



**PATIENT
ADVOCACY**
LEADERS SUMMIT

2012 COLORADO REGIONAL PALS

Improving Patient Advocacy Leadership in Health Care Reform

Colorado History Museum
Denver, CO

October 10, 2012

Colorado Gerontological Society
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Executive Summary

“Improving Patient Advocacy Leadership in Health Care Reform” was the theme of the 2012 Colorado Regional Patient Advocacy Leaders Summit on October 10, 2012 in Denver. PALS provided patient advocates with an inside view of the federal perspective from national leaders on the reform process, detailed discussions of Colorado-specific initiatives and action plans, as well as tools that can be used to work with patients who are affected by these changes. Patient advocacy leadership is the key to shaping health care reform for the future.

This conference was a collaborative effort between the Colorado Gerontological Society and Mental Health of America, National Multiple Sclerosis Society—Colorado Chapter, Rocky Mountain Stroke Center, The Bell Policy Center, PhRMA, and Patient Advocacy Leaders Summit (PALS), with funding made possible by GlaxoSmithKline.



Attendees at the 2012 Regional Patient Advocacy Leaders Summit, October 10, 2012.

Introduction

The concept of a Patient Advocacy Leaders Summit (PALS) was developed by GlaxoSmithKline (GSK) in 2002 as a way to bring together a diverse group of patient advocacy leaders to improve their advocacy capacity and identify ways to collaborate.

PALS involves patient advocates coming together to learn from issue experts and one another, collaborating to expand influence, refining advocacy skills, and exploring ways to work together to improve health and health care.



Attendees share information to improve collaboration between patient advocacy groups.

PALS Advisory Board is comprised of influential patient advocacy leaders

representing diverse organizations and geographic regions, to provide direction for PALS, and to ensure that all PALS programs meet the needs of the patient advocacy community. PALS has always subscribed to the motto “By Advocates, For Advocates”.

The 2012 Regional Colorado PALS, held on October 10, 2012 at the Colorado History Museum, Denver, provided a forum for 49 patient advocates from the major advocacy groups representing mental health, cancer, lung, Parkinson’s, Alzheimer’s, visual impairments, geriatrics, multiple sclerosis, end-of-life, the medically underserved, neurology, diabetes, arthritis, leukemia and lymphoma, minority health, Easter Seals, lupus, and stroke to receive updates on national health care and advocacy initiatives to move reform forward in Colorado.

Topics that were highlighted include health insurance exchanges, integration of dual eligibles, Medicaid expansion to low income and uninsured populations, and role of regional care coordination organizations. Advocates received tip sheets to better increase communication and work with constituents.

Goals

The goals of a 2012 Colorado Regional Patient Advocacy Leaders Summit (PALS) were:

To give health advocates an update on national health care reform and advocacy initiatives to move reform forward in Colorado.

To provide information on health insurance exchanges, integration of care for dual eligibles, Medicaid expansion, and the Regional Care Collaborative Organizations (RCCOs), including “tip sheets” that advocates can use to inform their constituents about these initiatives.

To discuss four priorities for health care advocacy for the 2013 legislative session.



Patient advocates discuss ways to work together on ACA initiatives.

Overview

The day long event featured Michael Cohen, Chair of the Board of National Patient Advocacy Leaders Summit who provided an overview of the Regional Patient Advocacy Leaders Summit (PALS) mission. His personal story of advocating for his daughter who



Michael Cohen, Chair of the Board of National Patient Advocacy Leaders Summit.

suffers from mental illness captured the attention of the audience as he shared the challenges and successes of seeking care for her over the years. Members of the audience experience these same challenges and successes in helping family, friends and patients to access the health care delivery system. Advocacy is bringing meaning and quality of life to patients who suffer from chronic disease whether from birth or as a result of disease encountered later in life.

Eileen Doherty, Executive Director of the Colorado Gerontological Society laid the framework for the day's events, outlining the goals, the format for the program, the goal of increasing networking and collaboration among patient advocates, the need to collaborate with existing community groups, and the importance of becoming involved in state and national initiatives that are currently underway.

Public policy debates bring advocates together with policy makers to design delivery systems that are responsive in meeting the needs of patients. These debates are crucial to building and designing patient centered care for those experiencing chronic disease.

The National Perspective

Ron Christie, Founder and CEO of Christie Strategies, LLC, challenged the audience to understand the Affordable Care Act. He noted that the Partnership for Better Health was an excellent avenue to encourage prevention, intervention, and innovation.



Ron Christie, Founder and CEO of Christie Strategies addresses PALS.

He described the negative connotation regarding the ACA and how states are responding to implementation. He particularly noted that many states are weary of such initiatives as Medicaid expansion given the lack of clarity in the act regarding the cost to states between 2014 and 2020.

Christie noted that problems with the unknown costs and insurer's unwillingness to participate in health insurance exchanges adds significant uncertainty to implementation that is scheduled to begin in 2014.

Christie noted that most decisions regarding the ACA will be made at the state level giving patient advocates significant opportunities to be involved in the process of shaping policies to better meet patient needs. Being

present at regulatory and policy development meetings is the best way for patient advocates to shape decisions which are in the best interests of the patient. The audience was challenged to form coalitions and to speak with one voice to maximize the ACA as one of the most historic opportunities to give patients a voice in their health care.

Marc Boutin, Executive Vice President and COO of the National Health Council followed with a strong message to patient advocates to come together with a united voice for people with chronic disease and disabilities. The broad membership of the National Health Council insures that patient centered care is focused on health care reform implementation policies.



Mark Boutin, National Health Council chats with PALS attendees.

The National Health Council works in three areas: delivery system reform, essential health benefits, and comparative effectiveness research.

The major reforms in the delivery system that are being considered are: to limit out-of-pocket costs, improve patient care teams, affordable reimbursement for care coordination, inclusion of comprehensive assessments and planning tools, respect for patient rights and preferences, and patient centered decision making.

The National Health Council works on comparative effectiveness research focusing on the engagement process in which patients, caregivers, and consumers are engaged in



Marc Boutin, National Health Council visits with patient

the process. Another area is to develop the research questions and evaluate the results with a focus on patient advocacy, role of caregivers, and participation of organizations which help to advocate on behalf of consumers.

The essential health benefits package is the most critical reform as it outlines the benefits and exclusions.

The role of the state in developing the benefits is critical to patients. Advocates must be involved in designing the benefit. Another critical component is managing of

the out-of-pocket expenses so they don't deter accessing health care services. Boutin noted that the discussion of the essential health benefit will form the basis of insurance coverage for those suffering from chronic disease.

The State Perspective

Colorado was in the midst of implementing regional care collaborative organizations (RCCOs) when the Affordable Care Act was passed. Greg Trollan, Health Care Policy and Financing, State of Colorado, Denver, discussed the overlap between the accountable care organization (ACOs) federal mandate and the Colorado RCCOs.

Colorado designated seven RCCOs to work with Medicaid providers to change patterns of service delivery with the intent of reducing overall health care costs. Preliminary results suggest that with access to utilization data, providers are able to deliver better care and to reduce overall health care costs.



Greg Trollan, Health Care Policy and Financing, State of Colorado

Trollan encouraged patient advocates to become involved in the seven RCCOs, providing advocates with contact information, as well as a map of the service areas.

Lorez Meinhold, Deputy Executive Director and Director of Community Partnerships, Health Care Policy and Financing, State of Colorado, Denver started her discussions with the



Lorez Meinhold, Deputy Executive Director and Director of Community Partnerships, HCPF.

Supreme Court decision stating that the ruling does not change Colorado's plans to expand Medicaid. She stated that Medicaid eligibility will expand to children and adults under 133% of the federal poverty level on January 1, 2014.

Meinhold went on to explain that Colorado has selected a benchmark plan encompassing the ten basic benefit categories of the health insurance exchanges. She explained that carriers can provide variation in benefits, but they must be substantially equal to the benchmark plan based

on actuarial value. She also reviewed the timeline for implementation encouraging advocates to be involved in the process and the many committees that are working on these initiatives.

The Legislative Perspective

A legislative panel featuring Sen Betty Boyd, (D), Senate Health and Human Services Committee; Rep Nancy Todd (D) House Assistant Minority Leader; Rep Cheri Gerou (R), Chair, Joint Budget Committee; and Rep Ken Summers (R), House Health and Environment was charged with reviewing for the audience the cost of Medicaid expansion.

Colorado may or may not have the budget to fund any portion of this state contribution for Medicaid expansion. The federal contribution may be reduced in the future because of federal budget reductions and Colorado may have to absorb additional administrative costs not funded by the federal government. However, should the state not implement the expansions, then Colorado hospitals may be negatively impacted because under the Affordable Care Act, payments to hospitals that treat large numbers of the uninsured may be reduced under the assumption that many of the uninsured would qualify for Medicaid under the new expansions. In addition, the law provides subsidies to make insurance coverage more affordable only for those individuals and families with incomes between 100 - 400% of the federal poverty level. If the Medicaid expansions are not implemented, those Coloradans under 100% of the federal poverty level, not covered by the 2009 Colorado Healthcare Affordability Act, may not receive any financial assistance to purchase private insurance.

Legislators were asked to discuss their views on Medicaid expansion and whether the state will be able to sustain the increased costs given all of the pressures on the state budgets with other mandates such as the Tax Payers Bill of Rights, education and other state services.



Legislator Panel moderated by (L to R) Robert Semro, The Bell Policy Center, featuring Sen Betty Boyd, (D), Senate Health and Human Services Committee; Rep Nancy Todd (D) Assistant Minority Leader; Rep Cheri Gerou (R), Chair, Joint Budget Committee; and Rep Ken Summers (R), House Health and Environment Committee.

Involving Patient Advocates

The last session of the day encouraged patient advocates to join together and to become more involved in the four areas of the Affordable Care Act:

- Integration of Dual Eligibles
- Regional Care Collaborative Organizations (RCCOs)
- Medicaid Expansion
- Health Insurance Exchanges

Facilitators from the planning committee were responsible for leading discussions on these four subject areas. Participants were invited to self select to the small groups to further their knowledge, as well as to learn more about how to become involved in the issues of interest. Tip Sheets were prepared and distributed to serve as a resource for advocates as they either become more involved with the state initiatives and/or to encourage their constituents to become more involved in these efforts.

A special outreach was made to encourage participants to become more involved in the Chronic Care Collaborative which has been active in advancing the discussions on health care policy as a collective voice for patient advocates for the past five years. The Collaborative has a set of principles that directs the involvement in these initiatives and is looking for new members.



Shannon McNulty leads the discussion on Health Insurance Exchanges for the special interest group.