in pain assessment and treatment is critical to improving pain relief, and managing risks associated with some pain treatments. This component of the Strategy focuses on establishing competencies and making resources available that can be used for education of professionals, and proposes measuring progress through the validity of the developed competencies, and the frequency that educational materials are accessed. While we acknowledge that some of the training and certification requirements that health professionals are subject to are outside of the purview of the Administration, we are nonetheless concerned that simply making resources available may not significantly change overall provider knowledge nationwide. We also recommend that metrics of progress toward this component of the Strategy be focused on the desired outcome and actual provider knowledge, rather than the process metric of accessed materials.

### **Public Education and Communication**

Pain and pain treatment are poorly understood by the public. ACS CAN strongly supports public education and communications about pain management. Much of the recent public focus on pain

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treatment has been tied to misuse and abuse of opioid analgesics, adding to the stigma faced by people living in pain. Therefore it is important that materials and messages developed and delivered as part of the Strategy are balanced and seek to remove the stigma of pain by informing the public about the prevalence of pain and available treatment options.

### Recommendations for Including Policy on Fighting Abuse of Pain Medications

Many of the major emerging hurdles to adequate pain treatment involve public policies adopted to fight abuse, addiction and diversion of prescription pain medications. Such policies can affect the practice of medicine in important ways. The Strategy would not fulfil its subtitle of "A Comprehensive Population Health-Level Strategy for Pain" if the role of abuse deterrent policies are not examined along with the interaction of addiction, abuse and law enforcement activities. The Strategy, as written, does not address these issues in a significant way, and we suggest these issues be incorporated within the Strategy components.

Thank you for the opportunity to share our thoughts on the draft Strategy, and we look forward to working with the Administration as it is further refined and implemented. If you have any questions about our comments please feel free to contact me or have your staff contact Mark Fleury at 202-585-3244 or mark.fleury@cancer.org.

Sincerely,

Christopher W. Hansen

President

American Cancer Society Cancer Action Network

Lindy W. John

#### About us:

ACS CAN, the nonprofit, nonpartisan advocacy affiliate of the American Cancer Society, supports evidence-based policy and legislative solutions designed to eliminate cancer as a major health problem. As the nation's leading advocate for public policies that are helping to defeat cancer, ACS CAN ensures that cancer patients, survivors, and their families have a voice in public policy matters at all levels of government.