



January 13, 2016

Tom Frieden, M.D., M.P.H.
Director, Centers for Disease Control and Prevention

Debra Houry, M.D., M.P.H.
Director, National Center for Injury Prevention and Control

United States Centers for Disease Control and Prevention
1600 Clifton Road
Atlanta, Georgia 30329-4027

Re: Draft Guideline for Prescribing Opioids for Chronic Pain, 2016 [CDC-2015-0112-0001]

Dear Drs. Frieden and Houry:

The Patient Quality of Life Coalition (PQLC) welcomes the opportunity to offer comments on the Centers for Disease Control and Prevention's (CDC's) Revised Draft Guideline for Prescribing Opioids for Chronic Pain, 2016. The PQLC is a coalition formed to advance the interests of patients, survivors and families facing serious illness. We are dedicated to improving quality of care and quality of life for all patients from pediatrics to geriatrics, as well as supporting public policies that improve and expand access to palliative care, and appropriate pain management for patients from the point of diagnosis forward.

We are mindful of the serious and growing public health crisis caused by the inappropriate use of opioid analgesics nationwide, and support evidence-based efforts to reduce harms and adverse events associated with such misuse. At the same time, we want to make sure public policies intended to reduce inappropriate use of opioids do not simultaneously create access barriers to pain management for patients for whom opioids are medically indicated, and who are benefiting from such treatment.

Given our collective interest in the issue, we are very concerned about the limited opportunity afforded by CDC until now for public input into the guideline development. We think this lack of transparency contributed in part to recommendations in the proposed guideline that are not wholly supported by the evidence, nor are they appropriately balanced to accommodate the legitimate needs of all patients who experience severe physical pain due to illness or injury.

As a coalition, we advocate for changes in public policy that remove health system barriers that hinder patient access to palliative care beginning at the point of diagnosis with serious illness and throughout the disease trajectory. As such, we commend the CDC for making clear within the “Scope and Audience” section that the guideline, (1) is not intended to apply to patients receiving palliative care and (2) references the Institute of Medicine’s definition of palliative care “as care that provides relief from pain and other symptoms, supports quality of life, and is focused on patients with serious advanced illness.”

The text of the “Scope and Audience” section also states that “the guideline is not intended to apply to patients in treatment for active cancer,” which is appropriate given the pain that is often associated with the disease. However, it raises the question as to why the guideline makes no similar exemption for patients who are undergoing treatment for conditions that cause extreme pain such as diabetic neuropathy, interstitial cystitis, dyspnea or any number of crippling injuries, including spinal-related issues such as sciatica. Dyspnea, for instance, occurs in over 50 percent of patients with underlying serious illness (e.g., COPD, heart failure, or chronic lung disease) and is correlated with lower quality of life and with physical, emotional, and cognitive changes including anorexia, fatigue, poor concentration, depression, and memory loss.¹ Opioids are widely accepted as the first line treatment of dyspnea after other disease-targeting or modifying therapies are optimized.^{2,3} We would urge CDC to consider the fact that patients undergoing treatment for these diseases and injuries often have intense pain and are in need of opioid analgesics in order to work, live independently, and maintain their quality of life. Their pain is every bit as real as the pain experienced by cancer patients.

The “Scope and Audience” section also makes a curious distinction between cancer patients in treatment, to whom the guideline does not apply, and “cancer survivors with chronic pain who have completed cancer treatment...” to whom the guideline does apply – the effect being to prejudice access to pain medicine against those who are no longer in active treatment. This makes no sense at all for cancer survivors, or for any other survivors of serious illness who continue to experience pain, and continue to be under medical supervision, after their active treatment is completed. From the standpoint of a patient and his or her provider, the existence of pain and its management does not, and should not, abruptly change on the day a final treatment is completed, so the distinction between active treatment and surveillance seems somewhat arbitrary.

Again, the members of the Patient Quality of Life Coalition believe that palliative care, which focuses on providing patients with relief from the symptoms, pain and stress of a serious illness, improves the quality of life for patients and families whatever the diagnosis. It can be provided by a team of doctors, nurses and other specialists to provide an extra layer of support, and it is

¹ Kamal AH, Maguire JM, Wheeler JL, et al. Dyspnea review for palliative care professional: assessment, burdens, and etiology. *J Palliat Med.* 2011 Oct;14(10):1167-1172

² Mahler DA. Opioids for refractory dyspnea. *Expert Rev Respir Med.* 2013 Apr;7(2):123-34; quiz 135.

³ Mahler DA, Selecky PA, Harrod CG, et al. American College of Chest Physicians consensus statement on the management of dyspnea patients with advanced lung or heart disease. *Chest.* 2010;137(3):674-691

appropriate at any age and at any stage in a serious illness, and can be provided together with curative treatment and afterward. Using this definition, which is congruous with the IOM definition of palliative care, we believe that all patients with serious illness or injury, or survivors who continue to experience pain as result of that illness or injury, and receiving palliative care services such as pain management should be exempt from the guideline.

If you have any questions, please feel free to contact Keysha Brooks-Coley with the Patient Quality of Life Coalition at Keysha.brooks-coley@cancer.org.

Sincerely,

American Academy of Hospice and Palliative Medicine

American Cancer Society Cancer Action Network

American Academy of Pain Management

Association of Oncology Social Work

Cancer Support Community

Center to Advance Palliative Care

Children's National Health System

CSU Institute for Palliative Care

Lung Cancer Alliance

Motion Picture & Television Fund

National Coalition for Hospice and Palliative Care

National Palliative Care Research Center

Oncology Nursing Society

Supportive Care Coalition

Trinity Health