



A STEP TOWARD

A CULTURAL TRANSFORMATION

IN THE WAY PAIN IS PERCEIVED, JUDGED AND TREATED

“If the future is to remain open and free, we need people who can tolerate the unknown, who will not need the support of completely worked out systems or traditional blueprints from the past.”

— *Margaret Mead*

A Step Toward a Cultural Transformation in the Way Pain is Perceived, Judged and Treated

Executive Summary

In anticipation of publication of the National Pain Strategy (NPS) Report, in June 2015 the Pain Action Alliance to Implement a National Strategy (PAINS), a coalition of national leaders and organizations committed to advancing the sixteen recommendations made in the Institute of Medicine’s report, *Relieving Pain in America: A Blueprint for Transforming Prevention, Care, Education and Research*, convened a Collaborators Conference in Washington, DC. The purpose of the meeting was to discern opportunities and challenges to implement the NPS report, to build enthusiasm for it and promote collaboration among attendees in order to move the Report from a vision to a reality. More than 100 prominent leaders from professional societies, academic institutions, federal agencies, patient advocacy groups, and policy organizations met to review the NPS Report and discuss each of its six sections.

In April 2015, after being reviewed by multiple federal agencies, the NPS Report was posted in the Federal Register for public commentary. In opening remarks, **Walter Koroshetz, MD**, Director of the National Institute of Neurological Disorders and Stroke (NINDS), told attendees that more than 770 public responses were received and the plan is expected to be released in the late summer/early fall. Expectations for it are high.

The report’s vision states,

“If the objectives of the National Pain Strategy are achieved, the nation would see a decrease in prevalence across the continuum of pain, from acute, to chronic, to high-impact chronic pain, and across the life span from pediatric through geriatric populations, to end of life, which would reduce the burden of pain for individuals, families, and society as a whole. Americans experiencing pain—across this broad continuum—would have timely access to a care system that meets their bio-psychosocial needs and takes into account individual preferences, risks, and social contexts. In other words, they would receive patient-centered care.”

Prior to the Collaborators Meeting, PAINS surveyed those registered and found that, overall, the NPS Report was well received by respondents; stakeholders expressed appreciation and support for it. One respondent said about the report, “It presents a rare opportunity for cultural change with across-the-board goals and strategies.” The three foci in which attendees were most interested were professional education and training (72.7%),

public education and communication (69.7%), and prevention and care (57.6%). However, concerns were also expressed about the lack of specificity and accountability, the absence of a timeline, and the fact that there has been no appropriation of funding designated for implementation of the plan.

In the opening keynote address of the two-day conference, **Dr. Sean Mackey**, Co-chair of the NPS Report Oversight Committee, said, “Eighty incredibly dedicated national experts covering a wide range of the bio-psychosocial aspects of pain — including expertise from clinical and public health, legal, ethical and payment, including both traditional and complementary medicine — volunteered their time to develop the plan.” He introduced the concept of “high-impact chronic pain,” which the NPS Report defines as “pain associated with substantial restriction of participation in work, social, and self-care activities for six months or more.” Mackey said that doing so was meant to address challenges there have been to the IOM report’s claim that “at least 100 million Americans live with chronic pain” and also that there is a clear need to better understand the numbers of people with high-impact chronic pain, how to provide them with the best care to avoid both under- and over-treatment, and to identify those at risk for developing high-impact chronic pain after injury or surgery.” He said, “The NPS is a great document. It is not a perfect document.” He urged those present and others committed to transforming pain care in America not to pick the document apart, but to support it in its entirety. He also argued for the development of clear messaging, explaining what the NPS Report is and what it is not. Compellingly, he asked all those present to speak with one voice and not let the perfect be the enemy of the good.

In brief reports, members of the six NPS Workgroups presented highlights of the section of the report they worked on, shared personal observations and then engaged with all those present in robust conversation. Key elements of the six sections included:

- **Population Research:** The need for research, including population, basic science, clinical translational, comparative effectiveness, and quality improvement were all discussed.
Greg Terman, member of the NPS Oversight Committee, said that with the help of others at CDC and NIH, a set of pain questions are being developed to be included in the National Health Interview Survey.
- **Disparities:** The importance of addressing historic disparities in health and healthcare was recognized as critical to successful implementation of the report in that they permeate the entire report. **Dr. J. Nadine Gracia**, Deputy Assistant Secretary for Minority Health, stated that improving the quality of pain care among minority and underserved populations is essential to addressing disparities and achieving the goals outlined in the NPS Report.
- **Prevention and Care:** Learning from efforts of the Department of Defense to improve pain care for veterans that have preceded the NPS Report was promoted by **Dr. Chester “Trip” Buckenmaier** in his report on Prevention and Care. In particular, he encouraged consideration of the Pain Assessment Screening Tool and Outcomes Registry (PASTOR), the Patient Reported Outcomes Measurement Information System (PROMIS) and the Defense and Veterans Pain Rating Scale (DVPRS).
- **Service Delivery and Reimbursement:** **Marianne Udow-Phillips** cautioned attendees not “to think that we are going to abandon fee-for-service” because she said large self-insured employers like it. Everyone recognized improved reimbursement as a keystone issue. Udow-Phillips encouraged the audience by saying that there is interest among payers in programs that improve quality and save money. She



called for small pilot programs to demonstrate the feasibility and efficacy of comprehensive pain care, including exploration of “fee-for-service with incentives.”

- **Professional Education:** Although professional education and training is recognized as critically important, **Dr. Rollin “Mac” Gallagher**, reporting on behalf of the Professional Education and Training Section, said, “We can’t wait for the medical schools and licensure groups to change.” Attendees were enthusiastic about and supportive of the NIH Pain Consortium’s program to develop Centers of Excellence in Pain Education. However, Dr. Dave Davis, Senior Director of Continuing Education and Improvement

at the Association of American Medical Colleges, agreed with Gallagher and encouraged more focus on continuing medical education for practicing clinicians, including biomedical, behavioral and complementary therapies. He also pointed to the importance of inter-professional education programs (IEPs).

- **Public Education and Communication:** **Penney Cowan** reported that two public education campaigns were recommended by the group, with the priority campaign being an extensive public awareness campaign about chronic pain and the secondary campaign being on safe medication use by patients. Four “core messages” developed by the Chronic Pain Advocacy Task Force (CPATF), a coalition of 17 consumer advocacy organizations, were presented. The messages clearly resonated with meeting attendees and became a major focus of actions following the conference.

Outside experts provided input and perspective for consideration from public health, politics, and addiction advocacy. **Dr. Georges Benjamin**, Executive Director of the American Public Health Association, encouraged the use of patient narratives about those living with extreme chronic pain. He also encouraged gaining more clarity about the problem and reframing the discussion using a public health framework. **Dr. Keith Wailoo**, historian and author of *Pain: A Political History*, shared how concerns about disability, physician-assisted suicide, the “War on Drugs,” and dramatic increases in addiction to prescription pain medications have shaped pain policy over the last seven decades and impacted the lives of those living with chronic pain. He also discussed how the so-called “red state vs. blue state” worldview negatively impacts those who live with chronic pain and other diseases, including addiction. **Dr. Jeff Levi**, CEO of Trust for America’s Health, began his presentation by saying, “All politics, perhaps especially health politics, is personal.” He said that “the pain community starts with the individual in pain and wants to find the best solutions for that individual.... The substance abuse prevention world starts with preventing addiction and looks in particular to find structural interventions that make it harder for someone to become addicted.” Dr. Levi, as had others throughout the day, called for finding common ground and suggested

specific strategies for doing so, with one of those strategies being to focus on harm reduction.

On the second day of the conference, participants broke into groups focused on each section of the report and then shared thoughts and ideas about how to advance the strategies and objectives in that section of the NPS Report. Those reports are incorporated in the full report in their entirety.

Key to the success of the meeting was the involvement of people living with chronic pain — a highly successful environmental lawyer injured in a bicycling accident fifteen years ago, a professor of bioethics and public health born with sickle cell disease, and **Cindy Steinberg**, a person who experienced a “crushing accident” more than a decade ago who has become a self-educated policy wonk and now dedicates her life to advocating for better care for the 100 million Americans who live with chronic pain.

Ms. Steinberg was the closing keynote speaker for the PAINS Collaborators Meeting. In an impassioned appeal, she called for PAINS and all those present to do four things:

1. Endorse the four core messages developed by CPATF.
2. Develop op-eds in support of the NPS Report at the time of its release.
3. Advocate for peer-reviewed articles about the Report.
4. Work together to develop a national communication strategy in time for Pain Awareness Month in September.

Based on a robust evaluation plan, PAINS believes the Collaborators Meeting achieved the goals that had been set for it. (Perceptions and opinions of attendees regarding the meeting are included entirely as received.) One reason PAINS invested significant resources into evaluation was to assess attendees' views about the role of PAINS in implementation of the National Pain Strategy Report. Based on responses to a meeting with key national leaders immediately following the conference, responses to a post-meeting survey, emails received from attendees, and a report from the meeting facilitator, PAINS believes that its greatest contribution is to continue to serve in the role of neutral convener and facilitator of collaboration among the many groups committed to advancing the NPS Report.

The conclusion of the report states the obvious, “A cultural transformation in the way pain is perceived, judged and treated” will require almost unimaginable resources, numbers of organizations and committed individuals, political will, and changes in attitudes. However, the dialogue, discourse and enthusiasm at the PAINS Collaborators Meeting encouraged those who convened and planned it and gave hope to all those present that the U.S. is at the precipice of a cultural shift in the way chronic pain is managed. The report's vision can become reality, but there is much to be done. There is no time to rest on one's laurels. As Henry Ford once said, “Coming together is a beginning, staying together is progress and working together is success.” ■

Introduction

In anticipation of publication of the National Pain Strategy (NPS) Report, in June 2015 the Pain Action Alliance to Implement a National Strategy (PAINS), a coalition of national leaders and organizations committed to advancing recommendations made in the Institute of Medicine's report, *Relieving Pain in America: A Blueprint for Transforming Prevention, Care, Education and Research*, convened a Collaborators Conference in Washington, DC. The purpose of the meeting was to discern opportunities and challenges to implementation of the report, to build enthusiasm for it and promote collaboration among attendees in order to move the NPS Report from a vision to a reality. More than 100 prominent leaders from professional societies, academic institutions, federal agencies, patient advocacy groups, and policy organizations met to review the NPS Report and discuss each of its six sections:

1. Population Research
2. Prevention and Care
3. Disparities
4. Service Delivery and Reimbursement
5. Professional Education and Training
6. Public Education and Communication

Anticipated *outcomes* included:

Specific feedback on the draft National Pain Strategy (NPS) Report to supplement the public comment period feedback and for consideration to include in the final NPS Report (to be released in the fall — TBD), including:

- What parts of the report are on target and have broad support from stakeholders;
- What parts of the report need more work or are problematic, why, and how they can be improved; and
- Ideas currently missing from the report that should be incorporated into the final NPS Report.

Momentum and a sense of urgency surrounding finalization and release of the NPS, as well as insights for catalyzing additional action around the NPS once finalized and released, and particularly

- Which stakeholders are interested in and have capacity to collaborate on priority areas of the NPS;
- Clarity around developing accountability for implementing the NPS; and
- Other ideas to build from or supplement the NPS to improve care access and delivery for those with chronic pain.

Determine PAINS' future role in advancing cultural change around chronic pain education and access to and delivery of care.

Background

In 2011, the Institute of Medicine (IOM) published *Relieving Pain in America: A Blueprint for Transforming Prevention, Care, Education and Research*; the report called for a “cultural transformation in the way pain is perceived, judged, and treated.” Sixteen recommendations were made and prioritized, and a timeline for transitioning chronic pain care in the United States from a biomedical to a “biopsychosocial” or comprehensive chronic pain care was established. Committee members set Recommendation 2.2 as the most immediate priority, which called for “the Secretary of the Department of Health and Human Services (HHS) to develop a comprehensive population health-level strategy for pain prevention, treatment, management, education, reimbursement and research that includes specific goals, actions, time frames, and resources” (<http://iprcc.nih.gov/docs/DraftHHSNationalPainStrategy.pdf>, pg. 7). In November 2012, Dr. Howard Koh, then Under Secretary of HHS, charged the Interagency for Pain Research Coordinating Committee (IPRCC) at the National Institutes of Health (NIH) with development of a National Pain Strategy (NPS) Report, and an Oversight Committee comprised of NIH staff and members of the IPRCC was established to lead the process.

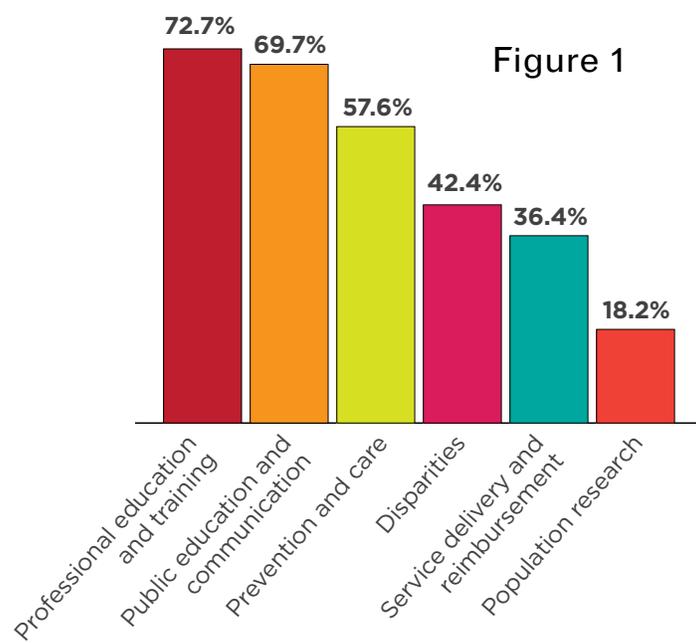
After the report was drafted, it underwent preliminary review by multiple federal agencies and was then posted in the Federal Register for public commentary in April 2015. During the 30-day review period, more than 770 responses were received from individuals, professional organizations, advocacy groups and others. The draft NPS Report was then returned to HHS for revision and approval. The final National Pain Strategy (NPS) Report is expected to be released in the late summer/early fall 2015 and expectations for the report are high.

The Vision Underpinning the National Pain Strategy Report (as stated in draft report):

If the objectives of the National Pain Strategy are achieved, the nation would see a decrease in prevalence across the continuum of pain, from acute, to chronic, to high-impact chronic pain, and across the life span from pediatric through geriatric populations, to end of life, which would reduce the burden of pain for individuals, families, and society as a whole. Americans experiencing pain – across this broad continuum – would have timely access to a care system that meets their biopsychosocial needs and takes into account individual preferences, risks, and social contexts. In other words, they would receive patient-centered care.

*Further, Americans in general would recognize chronic pain as a complex disease and a threat to public health and to a just and productive society. Because of this greater understanding, significant public resources would be invested in the areas of preventing pain, creating access to evidence-based and high-quality pain assessment and treatment services and improving self-management abilities among those with pain. In addition, individuals who live with chronic pain would be viewed and treated with compassion and respect. Specifically, substantial progress in the care system would be achieved as shown in **figure 1**.*

Clinicians would take active prevention measures to prevent the progression of acute to chronic pain and its associated disabilities.





Clinicians would undertake comprehensive assessments of patients with chronic pain, leading to an integrated plan of coordinated care, managed by an interdisciplinary team, when needed. Treatment would involve high-quality, state-of-the-art, multi-modal, evidence-based practices. While most pain care would be coordinated by primary care practitioners, specialists would be involved judiciously in the care of patients who have increased comorbidities, complexity, or risk.

People with all levels of pain would have access to educational materials and effective approaches for self-care and pain self-management programs that would help them prevent, cope with, and reduce pain and its disability, and they would have better information about the benefits and risks of pain management options. The information would be available to those who have low literacy or communication disabilities.

All Americans would be assured of obtaining preventive, assessment, treatment, and self-care interventions and support, regardless of age, gender, sex, race, ethnicity, income, education, geographic location, language proficiency, health literacy, or medical condition. All pain-related services would be provided without bias, discrimination, or stigma.

Specific advances supporting the evolution toward a public health approach to pain prevention and care would result from improvements in clinical education, public and institutional policies and population-level epidemiologic, health services, social science, medical informatics, implementation, basic and translational biomedical, and other relevant research, informed by clinician/scientist interactions.

Primary care clinicians and specialists in relevant fields need to know more about the bio-psychosocial characteristics and safe and appropriate management of pain. Clinicians' knowledge of pain and pain care would be broadened to encompass an understanding of individual variability in pain susceptibility and treatment effectiveness, how pain affects communication, the importance of shared and informed decision-making, ways to encourage pain self-management under mutually agreed-upon treatment plans, how clinician empathy and cultural sensitivity influences the effectiveness of care, and the role of complementary and integrative medicine.

Chief among the supporting policy approaches would be reimbursement incentives and payment structures that support population-based care models of proven effectiveness, especially in interdisciplinary settings, and encourage multimodal care geared toward improving a full range of patient outcomes.

Timely data regarding the health and economic burdens of chronic pain would guide federal and state governments and diverse health care organizations in their efforts to work toward these objectives. Such data would lay the groundwork for enhancing the effectiveness and safety of pain care overall and for specific population groups and would enable monitoring the effectiveness of policy initiatives, public education efforts, and changing treatment patterns.

Finally, electronic data on pain assessment and treatment would be standardized, and health systems would maintain pain data registries that include information on the psychosocial/functional impact of chronic pain and the costs and effectiveness of pain management interventions. These data resources would be used in an ongoing effort to evaluate, compare, and enhance health care systems, identify areas for further research, and assess therapies for quality and value.

Pre-meeting Survey Results

Prior to the Collaborators Meeting, a survey was distributed to all those who had registered. Approximately one-third responded. They provided insights into their overall view of the NPS Report, their perceptions about which of its strategies should be given the highest priority, and their views about the roles of governmental and non-governmental organizations in its implementation.

Overall, the NPS Report was well received by respondents and stakeholders expressed appreciation and support for it. One respondent said about the report, “It presents a rare opportunity for cultural change with across-the-board goals and strategies.” However, concerns were also expressed. One person said that they feared that the report, “reinforces biases against people living with chronic pain through idiosyncratic terminology (specifically high-impact chronic pain), an undue focus on the individual patient’s role in addressing chronic pain, and a lack of discernment between opioid addiction and opioid use to relieve pain.” Several respondents expressed concerns about a lack of specificity and accountability, the absence of a timeline, and the fact that there has been no appropriation of funding designated for implementation of the plan.

Strategies mentioned as priorities included:

- Improved professional education
- Identification of best practices and evidence-based programs
- Robust public health efforts
- Revamped reimbursement

HHS was seen as having four primary roles in implementation of the report: 1) acquiring funding; 2) coordinating inter-agency activities; 3) developing an entity to provide oversight; and 4) monitoring and evaluating progress. Organizations, including professional societies, academic institutions, advocacy groups, and others outside of the federal government, were seen as also having four important roles: 1) professional and public education; 2) dissemination of information; 3) fostering collaboration and participating in public/private partnerships; and 4) keeping pressure on HHS. The private sector was also seen as a secondary funder with payers, private foundations, and philanthropists identified as important so that non-profits engaged in the process not be overly dependent upon industry support.

Attendees rank ordered their interests in work-related overlap with the specific sections of the NPS Report in the following manner:

Dr. Mackey said the groups also attempted to introduce and solidify important concepts from *Relieving Pain* and current literature. He gave as one example the introduction of the concept of “high-impact chronic pain.”

Overall, those who attended the PAINS Collaborators Meeting came cautiously excited about the NPS Report, enthusiastic to learn more about it and HHS’ plans for its implementation, and eager to discuss their individual or organizational role(s) in making the report successful.

Opening Session

PAINS was honored that **Dr. Walter Koroshetz**, Director of the National Institute of Neurological Disorders and Stroke (NINDS), and **Dr. Linda Porter**, Policy Advisor for Pain at NINDS and Co-chair of the NPS Oversight Committee, shared

their insights and thoughts to launch the Collaborators Meeting. Both indicated that, along with other leaders at HHS, they had been gratified by the level of public interest and support there has been for this effort.

Dr. Koroshetz told attendees that there were more than 770 responses to the request for public comment when the draft report was posted in the Federal Register. He said that by far, most were positive and that suggestions made could be clustered around the need for more emphasis on six topics:

- Multi-modal care
- Population research
- Electronic medical records
- Pediatric pain
- Self-management
- Reimbursement, especially fee-for-service

Linda Porter told attendees that when the call went out for nominations for workgroup members, “hundreds of nominations were received.” She said that significant effort was made to see that each workgroup had “the right mix” of experts. **Dr. Porter** was very complimentary of all those who participated in the process and especially thanked her Co-chair, **Dr. Sean Mackey**.

In the opening keynote address, **Sean Mackey, MD**, Co-chair of the NPS Oversight Committee, former member of the IOM committee that published *Relieving Pain in America*, and Professor and Chief of the Stanford Division of Pain Medicine, addressed many of the issues that had been raised in the pre-meeting survey. Dr. Mackey had been asked to reflect on the process of developing the report and, based on his experience, what will be required for a successful implementation. In a touching moment, Dr. Mackey also shared that his parents are among the more than 100 million Americans who live with chronic pain.

He explained that under the auspices of the National Institutes of Health’s Interagency for Pain Research Coordinating Committee (IPRCC), “eighty incredibly dedicated national experts covering a wide range of the bio-psychosocial aspects of pain — including expertise from clinical and public health, legal, ethical and payment,

including both traditional and complementary medicine — volunteered their time to develop the plan.” Volunteers were divided into six working groups aligned with the IOM findings and recommendations. A member of the NPS Oversight Committee was assigned to each working group as a liaison. Workgroups were charged with producing interrelated sets of objectives and suggested action plans for each of the six areas listed above. Dr. Mackey said the groups also attempted to introduce and solidify important concepts from *Relieving Pain* and current literature.

He gave as one example the introduction of the concept of “high-impact chronic pain,” which the NPS Report defines as “pain associated with substantial restriction of participation in work, social, and self-care activities for six months or more.” Mackey said that doing so was meant to address challenges there have been to the IOM report’s claim that “at least 100 million Americans live with chronic pain.” He said that although “it is an astonishing number, it is accurate” and that it includes a wide range of people — from those who live with chronic pain that has a minor impact on their ability to manage day to day activities to those whose lives are impacted catastrophically by unrelenting chronic pain. He went on to say, “There is a clear need to better understand the numbers of people with high-impact chronic pain, how to provide them with the best care to avoid both under- and over-treatment, and to identify those at risk for developing high-impact chronic pain after injury or surgery.”

Mackey acknowledged that he had heard concerns from patient advocates about differentiating “high-impact chronic pain” from other chronic pain and disappointment that, although the report includes 18 specific strategies and dozens more objectives, it does not call for more basic and translational research or a National Institute of Pain at NIH. He said, “The NPS is a great document. It is not a perfect document.” He urged those present and others committed to transforming pain care in America not to pick the document apart, but to support it in its entirety. He also argued for the development of clear messaging explaining what the NPS Report is and what it is not. Compellingly, he asked all those present to “speak with one voice and not let the perfect be the enemy of the good.”

“The NPS is a great document. It is not a perfect document.” He urged those present and others committed to transforming pain care in America not to pick the document apart, but to support it in its entirety.

Dr. Mackey thanked PAINS for convening the conference and encouraged others to host similar events. He concluded by sharing an insight from former HHS Secretary Mike Leavitt in his book, *Finding Allies, Building Alliances*. In it, Leavitt claimed that the most successful collaborations come about through a sense of “common pain.” Mackey said “... while he (Leavitt) was referring to a different type of pain, his message remains clear. Our ‘common pain,’ i.e., the pain of trying to improve chronic pain care, relates to the challenges we all face in obtaining meaningful data about pain, optimal delivery of pain assessment, prevention and care, and education of the public and our professionals. Let us all collaborate around our ‘common pain’ and speak with one voice.” (For a copy of Dr. Mackey’s entire presentation, go to www.painsproject.org.)

Following Dr. Mackey’s remarks, presentations were made by individuals who had been directly involved in one of the six work groups. Lively discourse followed each report. This report attempts to briefly present the core elements of the reports made and the dialogue that followed.



Workgroup Reports

Population Research

Greg Terman, MD, Professor of Anesthesiology and the Graduate Program in Neurobiology and Behavior at the University of Washington, President-Elect of the American Pain Society and member of the NPS Oversight Committee, spoke on behalf of the Population Research Workgroup.

Dr. Terman reported on efforts of this workgroup to get a set of pain questions integrated into the National Health Interview Survey. He said that with the help of Chad Helmick at CDC and Linda Porter, progress is being made. Terman said that Medicare and Medicaid should be encouraged to

establish “meaningful use” criteria for chronic pain and that more infrastructure is needed for collecting and analyzing data.

In remarks made later in the conference, **Chris Veasley**, a member of the NPS Oversight Committee and the IPRCC, described the IPRCC’s Pain Research Strategy currently in development. The IPRCC is developing a plan for pain research across federal agencies. A panel of experts will be convened to provide recommendations in key pain research areas to move the field forward with the ultimate goal to relieve pain and improve pain care through evidence-based studies by enhancing the federal research agenda. Consistent with the IOM report, *Relieving Pain in America*, and the National Pain Strategy Report, key areas are:

- prevention of acute and chronic pain,
- acute pain and acute pain management,
- the transition from acute to chronic pain,
- chronic pain and chronic pain management, and
- disparities in pain and pain care.

NIH research is critical to a cultural transformation in chronic pain care. The mission of NIH research is to seek fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to enhance health, lengthen life, and reduce illness and disability. An NIH Federal Pain Research Strategy will provide a framework for development of the strategy upon which important cross-cutting issues will be addressed.

Established as part of the Affordable Care Act, the Patient-Centered Outcomes Research Institute’s (PCORI) focus is on comparative effectiveness research, guided by patients and their families and intended to make information available that will help patients make informed clinical decisions when confronted with complex health

issues. **Penny Mohr**, Senior Program Officer at PCORI, was very supportive of comments made about the importance of research, including population health research, basic science, clinical translational research, and comparative effectiveness research. Mohr said that PCORI has already invested significantly in pain and intends to do much more. She reiterated several times the importance of “patient-centered research” and including diverse populations in the process of developing research studies. Mohr’s remarks were very aligned with **Dr. J. Nadine Gracia**’s report on behalf of the Disparities Workgroup.

Disparities

In response to Greg Terman’s report on Population Research, **Dr. J. Nadine Gracia**, Deputy Assistant Secretary for Minority Health at HHS, agreed with Dr. Terman and noted that people of color who feel that they have had poor interactions with or poor treatment from doctors are far less likely to respond to such surveys and that we need information from all groups for a “cultural transformation.” Dr. Gracia cautioned that we must be careful to promote culturally and linguistically appropriate language in all efforts to implement the NPS Report. She also pointed out that, although there was a separate section of the report focused on disparities, these issues permeate every aspect of the report and encouraged all those present to be mindful of the disparities in health and healthcare no matter what section of the report in which they are most interested.

The military is willing to share programs and resources they have developed to help jump-start implementation of the NPS Report.

Care and Prevention

Dr. Chester “Trip” Buckenmaier agreed with Dr. Gracia, and in his report on behalf of the Care and Prevention Workgroup, pointed out that the military is the most diverse sector of our society. Dr. Buckenmaier said, “Veterans are dying from chronic pain” and that the Department of the Army and the Veterans Health Administration have been engaged in transforming pain care for veterans for several years. Furthermore, he offered that the military is willing to share programs and resources they have developed to help jump-start implementation of the NPS Report. Specific examples he gave included:

- **The Pain Assessment Screening Tool and Outcomes Registry (PASTOR)** - a survey instrument that produces a comprehensive 3-page clinician report of a patient’s chronic pain, which was developed for “performance measures used to determine the effectiveness of the policy in improving pain care for beneficiaries enrolled in the military health care system.”
- **The Patient Reported Outcomes Measurement Information System (PROMIS)** - a system of highly reliable, valid, flexible, precise, and responsive assessment tools that measure patient—reported health status. PROMIS was funded by NIH with what Dr. Buckenmaier referred to as “your public tax dollars.”
- **Defense and Veterans Pain Rating Scale (DVPRS)** — a new pain scale developed by the DoD that is rooted in function and part of PASTOR. The scale can be found at: <http://www.dvcipm.org/clinical-resources/pain-rating-scale>.

There was some discussion following Dr. Buckenmaier’s presentation about the advantage the VA has in improving chronic pain care in that it is a “closed system” and does not face the challenges in the private sector regarding reimbursement. Throughout the meeting, one

presenter after another commented on the need for new reimbursement structures. The remarks of **Marianne Udow-Phillips** representing the Service Delivery and Reimbursement Workgroup were of great interest to all those present.

There is interest among payers in programs that improve quality and save money.

Service Delivery and Reimbursement

Marianne Udow-Phillips is currently Director of the Center for Healthcare Research and Transformation at the University of Michigan. Prior to that, she had extensive experience in healthcare financing in both the public and private sectors. Before going to the University, she was director of the Michigan Department of Human Services and prior to that, she was Senior Vice President of Health Care Products and Provider Services at Blue Cross Blue Shield of Michigan. She cautioned those present not to “think that we are going to abandon fee-for-service” because she said, “private payers like fee-for-service,” especially large self-insured employers who believe it “protects their bottom line” in lieu of “pre-paid” or “bundled payment” models. However, she encouraged the audience by saying that there is interest among payers in programs that improve quality and save money. She discussed a hybrid reimbursement model which she referred to as “fee-for-service with incentives” and said small pilot programs are needed to demonstrate the feasibility of comprehensive pain care models.

Professional Education and Training

Rollin “Mac” Gallagher, MD, spoke on behalf of the Professional Education and Training Workgroup. Dr. Gallagher, Deputy National Program Director for Pain Management at the Veterans Health Administration and Past President of the American Academy of Pain Medicine, said, “We can’t wait for the medical schools and licensure groups to change.” **Dave Davis, MD**, Senior Director of Continuing Education and Improvement at the Association of American Medical Colleges, agreed with him. Dr. Davis pointed out that there is a “10-12 year pipeline” from beginning to practice for physicians and encouraged educating practicing healthcare clinicians, but he warned such efforts must be “more than lectures.” He also encouraged the group to recognize the shift toward inter-professional education programs (IEPs) and their importance.

Most people living with chronic pain utilize complementary and alternative medicine services and inter-disciplinary pain care teams will benefit from knowledge and expertise about these treatment options.

Dr. Paul Arnstein, former president of the American Society for Pain Management Nursing, and others acknowledged the importance of this transition and commented on the NPS Report’s incorporation of the “Core Competencies for Pain Education” developed by an inter-professional group and supported by national healthcare organizations across the major health professions. It was strongly suggested by several that this framework serve as a “starting point for accrediting and credentialing organizations to help guide educators to develop and revise curriculum that advances care for effectively preventing and managing pain.”

Martha Menard, PhD, LMT, co-Executive Director of the Academic Consortium for Complementary and Alternative Health Care, raised the importance of including complementary and alternative healthcare providers as new models emerge. She pointed out that most people living with chronic pain utilize these services and that inter-

disciplinary pain care teams will benefit from knowledge and expertise about these treatment options. She noted that the Veterans Health Administration has recognized the benefit of these treatment modalities and mandated that veterans have access to them. She also noted that Section 2706 of the Patient Protection and Affordable Care Act, known as the Non-discrimination in Health Care Clause, requires that insurers include and reimburse all licensed healthcare providers acting within the scope of their practice.

Katherine Galluzzi, DO, Chair of the American Osteopathic Association Council on Palliative Care Issues, spoke from the perspective of the practicing clinician about how important the team is in managing chronic pain, including the patient and complementary and alternative providers as appropriate, and said that as strange as it may sound to many physicians, “we (the doctors) don’t always have to be the ‘captain’ of the team.”

David Thomas, PhD, Chair of the National Institute of Drug Abuse, founding member of the NIH Pain Consortium and Director of its Centers of Excellence in Pain Education (CoEPE), reported on the Pain Consortium’s efforts to transform pain education for healthcare professionals early in their training. There are currently twelve CoEPE grants supporting development of inter-professional curricula and resource materials which are all open access. He said that there will be a second round of grants announced “any day.”

Public Education and Communication

The report from the Public Education and Communication Workgroup spurred additional discussion along these lines. Everyone agreed on the importance of medical education but additionally agreed that the public needs to be educated for the NPS Report to be successfully implemented.

Penney Cowan, Co-chair of the Public Engagement and Communication Workgroup, reported that two public education campaigns were recommended by her workgroup, with the priority report being an extensive public awareness campaign about pain as a disease and the secondary campaign to focus on promoting safe medication use by patients. **Amy**

Goldstein, Director of the American Academy of Pain Management’s State Pain Policy Advocacy Network (SPPAN), spoke about the Consumer Pain Advocacy Task Force (CPATF), a coalition of 17 consumer advocacy groups that have been working together for several months to promote the NPS Report’s public engagement and education goals and objectives.



Two public education campaigns were recommended by her workgroup, with the priority report being an extensive public awareness campaign about pain as a disease and the secondary campaign to focus on promoting safe medication use by patients.

Goldstein presented four core messages agreed upon by the task force and their action plans to promote implementation of the final NPS Report. She indicated that CPATF believes that these messages could be the framework for a national pain awareness campaign. The messages assert that:

1. Chronic pain is a real and complex disease that may exist by itself or be linked with other medical conditions.
2. Chronic pain is unrecognized and under-resourced public health crisis with devastating personal and economic impact.
3. Effective pain care requires access to a wide range of treatment options.
4. Allowing people to suffer with unmanaged pain is immoral and unethical.

These messages clearly resonated with conference attendees; they were integrated into the call for action introduced in the final keynote presentation by Cindy Steinberg and became a major focus of post-meeting action for PAINS and others immediately following the conference (to be covered later in the report).

Input from Outside Experts

Dr. Georges Benjamin, Executive Director of the American Public Health Association, encouraged a public health approach. He strongly suggested the use of patient narratives in educating the public about this reform effort. He said that those responsible for implementation of the report need to answer three questions fundamental to a successful public health campaign:

1. **Is it a significant problem?**
2. **Do we have adequate data from which to make sound decisions?**
3. **Have we clearly defined the problem?**

He said that the problems associated with addiction to prescription pain medications have drawn a lot of attention from the CDC and other public health agencies and encouraged reformers to clarify the relationship between these two important public health issues and to “reframe” the issue. He gave as an example how the anti-tobacco campaign was reframed to focus on the health of children being exposed to second-hand smoke. He cautioned against getting into a yelling match with addiction advocacy groups. He said what is important “is not who can yell the loudest, but who can sell their message.”

Keith Wailoo, PhD, author of *Pain: A Political History* and Townsend Martin Professor of History and Public Affairs at the Woodrow Wilson School of Public and International Affairs at Princeton University, is well aware of the issues those with chronic pain have to address day after day. Dr. Wailoo presented his research on pain in the United States which spans more than 70 years. His findings illuminate how current social norms and mores, clinical practices, laws, regulations and public policies have evolved over the past seven decades.

In his presentation, Dr. Wailoo pointed out that the subjective nature of chronic pain and its association with high-cost disability claims have complicated other efforts

to improve chronic pain care similar to the NPS Report. He shared historic debates among John Bonica, the father of modern pain medicine, and other well-regarded clinicians about how best to treat chronic pain and what, if anything, those who live with it deserve from medicine and society. He described how court decisions have directly impacted clinical care.

Dr. Wailoo discussed how Oregon's decision to legalize physician-assisted suicide and the interest of other states in similar legislation in the 1990s garnered support from both liberals and conservatives for improved chronic pain care and led to the proliferation of opioid prescribing. Ironically, many argue that this sequence of events led to what the CDC has referred to as an "epidemic" of opioid addiction and a major shift in political attitudes about pain care. The dramatic increase in addiction to prescription pain medications and unintended deaths associated with them (what the IOM report referred to as the *opioid conundrum*) have unintentionally harmed those who suffer from chronic pain. Concerns about these problems have resulted in changes in political attitudes and clinical practice. In response to the so-called *opioid conundrum*, state legislators

have hurriedly passed legislation intended to address this problem and unintendedly made it much more difficult for physicians to provide quality pain care treatment, made access to medications pain patients may rely on much more difficult, increased negative attitudes and stereotypes and further stigmatized those living with chronic pain as "drug seekers," limited reimbursement for needed services, and eroded the therapeutic relationship between physicians and chronic pain patients.

Dr. Wailoo also pointed out that the lack of knowledge and understanding about meaningful distinctions between tolerance, dependence and addiction apparent in many of these laws continues to complicate efforts to balance policies intended to improve pain care and reduce addiction to prescription pain medications. Paradoxically, at the same time, our society is rethinking the so-called "War on Drugs" — its lack of impact on drug abuse and addiction and the harm that has been done by a legalistic approach. While those who live with addictive disorders continue to populate overcrowded prisons, marijuana is being legalized in state by state for both medical and recreational use.



Chronic pain has become highly politicized and practice and policies are often strongly influenced by the “red-state vs. blue-state” mentality that drives much public health policy.



Dr. Wailoo argued that, like many other health issues confronting our society today, chronic pain has become highly politicized and that practice and policies are often strongly influenced by the “red-state vs. blue-state” mentality that drives much public health policy — with conservatives focused on preventing addiction and unintended deaths associated with abuse of prescription pain medications and progressives focused on ameliorating suffering and eliminating pain. He said that, tragically, this situation has significantly harmed both populations and stalemated public health efforts to improve chronic pain care and reduce addiction to prescription pain medications.

He too called for public education and development of communication strategies to help the public gain

understanding of both patient populations, i.e., chronic pain and addiction. He called on advocates to work together to build policy agendas that do not work against one another or pit people struggling to live with chronic pain against those who struggle to live with addiction. In the discussion following Dr. Wailoo’s presentation, **Dr. Bob Twillman**, Executive Director of the American Academy of Pain Management, pointed out that currently overly simplistic policy and action around harm reduction is focused solely on cutting down on the supply of prescription narcotics. For policy and action to be effective, we have to address the demand side. We also need better research to inform us in which patients should we use opioids, at what doses, for how long, with which adjunctive treatments, and with what precautions. Bottom line, we need more comprehensive care that is reimbursable.

Dr. Wailoo’s remarks and the discourse it spurred segued perfectly with Dr. Jeff Levi’s presentation that followed his.

Jeff Levi, PhD, the Executive Director of Trust for America’s Health (TFAH) and Professor of Health Policy at the Milken Institute for Public Health at George Washington University, had been asked to provide an overview of how the prescription abuse and pain communities can work together and have meaningful conversation about how each group can achieve its goals without compromising the other group’s priorities. He started his remarks by saying, “All politics, perhaps especially health politics, is personal.” Levi told the group that his health politics comes from a consumer engagement perspective and began at the start of the HIV epidemic when he advocated for people to be involved in the decisions that affect their lives, including scientific and public health policy decisions, regulator decisions, and clinical care decisions. He said his learnings from this experience included that:

- Policy can be made in a period of scientific uncertainty.
- Unlikely alliances can be made and be effective.
- Much health policy is made because of our nation's willingness to stigmatize people by race, gender, sexual orientation, and medical condition.
- Even when we recognize that beliefs are wrong, it takes decades to erase bad policy decisions.

Dr. Levi asserted that “the pain community starts with the individual in pain — and wants to find the best solutions for that individual. Unintended side effects, such as addiction, are to be prevented as much as possible, but the driving force behind advocacy and policy is around relieving pain.” However, “the substance abuse prevention world starts with preventing addiction and looks in particular to find structural interventions that make it harder for someone to become addicted. Some of those interventions do not conflict with the interests of the pain community, e.g., better training of physicians in the use of opioids, abuse deterrent formulations, but some may, if implemented the wrong way, limit pharmacy access, dosage and size of a prescription.” He pointed out that some policy interventions are “mutually bad” and gave a law enforcement approach to opioid use instead of a public health approach as an example. He said that although addiction is more common among older adults, policy decisions are often driven by “families of kids who have overdosed, some of whom were appropriately or inappropriately prescribed these medications” because it is “easier to talk about innocent kids who overdose just as it was easier to talk about newborns or hemophiliacs infected with HIV rather than gay men or IV drug users.”

It is “easier to talk about innocent kids who overdose just as it was easier to talk about newborns or hemophiliacs infected with HIV rather than gay men or IV drug users.”

As had others before him, Dr. Levi called for bringing people together from pain and addiction advocacy groups to find “common ground.” He suggested specific strategies for doing that, including pointing out that:

- Research has failed both communities and had it done its job well, neither group would be ‘in this pickle.’
- The regulatory process has failed both communities.
- The clinical system is not serving either well.
- Stigma hurts both communities.

He challenged those present to be vigilant about language and policy, to assure that each community is adequately represented in each other's discussions, and to even “be willing to expand their own agenda” — not to just demonstrate good intentions but to act in a meaningful way that may result in spending political capital to support something important to the other advocacy group even though it may not be a priority of their primary group. Levi's comments spurred a robust discussion, which included the possibility of jointly developing public education and communication campaigns to include common policy concerns and core messages and not inadvertently damage the possibility of either group, i.e., advocates for better chronic pain care and advocates to reduce opioid addiction, from achieving its priority policy goals.

Having heard from those who developed the National Pain Strategy Report, including leaders from federal agencies, researchers, those who educate healthcare professionals, reimbursement experts, public health leaders, patient advocacy organizations, policy experts and people living with chronic pain, conference attendees broke into “affinity groups” organized around the six sections of the NPS Report. Each group was then asked to report their top findings and recommendations to all those in attendance. The order in which their recommendations are listed is not intended to imply priority.

Breakout Group Reports

Disparities

- Pain disparities must be addressed at all levels and by all work groups in the National Pain Strategy report. It must be viewed as a responsibility by everyone dealing with pain care, not just by minorities or other vulnerable populations.
- Provider/professional education emphasizing cultural sensitivity — not cultural stereotyping — should be a high priority. Educational efforts need to be ubiquitous and repeated throughout all phases of training.
- There is a carelessness about cultural assumptions related to pain, and this in itself is a form of bias that perpetuates disparities and needs to be addressed. For example, even though whites are far more likely than blacks or Hispanics to die as a result of prescription drug overdose, it is nonetheless true that blacks are disproportionately asked to do urine drug screens and to agree to pain treatment agreements (contracts) than are whites.

Service Delivery & Reimbursement

- There is an existing service delivery model that has been proven to work — that of value based systems like VA/DOD use; we need to find a way to move this model to the civilian payer system, ensuring it is team-based patient/family focused care.
- This change is not going to come thru NIH (no randomized trials and can't wait on them); instead, possible targets could be CMMI, PCORI, Medicaid, and/or state employee health insurers.
- Policy considerations:
 - Demonstrate the harm of the current system
 - Ensure that rehabilitative and habilitative services and devices (as called for under the ACA) are being provided at the state level.

Prevention & Care

The bio-psychosocial model is a good model of pain care; it's the reimbursement model that is broken. We need to test new service delivery and reimbursement models via demonstration projects and analyze cost savings and/or cost-benefit.

- Look at hospice or CMS for possible ways to fund interdisciplinary teams.
- Make sure everyone is at the table and that we break down silos between all the team members and educate them together. Look at the military model for how they do this.
- Must have education for patients about community support systems.
- Put the emphasis on managing pain for improved function, rather than chasing the elusive '0' on a pain scale, and on team-based aggressive acute pain management to improve chances of better outcomes.

Professional Education

- Develop and disseminate core competencies for education and licensure and find the right approach to foster clinician change. (Example: There has been some success with utilizing virtual reality training tools to uncover biases and change behavior; by altering patient appearance and characteristics, observe the clinician behavior and then report back.)
- Develop a web-based pain education portal of standardized materials that is high quality and validated.
- Professional education is not just medical education; empathic treatment needs to be stressed in all education components and there needs to be more education on working and communicating as a team.

Population Research

- Identified opportunities for collaboration:
 - American College of Surgery/NIMHD interest in surgical disparities
 - PCORI — chronic low back pain
 - VA
 - CMS/Medicare/Medicaid
- Prevention research is missing from the NPS, opportunity exists for PAINS to ensure it will be addressed in the Federal Pain Research Strategy.
- Move forward the idea of trying to make sure there are chronic pain-related questions in the EMR. Incentivize that kind of data entry into the EMR at the primary care level.
- Encourage public release of the NHIS data (Healthy People 2020 surveys) in timely fashion (not typical 1-3 year hold).

Public Education and Communication

- Pain Education Campaign — support the four CPATF messages and include priority message that people with chronic pain need access to integrative treatment.
- Collaborate/build bridges with the harm reduction/addiction community (look for examples at state level on how to do this).
- Funding — don't wait for the Feds; PAINS can be a convener of groups to come together to figure out funding, sharing expertise as well as resources.

Involvement of Those Living with Chronic Pain

PAINS' meeting agenda was designed to allow attendees to hear directly from several people living with chronic pain. **Michael Hockley, JD**, a highly regarded environmental lawyer who has lived with chronic pain for fifteen years since a bicycle accident, spoke to members of PAINS Steering Committee, faculty and funders the night before the conference. His candid remarks reminded all those present of the enormity of the task ahead of us.

Carlton Haywood, Jr., PhD, MA, Assistant Professor of Medicine at Johns Hopkins School and a person living with sickle cell disease, was scheduled to speak the first day of the conference. Unfortunately, a flare-up of his disease prevented him from being able to attend the meeting.

Dr. Haywood, however, sent a letter of apology which was read at the time he had been scheduled to speak.

He wrote,

I was born with sickle cell disease, which is a life-threatening genetic condition of the blood that causes a number of deleterious effects on my body, not the least of which are frequently recurring episodes of severe acute pain interspersed with a high burden of daily chronic pain. Unfortunately, I am currently in the midst of battling what has been a spike this week in both sources of my pain (acute and chronic). Sadly, my attempts to relieve my pain this week have not been successful enough to allow me to attend this meeting.

As frustrating as I find this particular episode and resulting absence, I am more frustrated by the fact that my entire life has been subject to circumstances just like this. I make plans to do or to participate in opportunities for work or for entertainment that bring fulfillment to my life, only to have to live each day with the uncertainty of not knowing if my level of pain on any given day will be such that I will be physically able to actually follow through with my plans.

A reduction of this daily uncertainty, and almost as frequent frustration, is but one of the many potentially positive outcomes that may result from success in the adaptation and implementation of the National Pain Strategy Report.

Dr. Haywood's letter was a poignant reminder to all those present of the importance of the National Pain Strategy Report and the opportunity it presents to those who struggle to live with chronic pain. (To see a documentary about Dr. Haywood, go to <http://bioethicsbulletin.org/archive/sickle-cell-researcher-also-suffers-from-forgotten-disease>.)

Many find it hard to imagine that in the U.S., a country with incredible biomedical capacity, wealth and other resources, people like Dr. Carlton Haywood often cannot get the care they need and are thought by many as weak-spirited, malingerers or drug seekers.

The second day of the conference began with a pre-view of the forthcoming documentary, *The Painful Truth*. The documentary and book with the same title were both produced by Dr. Lynn Webster, former president of the American Academy of Pain Medicine, and will be released this fall. Both focus on the stories of nine patients treated by Dr. Webster over his career, including a woman injured in a random mall shooting where her daughter, a teenager, was killed and an NFL football player.

Cindy Steinberg, the quintessential patient advocate, was asked to deliver the closing keynote on day two of the conference and to issue a "call to action" to all those present. Following a "crushing accident" fifteen years ago, she dedicated her life to improving the lives of those who live with chronic pain. As a volunteer, she currently serves as National Director of Policy and Advocacy for the U.S. Pain Foundation, a member of the Steering Council of the Massachusetts Pain Initiative, a member of the NIH Interagency Pain Research Coordinating Committee and many other state and national commissions and task forces. She served as a member of the NPS Report's Care and Prevention Workgroup and was asked by PAINS to issue a call to action at the end of the PAINS Collaborators Meeting.

In an impassioned appeal, she called on PAINS and others at the conference to do four specific things:

- Endorse the four core messages developed by the CPATF, a coalition of 17 patient advocacy groups convened by SPPAN, which had been presented earlier in the meeting by Amy Goldstein, SPPAN's Director, and to seek endorsement for them from other national organizations:

- **Chronic pain is a real and complex disease that may exist by itself or be linked with other medical conditions.**
- **Chronic pain is unrecognized and under-resourced public health crisis with devastating personal and economic impact.**
- **Effective pain care requires access to a wide range of treatment options.**
- **Allowing people to suffer with unmanaged pain is immoral and unethical.**

- Solicit and support development of op-eds in support of the NPS Report
- Advocate for and facilitate placement of articles in peer-reviewed journals
- Develop a communication strategy for September as Pain Awareness Month

Steinberg's comments were powerful, resonated with all those present, and were the perfect closing remarks. They made all those present remember how important this work is to the lives of so many, highlighted the unique opportunity presented by the National Pain Strategy, and recommended concrete, measureable actions to PAINS and all others present.

Meeting Evaluation

In her closing remarks, **Myra Christopher**, Director of PAINS and the Kathleen M. Foley Chair in Pain and Palliative Care at the Center for Practical Bioethics, thanked all those present for the work they do to improve the lives of people who struggle to live with chronic pain and said that in her view, the mark of a good meeting is that people have more energy at the end of the meeting than they demonstrated at the beginning of the meeting, and it appeared that this had happened at the Collaborators Meeting.

PAINS contracted with **Dr. Darcy McMaughan**, Assistant Professor of Health Policy and Management and Director of the Program on Disability Research and Community-based Care at Texas A&M, to develop, disseminate and analyze a post-meeting survey to those who had attended the Collaborators Meeting. She requested feedback from meeting participants about whether the meeting met expectations, their experiences during the meeting, and if the path towards implementation was clarified as a result of the meeting. Forty-three percent (43%) responded to the survey and provided insights into the attendee expectations for the meeting, impressions of the path to implementation of the NPS, and plans for future work and collaborations focusing on chronic pain.

The meeting's facilitator, **Abby Dilley**, Vice President of Programs and a Senior Mediator with RESOLVE, was also asked to provide her observations about the meeting and its potential impact. Responses to the survey and Dilley's report validated Christopher's perception.

Survey Responses

The purpose of this response overview is to summarize the experiences and impression of attendees of the 2015 NPS Collaborators Meeting in an effort to move the chronic pain agenda forward.

Overall, the majority (83%) of meeting attendees who responded to the post-meeting survey felt the 2015 NPS Collaborators Meeting *met or exceeded their expectations*.

Attendees felt the meeting:

- Provided an excellent forum for collaboration with diverse stakeholders, especially stakeholders in the addiction community;
- Included well-informed presenters;
- Presented information on future plans allowing for strategic development; and
- Set a tone that allowed for discussion of complex issues in a cooperative, non-judgmental manner.

Almost all the attendees who responded (94%) found the path ahead more promising after attending the meeting.

In general, respondents appreciated the overall tone and collaborative nature of the meeting. They appreciated an opportunity to learn more about the NPS and about other potential partners in pursuing a national agenda around chronic pain. While some respondents felt it

was too early to determine their level of support for the NPS, others left the meeting with intensified support for the report. Many (67%) are currently working on projects or developing plans to collaborate on chronic pain initiatives. A majority (80%) of the attendees who responded also felt the meeting *clarified the path ahead for the NPS* in terms of priorities, implementation, next steps, funding, leadership and accountability. These actions plans were especially clarified during the breakout sessions. However, respondents did not identify any specific action plans related to the NPS. Almost all the attendees who responded (94%) found *the path ahead more promising after attending the meeting*. They reported a sense of energy, commitment and momentum.

Although many of the responses were positive, four respondents felt the meeting *fell short in some areas or was a waste of time*. Two respondents felt *the path ahead was less promising* post-meeting. Respondents expressed concern that policy makers would not make chronic pain a high priority issue and suggested that chronic pain stakeholders develop a specific strategy for collaborating with payers in the health care system.

Respondents also reported that:

- The meeting did not focus enough on concrete action plans;
- The charge to stakeholders was too vague;
- It is unclear who is taking the lead on NPS initiatives; and
- There was, on the one hand, too much focus on a medical model of pain through the perspective of medical doctors and that nurses and nurse practitioners were left out. Others suggested, however, that the voice of medical providers was overcome by the collective voice of consumers.

Respondents identified areas that need improvement before moving forward:

- The chronic pain stakeholder community needs to clarify and simplify short-term and long-term goals;
- There needs to be more focus on depth of action plans rather than breadth; and
- Emphasis needs to be placed on recruiting the next generation of stakeholders.

The overall consensus was that PAINS has a definitive role in achieving these needed improvements through fostering *collaboration* and *coordination* of chronic pain

focused activities, such as:

- Assisting with the developing of concrete action plans;
- Strategizing around ways to address the 'reimbursement problem;' and
- Helping to develop a common message and goal between the addiction community and the chronic pain community.

Respondents also see PAINS having a necessary and key role as a neutral *convener* and a *conduit* of information by:

- Providing information on how to form local chronic pain advocacy groups; and
- Facilitating more opportunities for discussion and collaboration across diverse stakeholders through meetings like the 2015 NPS Collaborators Meeting.



In her role as facilitator, **Abby Dilley**, Vice President of RESOLVE, was asked to submit a report sharing her observations and thoughts about the Collaborators Meeting. She indicated that she believed the meeting had accomplished the wide variety of goals set for it, including providing input on the NPS, identifying ideas for building action to press for its finalization and implementation, and identifying opportunities and challenges in shaping a focused, coordinated campaign to further achieve the cultural change and associated access to and improvement of quality pain care. She commented that challenges to both the NPS Report and PAINS' commitment to advancing it include developing strategic prioritized plans about how to best leverage opportunities the report will present and how to acquire adequate resources to support those plans.

Emails from many participants also affirmed the benefit of the Collaborators Meeting and encouraged PAINS to test its ability to facilitate collaborative efforts.

Immediate Activities Following the Meeting

Given this encouragement and the actions called for in the final keynote address and recurring comments throughout the Collaborators Meeting, PAINS negotiated acceptance of a version of the four core messages proffered by the CPATF and sought endorsement of them from those who attended the meeting.

With permission and support from the American Academy of Pain Management and their State Pain Policy Advocacy Network that had convened the 17 patient advocacy groups that crafted the four core messages presented at the meeting, PAINS went about the process of vetting them with leaders from major national organizations that had participated in the meeting. It was clear from the beginning that there was consensus for shared messaging as Sean Mackey had called for in the opening keynote address, awareness of the power of collective action, and respect for those who had worked hard to develop the messages. However, it was obvious that there

were concerns about specific language contained in the messages. PAINS went about a process of mediation and “shuttle diplomacy” by email.

The first effort was to affirm general agreement. It was important next to determine where there were specific concerns and why there were. Participants in this process were concerned about appearing to be disrespectful of the consumer advocacy groups that had worked on them, but leadership at American Academy of Pain Management quickly assuaged those concerns from their perspective and vetted the idea of amending them with those who participated in the Task Force.

PAINS was quickly given a green light. Through a very iterative process, over the course of a few days, agreement emerged and more than 50 national organizations and leaders working to improve chronic pain care endorsed the following messages:

- *Chronic pain is a real and complex disease that may exist by itself or be linked with other medical conditions.*
- *Chronic pain is both an under-recognized and under-resourced public health crisis with devastating personal and economic impact.*
- *Effective chronic pain care requires access to a wide range of treatment options, including biomedical, behavioral health and complementary treatment.*
- *Denying appropriate care to people with chronic pain is unethical and can lead to unnecessary suffering, depression, disability and even suicide.*

The messages were posted on PAINS website (www.painsproject.org) with acknowledgement of CPATF’s contribution along with an invitation to others to join those who initially agreed to endorse them. Names of those organizations and individuals were posted on the PAINS website, and all those were asked to do likewise, i.e., to post them on their website and to circulate them through their regular communication channels.

On July 17, PAINS issued a press release calling on HHS to:

- incorporate these messages into the final version of the National Pain Strategy Report;
- Release the report no later than the end of September 2015;
- Immediately establish a committee to oversee the report’s implementation.

The press release also called on Congress to provide adequate funding for its implementation.

The National Pain Strategy Report presents a once in a lifetime opportunity to improve the lives of more than 100 million people in the U.S. who live with chronic pain, but its implementation will require a Herculean effort.

The press release was sent to the fifty organizations that had signed onto the core messages, and PAINS encouraged each organization to send a similar release.

PAINS plans to promulgate and further promote the messages and endorsement of them through direct communication with HHS, this report, PAINS monthly updates, future meetings with PAINS Citizen/Leader Advisory Group, national conferences, educational briefs, September as Pain Awareness Campaign, and to

incorporate them into the communication work currently doing done with the Center for Excellence in Healthcare Communication for Under-served Populations at the University of Kansas.

Conclusion

The National Pain Strategy Report presents a once in a lifetime opportunity to improve the lives of more than 100 million people in the U.S. who live with chronic pain, but its implementation will require a Herculean effort. It will challenge many of us to work together in new ways and with new partners — often outside our comfort zone. PAINS hopes that the Collaborators Meeting inspired all those present to commit to making the vision articulated in the NPS Report a reality.

One of the most rewarding comments PAINS received following the June meeting was from **Janice Schuster**, a journalist who lives with chronic pain. She wrote:

By nature and habit, I am a quiet person, more comfortable sharing ideas in print than in person. So I startled myself while attending the two-day PAINS Collaborators Meeting in Washington, DC. The fact that I did so simply reflects the sense I had of having found a place where all voices were welcome and respected, and where my experiences as a person with pain and as a writer were worth sharing. In an era where so many patients continue to feel excluded from major professional meetings, PAINS leaders took pains to include us, and to anticipate our needs. The conference room even had two beds, comfortably made up, for those with MSK problems to stretch and move and participate.

Having attended scores of healthcare conferences and panel discussions, I know how programs can, at times, devolve into a PowerPoint parade, with data and ideas that simply reinforce what the choir knows. The PAINS conference did not. Gathered with the very specific goal of finding ways to implement and publicize the National Pain Strategy (NPS), each presenter stayed on point and focused. By the end of the first long day of listening, I felt not exhausted, but rejuvenated. I had learned so much that was essential and relevant. More than that, the day's updates on federal efforts to make the NPS a reality gave me hope that, in my lifetime, we will find better strategies and interventions that are safe and effective, and that reach the millions who live with chronic pain problems.

**Doing the right thing isn't hard;
what is hard is knowing what
the right thing to do is.**

We are grateful for Schuster's comments but recognize that PAINS has much more work to do. In an episode of *West Wing*, President Bartlett said to one of his aides, "Doing the right thing isn't hard; what is hard is knowing what the right thing to do is." Like many other organizations represented at the June meeting, PAINS is trying to figure out what that is and is aware that, in light of the opportunity the NPS Report presents, many other organizations are thinking that through as well.

Since publication of *Relieving Pain in America*, PAINS has convened four national meetings. Like the Collaborators Meeting in June, each one has included people living with chronic pain, representatives from professional societies, academic institutions, policy making groups (state and federal), industry, private foundations,

There are many others who must be at the table, including those who are working to reduce addiction to prescription pain medications and unintended deaths associated with them, and third-party payers who may believe the NPS Report will harm their bottom line.

communication experts, and others. Following each of those meetings, participants have commented that they had never before had the opportunity to interact with such a diverse group of participants.

PAINS has worked hard to accomplish this but knows that there are many others who must be at the table, including those who are working to reduce addiction to prescription pain medications and unintended deaths associated with them, third-party payers who may believe the NPS Report will harm their bottom line, professional groups deeply entrenched in the status quo, and health systems that think they cannot take on one more thing in the midst of reforms driven by the

Affordable Care Act. Convening diverse groups is important, but it is not enough.

Henry Ford once said, “Coming together is a beginning, staying together is progress, and working together is success.”

PAINS believes that our greatest contribution to the successful implementation of the National Pain Strategy Report is to continue to serve as a neutral convener and to do all that we can to build bridges between groups with capacity and interest to be involved in a “cultural transformation in the way pain is perceived, judged and treated” and to help them work productively together.

The resources, numbers of organizations and committed people, political will and change in attitudes that will be required to successfully implement the National Pain Strategy Report is almost unimaginable. Cultural transformations aren’t easy, and every person and organization that attended the Collaborators Meeting has a significant role to play. At the end of PAINS second national meeting, a participant shared a Mother Teresa quote:

**“I can do things you cannot do;
you can do things I cannot;
together we can do great things.”**

It seems to be a good way to end this report. ■