



Environmental Scan

**Chronic Pain Management and the Practical
Implications of Addressing Recommendations Put Forth
in the Institute of Medicine (IOM) Report,
*Relieving Pain in America***

March 2013

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The Center for Practical Bioethics (the Center) contracted with CPR Strategic Marketing Communications (CPR), a private firm in New Jersey, to develop this report. The report is being done in conjunction with the Pain Action Alliance to Implement a National Strategy (PAINS), a project of the Center. CPR has no relationship, financial or otherwise, with any of the organizations mentioned in this report or those interviewed.

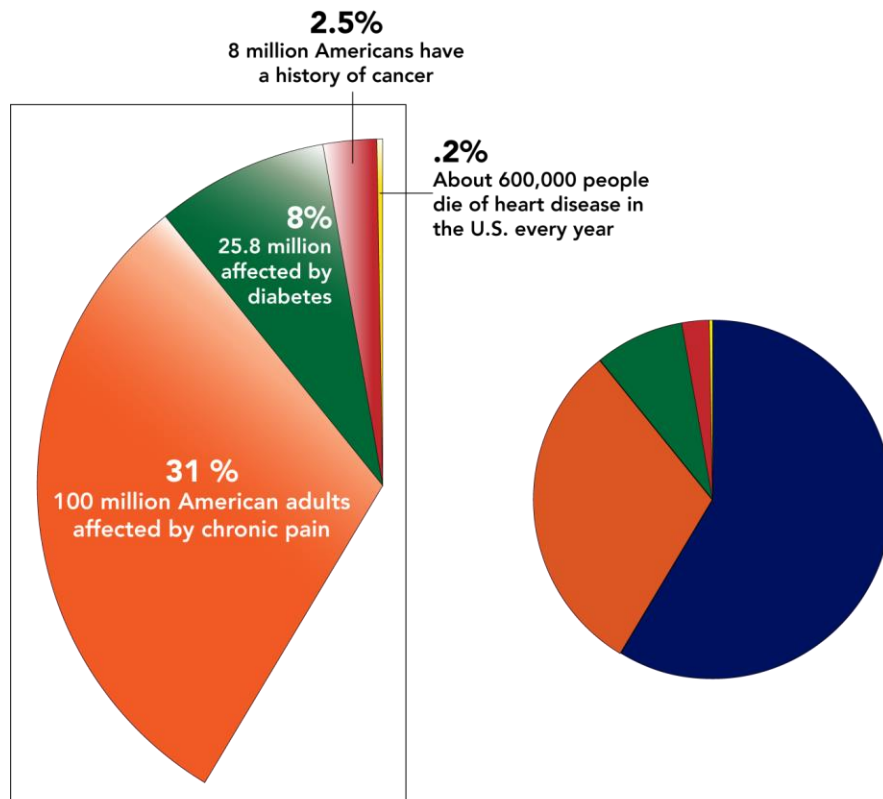
METHODOLOGY

CPR did a brief review of available data, but relied on *Relieving Pain in America: A Blueprint for Transforming Prevention, Care, Education and Research* as the primary source underpinning this report. (See Appendix A for a brief of this report.) Websites of more than three dozen organizations, including professional societies, policy organizations, advocacy groups and others known to be working to improve pain care were reviewed, specifically for activities related to consumer education, policy advocacy and research promotion. One-on-one interviews were done with 11 national thought leaders, including the chair and vice chair of the Institute of Medicine's Committee on Advancing Pain Research, Care and Education, which was responsible for *Relieving Pain in America*.

REVIEW OF AVAILABLE DATA

When pain becomes ongoing or recurrent beyond the usual course of acute illness or injury, it becomes life altering – resulting in job loss, compromised relationships and a diminished sense of self-worth. Chronic pain affects at least 100 million American adults¹—more than the total affected by heart disease, cancer, and diabetes combined. In humanistic terms, the cost of chronic pain to those who struggle to live with this problem is incalculable. However, it is known that the suicide rate for this population is twice that of the general population².

In economic terms, when the cost of treatment and loss of productivity are combined, the numbers are staggering. Pain costs the nation up to \$635 billion each year.³ One study found that a reported 36 million Americans missed work in the previous year due to pain, and 83 million indicated that pain affected their participation in various activities.⁴ The prevalence of pain has a tremendous impact on business. The annual value of lost productivity associated with pain in 2010 ranged between \$297.4 billion to 335.5 billion.⁵

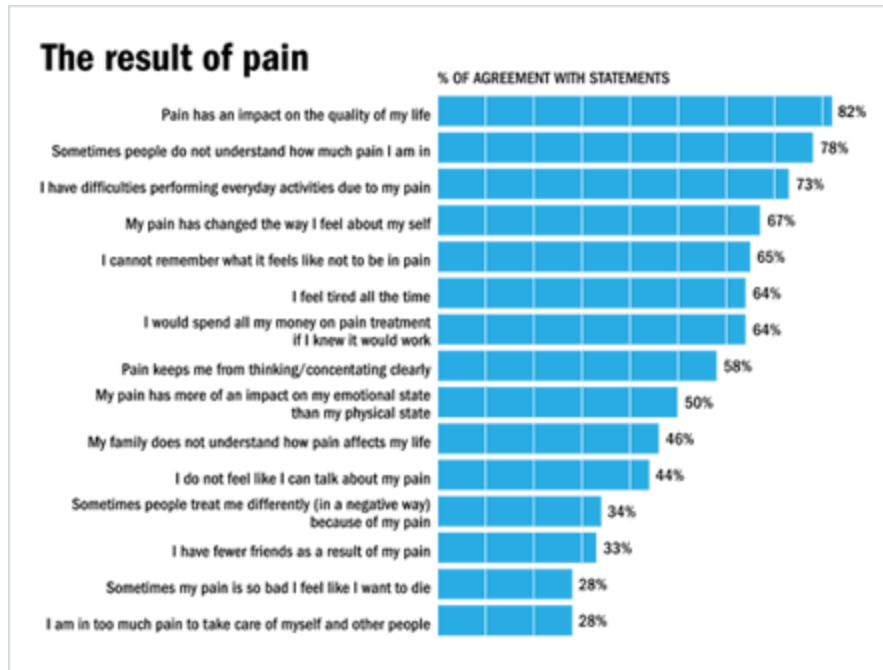


U.S. Population: approximately 313,914,040
*Source: U.S. Census Bureau

Pain is the most frequent reason patients visit an emergency department (ED), accounting for over 70 percent of ED visits.⁶ Acute pain is also a common problem in family practice, sports medicine, and especially in internal medicine. Despite substantial advances in pain research in recent decades, inadequate acute and chronic pain control continues to be the norm. A number of studies show that fewer than half of post-operative patients receive adequate pain relief, despite the fact that poor pain management puts patients at risk, creates needless suffering, and increases costs of care.⁷

It is also well documented that certain populations, including women, children, seniors, people of color, and those in lower socio-economic status, bear the burden of chronic pain disproportionately. Given the high cost of pain in human lives, dollars, and social consequences, relieving pain should become a key priority across the healthcare continuum. *Relieving Pain in America* calls for a “cultural transformation in the way pain is perceived, judged and treated.” To spark this transformation, a far-reaching and ongoing chronic pain awareness campaign is urgently needed to counteract this public health crisis, articulate the collective voices of pain patients and communicate it to decision makers in both the public and private sectors.

The goal of pain management is to improve a patient’s quality of life. Paradoxically, advances in medicine that have led to greater survival rates among patients with cancer, heart disease, HIV/AIDS, stroke, traumatic brain injury and many other diseases have increased the number of people living with chronic pain.



Source: [Pain Story](#), a survey sponsored by a restricted educational grant from, and prepared in association with, Mundipharma International Limited

Chronic pain serves no purpose. It is destructive; it can result in lost relationships, jobs, dreams, even notions of self. It is also tremendously costly to our society. As one of the most significant public health issues facing the country today – and into the future – key challenges to educating and enlightening the public about the impact of chronic pain must be fully understood and overcome, an integrative approach to pain management and improving pain care that incorporates both the traditional biomedical approach and complementary medicine must be developed, and research must be advanced. Much work is currently being done by public and private organizations to help people with pain improve their quality of life, from coping workshops to basic science research. However, many of these efforts are small in scope, narrowly focused, underfunded, or in early stages of development.

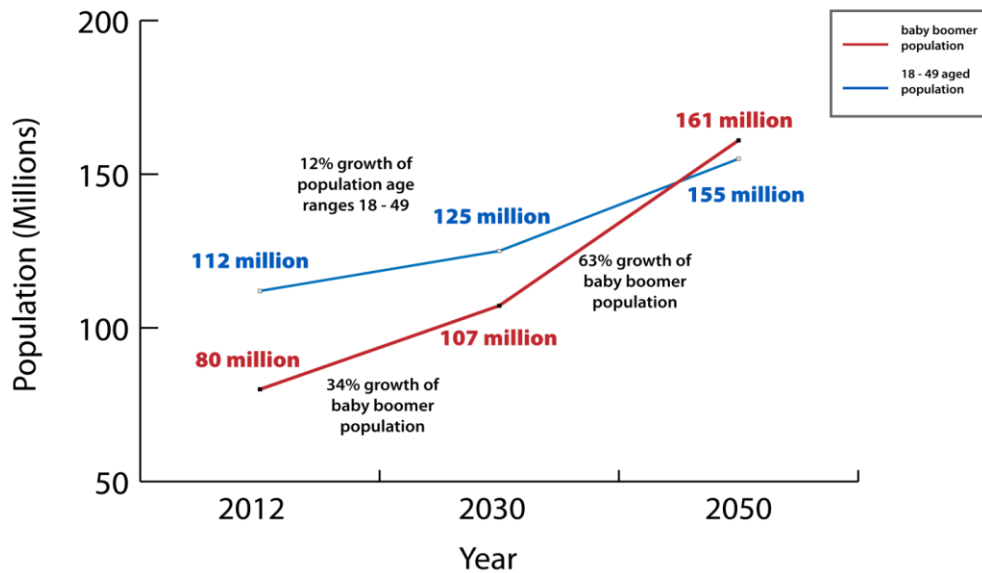
Findings

In the last decade there has been growing concern about the under-treatment of chronic pain. The World Health Organization (WHO) has declared that chronic pain is globally the number-one public health issue, and the IOM reveals that the same is true in the US – a situation that is expected to become increasingly severe in light of four enormous forces of change that are about to meet at the epicenter of the nation’s healthcare system:

- *Influx of newly insured patients* – The 30 million Americans expected to get insurance under the Patient Protection and Affordable Care Act (ACA) are expected to be poorer, older, less likely to have full-time employment, less likely to have a college degree and more likely to speak a language other than English, compared with the current population.⁸ This means they will require intense care for as yet unknown health needs, prompting providers to spend more time in initial patient assessments due to a lack of medical records.

- *Rising prevalence of obesity* – Increased weight places a burden on bones and joints and leads to higher rates of joint replacement surgeries, which in themselves cause acute pain and may lead to persistent or chronic pain. In addition, obesity is known to be associated with migraine.⁹
- *Aging Baby Boomer generation* – As the generation of Americans born between 1946 and 1964 – Baby Boomers - age, the impact of chronic pain will increase. More than half of patients reporting chronic pain are older than 55, and because Baby Boomers tend to lead active, productive lifestyles, they are likely to live longer than previous generations. In the coming years, chronic pain will become an even more significant public health crisis than it is today.
- *Looming provider shortage* – Given the increases in covered lives and the aging population, there will be a dire shortage of healthcare providers. Currently, there is a shortage of more than 13,000 physicians, with the expected shortfall to grow 10-fold within 12 years.¹⁰

Baby Boomer Generation: the Coming Chronic Pain Health Crisis



Source: [Marketing Charts](#)

This perfect storm gives rise to the need to increase awareness about the economic and social impact of chronic pain, as well as issues related to care, education and topical issues that deflect attention away from this growing public health crisis.

WEBSITE REVIEWS

In addition to an abbreviated literature review and interviews with national thought leaders, websites of 38 organizations known to be committed to improving pain care were reviewed for three activities:

- Public Education
- Policy Advocacy
- Research Promotion

(For a complete list of websites reviewed, see Appendix B.) Organizations included professional societies, disease-specific advocacy organizations, policy groups, wellness-oriented groups and foundations.

Website Review Results

Policy Advocacy: A number of organizations support robust advocacy programs and participate in the Pain Care Forum, an informal group that meets monthly in Washington, D.C., to discuss legislative activities related to pain care, track healthcare policy, and provide information and tools to foster effective advocacy. Some of those include the American Academy of Family Physicians, the American Academy of Hospice and Palliative Medicine, the American Academy of Pain Medicine (AAPM), American Association of Nurse Anesthetists, the American Pain Society, and the American Society for Pain Management Nursing. The American Academy of Pain Management advocates on behalf of its members by representing and supporting them on both the state and federal level and by providing them with the tools and leadership skills they need to be empowered and effective advocates themselves. However, more than 20 percent of websites reviewed did not demonstrate significant activity specifically related to pain.

Consumer education: Approximately 62 percent (24:39) of the websites reviewed provide some sort of consumer education. The American Chronic Pain Association offers extensive resources on their website to connect adults living with pain, provides educational resources, and has organized a loose consortium of organizations with an interest in the personal, economic, and social impact of pain on society. The American Academy of Pain Management provides education through online and live programs, print materials and customer directories for finding a clinician, including the State Pain Policy Advocacy Network (SPPAN). Other organizations that provide resources to consumers include:

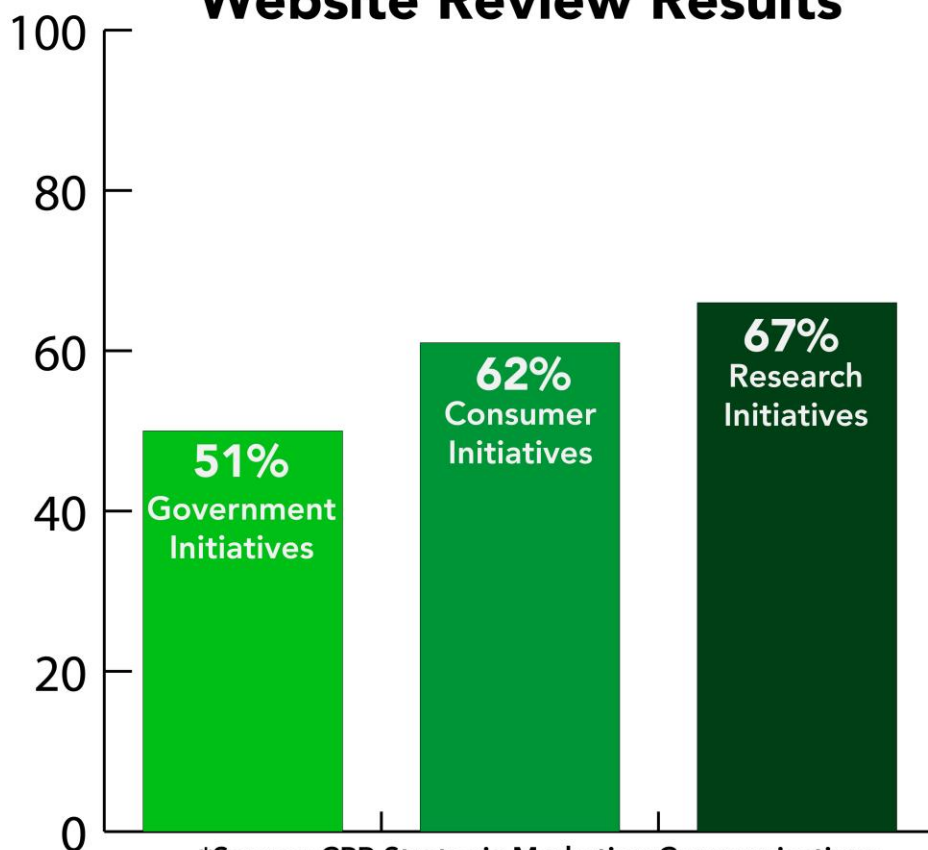
- American Academy of Family Physicians features pain-related webcasts (example: Women with Chronic Pain and Fibromyalgia)
- American Academy of Hospice and Palliative Care publishes the *Journal of Pain and Symptom Management*
- American Academy of Pain Medicine offers the “Aches and Gains” radio show, pain tools such as daily activity checklist and pain logs, physician visit prep, pain awareness events and other patient education resources
- American Association of Neurological Surgeons offers educational materials about joint pain
- American Geriatrics Society offers practice guidelines and various pain study results
- National Vulvodynia Association (NVA) strives to increase public awareness and understanding of vulvodynia, providing extensive information to healthcare reporters, editors and producers and promoting their efforts in *Marie Claire*, *Good Housekeeping*, *Health* and major newspapers and television shows, as well as conducting health surveys and gathering patient testimonials

Other organizations offer community leadership resources, issue press releases, host conferences and provide toolkits. For the most part, however, these efforts are slanted toward a particular disease rather than being focused solely on chronic pain. Furthermore, there are no unifying themes or consistent messages across these websites.

Research promotion: Two-thirds (26:39) of the websites reviewed demonstrated that those organizations promote and disseminate research related to chronic pain through a variety of mechanisms, e.g., professional journals, meetings, special events and their websites themselves. The

American Academy of Family Physicians' promotion is focused on pain management and opioid abuse; American Academy of Hospice and Palliative Care hosts special events and annual assemblies; the American Academy of Pain Management offers an annual clinical meeting, hosting more than 700 clinicians across all disciplines. The American Association of Neurological Surgeons/Congress of Neurological Surgeons (Joint Pain Section) publishes in important journals, as does American Osteopathic Association, American Pain Society, American Society for Pain Management Nursing, American Society on Aging, Arthritis Foundation and the Federation of State Medical Boards, to name a few. The International Association for the Study of Pain (IASP) sponsors research symposia on specific pain-related topics and provides grants, awards, and fellowships to support international pain research. Also, the National Community Pharmacists Association was awarded a \$100,000 grant to advance the foundation's efforts to stimulate community pharmacy-based research that helps improve patient care and education.

Website Review Results



***Source: CPR Strategic Marketing Communications**
38 websites evaluated for pain awareness initiatives spanned criteria including appraisal of consumer education activities, research promotion, and government action

INTERVIEWS WITH KEY STAKEHOLDERS

Nearly a dozen key stakeholders and thought leaders participated in interviews aimed at assessing key challenges to transforming chronic pain care in America. Healthcare professionals (including physicians and nurses), patient advocates, educators, and researchers participated. Perspectives represented included public health, anesthesiology, primary care, pain medicine, psychology, oncology, pediatrics and neurology.

The intent was to absorb and distill this group's views on related issues and the severity of chronic pain as a public health crisis in order to determine whether or not a national alliance and pain awareness campaign would serve to mitigate this crisis and contribute to healthcare reform efforts in the US, thereby supporting recommendations outlined in the IOM's *Relieving Pain in America: A Blueprint for Transforming Prevention, Care, Education, and Research*.

Participants included:

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President/Founder, National Fibromyalgia & Chronic Pain Association

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Director, Center for Managing Chronic Disease, University of Michigan
Vice Chair, IOM Committee on Advancing Pain Research, Care, and Education

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McCullough Professor of Cancer Research
Chair, Department of Symptom Research Division of Internal Medicine
University of Texas, M.D. Anderson Cancer Center

Penney Cowan

Founder and Executive Director, American Chronic Pain Association

Jim G. Lemons, Ed.D.

Founder and Director, The Lemons Center for Behavioral Pain Management

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Professor Emeritus, Neurological Surgery and Anesthesia and Pain Medicine,
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Judith A. Paice, Ph.D., R.N.

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Joseph Pierle, M.P.A.

Chief Executive Officer, Missouri Primary Care Association

Philip A. Pizzo, M.D.

Former Dean and Professor of Pediatrics and of Microbiology and Immunology,
Stanford University School of Medicine
Chair, IOM Committee on Advancing Pain Care, Research and Education

Dennis C. Turk, Ph.D.

John & Emma Bonica Professor of Anesthesiology & Pain Research,
Dept. of Anesthesiology & Pain Research, University of Washington

Lynn Webster, M.D.

Co-founder, Chief Medical Director, CRI Lifetree

Lonnie Zeltzer, M.D.

Director, Pediatric Pain Program, Distinguished Professor of Pediatrics, Anesthesiology, Psychiatry and Biobehavioral Sciences at the David Geffen School of Medicine at UCLA

Each interview lasted approximately 30 minutes. The format was composed of open-ended questions (Appendix C) regarding the perception of people living with chronic pain in the US, and key strategies for a national campaign to improve the treatment of pain (including a national communication effort), challenges to such efforts and strategies for overcoming them. The four key mandates that emerged from the interviews were:

- Educate the American Public about the Impact of Chronic Pain
- Provide Inter-disciplinary Bio-psychosocial Pain Care
- Incorporate Integrative Pain Treatment into the Education of Healthcare Professionals and Improve Research
- Change the Conversation from Drug Safety Issues to Pain Management

INTERVIEW RESULTS

Educate the American Public about the Impact of Chronic Pain

The overwhelming consensus among interviewees concerns the pervasive lack of understanding about chronic pain and those who live with it. Pain is viewed as a symptom secondary to the primary disease, with a societal tendency to take exclusive interest in a particular disease and not the pain it may cause. The approach to healthcare has become siloed by disease or medical specialty, which causes a major impediment toward encouraging a broader, more holistic approach toward the treatment of pain. Furthermore, public policy fails to support education about pain, preventing the full extent of the issues to come to light in any profound way.

Understanding and treating chronic pain requires time and patience on the part of healthcare providers. In the reform environment that has emerged in response to the Patient Protection and Affordable Care Act, a number of interviewees expressed the belief that, as the US healthcare system transitions toward a more patient-centric approach, a tremendous opportunity exists to further pain education. Without the proper tools and training, that opportunity could prove to be elusive.

The key issue, unanimously agreed upon by the interviewees, was that public awareness and engagement remains a key driver for change. To accomplish this, messages about chronic pain must be strong and consistent to compete against those being touted by drug and device manufacturers, who spend fortunes to sell products with messages that are all too often irresponsible and/or erroneous. Distinguishing pain management issues from the abuse of prescription drugs will be critical for success.

Furthermore, the pain awareness campaign must be waged on various fronts: mounting education and support systems for providers and clinicians to be more effective, funding research to generate hard outcomes for interventions, engaging/educating the public, and enlightening insurance companies and other payers about the true costs of chronic pain. Too often, reimbursement policies impede an integrated approach to managing chronic pain. Even when insurers cover different types of treatments, such as medications, procedures and physician visits, many insurance companies will not assign a care manager to help coordinate care to those living with chronic pain. The lack of reimbursement for complex chronic pain care is a disincentive to physicians treating people with persistent pain and must be addressed if progress is to be made.

In looking at other major health initiatives that have caused a dramatic shift in perception, treatment and economic support, it's clear that they began as major public education efforts.

A number of national organizations, including patient advocacy organizations and disease-specific support groups, have endeavored for years to educate the public with toolkits, educational literature and awareness initiatives. The American Chronic Pain Association created September as Pain Awareness Month for this purpose and it has gotten some traction. However, the majority of those who participated in this scan agree that a more robust effort is necessary and agreed upon messages must be delivered in a more concerted way and continuously repeated to make a meaningful impact.

A major problem is that critical messages about chronic pain tend to primarily reach well-educated, middle- and upper-class populations, who tend to be more proactive about seeking help and accessing information and resources online. A campaign including targeted awareness and educational programs can get this message to under-served populations in a way that is relatable and impactful. A number of interviewees assert that a collective voice of pain patients must be captured and delivered to the right audiences and decision-makers who can make a difference.

Because the societal and economic costs touch everyone, the majority of those interviewed agreed that the worst case scenario for the future of all Americans, especially the 100 million who struggle to live with chronic pain, is to do nothing in the face of the chronic pain health crisis.

Recommended Strategies

The issue of chronic pain must be made visible, present, and targeted to reach all populations. In addition, the campaign must be multi-pronged and ongoing, with engaging messages delivered through innovative channels. Several interviewees cited the *Back Pain: Don't Take It Lying Down* media campaign which ran between September 1997 and December 1999 in Victoria, Australia, that provided simple evidence-based advice about back pain. Following the brief campaign, there were significant improvements in both community and physicians' beliefs about back pain, as well as a decline in the number of workers' compensation back claims.

To be effective, a national pain awareness campaign in the US must be carefully orchestrated and involve many organizations. At the core, its purpose should be to educate people about bio-psychosocial or integrative pain management, including alternative therapies, to drive public demand for improved pain care. Messaging must not simply be about better therapies or ending pain but also about:

- Living well with pain
- Maintaining hope
- The importance of speaking out
- Rejecting stereotypes

Those living with pain need to learn and share with others the concept that pain management goes beyond medical treatment and opioids. It may also involve self-management programs, complementary and alternative treatments, diet and nutrition counseling, psychological therapy, spiritual support, physical rehabilitation, and job readjustment. Evidence-based self-management education (SMEs) programs are increasing nationwide – some at little or no cost. For example, the Arthritis Foundation has structured SMEs for all mobility levels, which have been proven to effectively help with pain.

The campaign must be aimed at those with pain and built upon their contribution to the discussion in order to engender greater understanding among those who don't have pain. The overriding message must be that those living with chronic pain are deserving of individualized comprehensive care. It requires persistent treatment and compassion from others.

It will be equally important to reach insurance companies and other payers in order to convince them that chronic pain is just as costly as other chronic conditions, like diabetes and asthma. Until such time as insurers play a greater role in coordinating integrated care, people in pain must be proactive about their healthcare needs – exercising, caring for their mental well-being, eating right and getting proper amounts of sleep. They should also determine what rewards and incentives their insurers offer for facilitating better lifestyle choices, such as discounts for memberships at fitness clubs or educational programs for blood pressure control, smoking cessation and nutritional counseling.

Based on participant feedback, a concerted effort by a pain awareness alliance to help all Americans understand the nature of pain, as well as its various modalities for treatment, will eventually be a significant step forward for the entire healthcare system. The campaign's highest contribution will be, first and foremost, to focus on those living with chronic pain and to engage them in a way that will build momentum.

Currently, a number of disease-specific groups are working to promote public awareness and understanding among those living with pain, their families and friends, healthcare professionals and policy makers. A less siloed approach will shift this discussion to a wider audience, reach those who are less able to help themselves, and give the silent sufferers of pain a voice while strongly uniting the community.

It will be essential for patients living with chronic pain to share their stories. In order to transform public opinion and public policy, chronic pain needs to be defined in compelling, graphic language. Many feel like prisoners in their own bodies, but policy makers remain indifferent because they only look at short-term costs and not the crippling long-term costs of pain management. To combat this, the pain community must come together and help craft the language to express the horribly debilitating effects of chronic pain and its negative impact on their lives and the lives of their families.

Provide Inter-disciplinary Bio-psychosocial Pain Care

The dominant pain care model today is a biomedical approach, i.e., prescription pain medications, steroid injections and nerve blocks. In some cases, a bio-psychosocial approach can improve patient outcomes, may assuage physicians' concerns about iatrogenic addiction, and avoid unnecessary regulation and oversight by state licensing boards or law enforcement.¹¹

Fortunately, new healthcare delivery arrangements, such as accountable care organizations (ACOs), are focusing more on outcomes, holistic approaches and patient satisfaction – not just the diagnosis. There is much more emphasis also on the role of the patient and patient education. This has opened the door for clinicians to address pain in a different way. However, reform efforts are currently heavily focused on reducing cost in the healthcare system, and although many believe integrative pain management is cost effective, there is a paucity of data.

A few key programs aim to address these problems and to shift people living with chronic pain from passive patient to active participant. Graphical tools have been developed to bridge gaps in communication between patient and provider. An excellent model of integrative care and

multidisciplinary treatment is the US Department of Veterans Affairs (VA), which works with veterans in pain.

Recommended Strategies

The majority of interviewees indicated that a well-organized national communication plan coordinated at every level and designed around differences in communities and cultures would drive changes in the way chronic pain is managed in the healthcare delivery system and beyond.

Chronic pain can lead to depression, anxiety and, according to new research, patients suffering chronic pain are more likely than others to consider suicide.¹² A study by researchers in the US found this increased risk remained even when the possible effect of mental illness was accounted for.

Understanding the root of the pain, as well as the patient's health as a whole, plays an important role. As quality of care improves, through better understanding and communication between caregiver and patients in pain, resources will be more appropriately utilized and many believe costs will be contained.

Furthermore, the practice of pain medicine should take an inter-disciplinary approach. At times, incorporating modalities from various specialties to ensure the comprehensive evaluation and treatment of the pain patient will be appropriate -- although not necessarily in every case. It's important to continue advocating for evidence-based therapies. Furthermore, an inter-disciplinary, holistic approach must be based on best practices and the goals and values of the individual. A provider/patient relationship based on trust and focused on well-being is critical to this approach.

Better understanding of the transition of acute pain to chronic pain will enable physicians to prevent many cases of chronic pain.

Incorporate Integrative Pain Management into the Education of Healthcare Professionals and Improve Research

It is estimated that there are fewer than 5,000 pain specialists in the US. The burden of treating chronic pain falls mainly on primary-care physicians (PCPs), who are not educated in pain management and whose numbers are shrinking. In medical school, students receive only a few hours at most of education on pain treatment.¹³ In 2012, the NIH Pain Consortium funded 11 Centers of Excellence in Pain Education that are charged with developing inter-disciplinary pain education curricula targeted at healthcare professionals early in their training.

As for research, in FY 2011, the NIH supported \$386 million to focus on chronic pain.¹⁴ Although a huge amount of money, according to the NIH website, this accounts for less than 1% of total NIH funding in the same year. The NIH Pain Consortium, comprised of representatives from almost all of the NIH Institutes and Centers of Excellence, seeks to enhance pain research and has established the Interagency Pain Research Coordinating Committee that has surveyed federally funded pain research, including alternative medicine, and is prioritizing funding.

Despite this, many of those interviewed expressed concern that investment in pain research is seriously out of proportion with the widespread chronic pain incidence in American society. Across academia, many see their pain research funds shrinking. Nevertheless, research will continue to be important for improved patient outcomes and greater understanding of the impact of chronic pain for physicians, patients and the public. Some cancer research has shifted toward understanding the impact of drugs and surgery as a cause of chronic pain in cancer patients and devising methods to reduce treatment related to pain. For example, neuropathy has been a major cause for ceasing cancer therapy.

Recommended Strategies

Primary care providers, including physicians and advance practice nurses in training and in practice, must be taught to listen to the patient's narrative, not simply respond to lab results. The first step is to engage and educate the medical and nursing community by developing continuing education (CE) programs about chronic pain management. To increase understanding among the array of health professionals who deal with pain, undergraduate and graduate training programs must begin offering standardized information about pain and incorporate experiential learning about pain in inter-professional settings. Improving education and communication between PCPs and pain specialists is especially important. Furthermore, licensure, certification, and recertification examinations should include assessments of a providers' pain education.

As the patient population expands, it will become increasingly essential that all physicians and nurses, particularly those at the front lines of patient care, have the skills to effectively assess pain and determine an appropriate course of action in the clinical setting.

A national awareness campaign must advocate for better and broader research surrounding chronic pain and all of its scientific, social and economic ramifications.

New research indicates that changes in the brain and nervous system that cause pain to persist can be reversed. With advances in knowledge, when chronic pain does occur, interventions will reduce the pain, but limit side effects through tools such as precisely targeted drugs, gene therapy, biologics, brain stimulation devices, and behavioral strategies. Biomarkers and non-invasive imaging methods will better diagnose pain and enable physicians and patients to optimize treatments. Together, these advances will provide personalized and targeted therapies for each patient.

The influence of an informed and engaged public on medical education, research and policy is powerful. It can clearly be seen in care of those with HIV and breast cancer.

Change the Conversation from Drug Safety Issues to Pain Management

The traditional medical model has created a revolving door in healthcare when it comes to chronic illness and, in particular, chronic pain because the body develops tolerances to pharmacological treatment. Patients are compelled to return for care sooner and on a continuous basis for pharmacological management of chronic pain. This excessive emphasis on prescription pain medications, especially opioids, stems from the fact that for physicians, it is easier to prescribe medications than it is to take a more in-depth analysis of the patient's pain and find the right mix of treatments that might include alternatives.

There are frequent references to the importance of balanced policy approaches and that those working to curb the abuse of prescription pain medications are committed to making sure that their efforts do not make it more difficult for those with chronic pain to access treatments they need, including opioid therapy. However, there is compelling evidence that this is occurring. An overwhelming and disproportionate amount of media and political attention has been devoted to painkiller abuse and addiction. Conversely, very little attention is given to chronic pain, which affects a far greater number of people. About 9.3 percent of the population has drug or alcohol problems serious enough to require treatment, while severe chronic pain affects at least one in three Americans.¹⁵

This “imbalance” has created a situation in which patients who had been on a stable and effective low dose of medication for years have been suddenly cut off of medications or “fired” by their physicians because of increasingly strict drug policies. In many cases, patients must visit their physician every month or travel hours to see a physician who will prescribe the medication they need for chronic pain.¹⁶ In some cases, physicians feel compelled to prescribe less than they deem appropriate out of fear of law enforcement, despite the fact that the majority of people with pain use their prescription drugs properly, are not a source of misuse, and should not be stigmatized or denied access because of the misdeeds or carelessness of others.¹⁷

The abuse of opioids, while an important issue that patients and prescribers alike must understand, overshadows the chronic pain discussion and undermines initiatives to increase research and improve treatment, absorbing important resources that should go for larger sociological, physiological and psychological issues related to chronic pain.

Furthermore, the issue of diversion – use of prescription drugs for non-medical or recreational purposes – complicates the discussion about chronic pain treatment and seriously erodes the attitudes of patients, their families and physicians towards chronic pain. Therefore, the national pain awareness campaign must address the tension between these two important public health issues in order to shift the narrative away from addiction and toward the importance of drug safety only, toward the importance of preventing chronic pain, treating it appropriately, the benefit of bio-psychosocial approaches, and the importance of responsibly taking medications and keeping them out of the wrong hands.

The overriding recommendation from those interviewed was that the pain awareness campaign must shift focus away from pharmacological interventions exclusively toward a message about other strategies for coping with complicated pain issues. The campaign should also focus on insurers, third party payer policies and drug formularies that have become severely diminished, restricting what physicians can prescribe and involving approval forms, faxing and other layers of administration that prevent or delay treatment.

In January of 2013, the Food and Drug Administration (FDA) advisory board recommended shifting hydrocodone to Schedule II, i.e. making it a drug with abuse potential. This is significant because this is the only pain treatment many individuals receive for their pain, especially underserved populations who are often treated by nurses and physician assistants. Intended to help reduce addiction and unintended deaths associated with drug overdoses, many fear that this action will have the unintended consequence of increasing the already unacceptable disparities in pain care.

Recommended Strategies

Both the under-treatment of pain and the abuse of prescription pain medications are important public health problems. But policies initiated to address the abuse of prescription medications, especially opioids and adjuvant analgesics, have significantly – and negatively – impacted the care of those who live with chronic pain. Governmental agencies must be educated about the unintended consequences drug policies have caused those living with chronic pain and be held accountable for remedying these problems. A national pain awareness campaign must take responsive and pro-active grass roots efforts towards influencing legislation and integrate it into a comprehensive, organized robust force for change.

CONCLUSION

Researchers at CPR Strategic Marketing Communications analyzed the wealth of information gathered to define themes and identify trends. Based on interviews with key thought leaders, a consensus emerged identifying overarching issues and the urgent importance of a robust, well-orchestrated and long-term national pain awareness campaign that will require a national coordinated effort.

Resolving the chronic pain problem in the US will take enormous effort and years to accomplish. Without question, those efforts can be maximized and the time required condensed by a national public education and engagement campaign. As mentioned before, there is ample evidence of the impact such a campaign can have on the delivery of healthcare. Treatment of those who live with HIV and women with breast cancer are just two examples. No single organization has the capacity, credibility, influence or resources to accomplish the “cultural transformation in the way pain is perceived, judged and treated” as called for in the IOM report *Relieving Pain in America*. It will take many organizations to accomplish this goal.

Many organizations and individual leaders have spent decades on this problem. Their experience and knowledge is critical to developing a national public education/engagement campaign and they are essential in leading such an effort. Although there is good reason for different organizations to provide their constituents with particularized information, it is essential that all those engaged in this reform effort speak with one voice and deliver the same core messages.

To accomplish this, an organization needs to assume responsibility for working with various organizations, learning from them what has been tried, what has worked, and what has not. A unified campaign should be developed that will be shared with all those committed to the goal of improving the lives of those who struggle to live with chronic pain.

The Pain Action Alliance to Implement a National Strategy (PAINS), a program of the Center for Practical Bioethics, has stepped forward and offered to assume this responsibility. The Center has leaders who have been recognized for their work to improve chronic pain treatment, and they have experience in coordinating national programs. The Center has invested significant resources and nearly two years in creating a group that could initiate a successful public education/engagement campaign that would benefit all the organizations involved, but most importantly improve the lives of the 100 million Americans who struggle with chronic pain.

For more information about PAINS, see Appendix D.

¹ The American Academy of Pain Medicine; http://www.painmed.org/patientcenter/facts_on_pain.aspx; accessed February 13, 2013.

² Tang, N.K., and C. Crane 2006. Suicidality in chronic pain: A review of the prevalence, risk factors and psychological links. *Psychological Medicine* 36 (5):575-586.

³ American Academy of Pain Medicine.

⁴ American Academy of Pain Medicine.

⁵ American Academy of Pain Medicine.

⁶ International Association for the Study of Pain; Global Year Against Acute Pain; 2010; http://www.iasp-pain.org/AM/Template.cfm?Section=Fact_Sheets3&Template=/CM/ContentDisplay.cfm&ContentID=11783; access February 13, 2013.

⁷ IASP

⁸ Elliott, Victoria Stagg; Influx of newly insured a prompt for practices to rethink patient flow; American Medical News; October 22, 2012; <http://www.ama-assn.org/amednews/2012/10/22/bil21022.htm>; accessed February 13, 2013.

⁹ Peterlin, B.L., et al Headache 50(1):52-62.

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¹⁶ Szalavitz, Maia; June 29, 2011.

¹⁷ Szalavitz, Maia; June 29, 2011.

Appendix A

Relieving Pain in America: A Blueprint for Transforming Prevention, Care, Education and Research

Chronic pain costs the nation up to \$635 billion each year in medical treatment and lost productivity. The *2010 Patient Protection and Affordable Care Act* required the Department of Health and Human Services (HHS) to enlist the IOM in examining pain as a public health problem.

In this report, the IOM offers a blueprint for action in transforming prevention, care, education, and research, with the goal of providing relief for people with pain in America. To reach the vast multitude of people with various types of pain, the nation must adopt a population-level prevention and management strategy. The IOM recommends that HHS develop a comprehensive plan with specific goals, actions, and timeframes. Better data are needed to help shape efforts, especially on the groups of people currently underdiagnosed and undertreated, and the IOM encourages federal and state agencies and private organizations to accelerate the collection of data on pain incidence, prevalence, and treatments. Because pain varies from patient to patient, healthcare providers should increasingly aim at tailoring pain care to each person's experience, and self-management of pain should be promoted. In addition, because there are major gaps in knowledge about pain across health care and society alike, the IOM recommends that federal agencies and other stakeholders redesign education programs to bridge these gaps. Pain is a major driver for visits to physicians, a major reason for taking medications, a major cause of disability, and a key factor in quality of life and productivity. Given the burden of pain in human lives, dollars, and social consequences, relieving pain should be a national priority.

The entire brief can be found at: <http://www.iom.edu/~media/Files/Report%20Files/2011/Relieving-Pain-in-America-A-Blueprint-for-Transforming-Prevention-Care-Education-Research/Pain%20Research%202011%20Report%20Brief.pdf>

Appendix B

Academic Consortium for Complementary and Alternative Health Care (<http://accahc.org/>)
American Academy of Family Physicians (<http://www.aafp.org>)
American Academy of Hospice and Palliative Care (<http://www.aahpm.org/>)
American Academy of Pain Medicine (<http://www.painmed.org/>)
American Academy of Pain Management (<http://www.aapainmanage.org/>)
American Association of Critical-Care Nurses (www.aacn.org)
American Association of Neurological Surgeons/Congress of Neurological Surgeons (Joint Pain Section) (<http://www.aans.org/>)
American Association of Nurse Anesthetists (<http://www.aana.com>)
American Cancer Society (<http://www.cancer.org/>)
American Chiropractic Association (www.acatoday.org)
American Chronic Pain Association (<http://www.theacpa.org/>)
American Dental Association (www.ada.org/)
American Medical Association (<http://www.ama-assn.org/>)
American Osteopathic Association, (www.osteopathic.org/)
American Pain Society (<http://www.americanpainsociety.org/>)
American Public Health Association (<http://www.apha.org/>)
American Society for Pain Management Nursing (<http://www.aspmn.org/>)
American Society on Aging (<http://www.asaging.org/>)
Arthritis Foundation (<http://www.arthritis.org/>)
Center for Practical Bioethics (www.practicalbioethics.org/)
Consortium for Academic Health Centers for Integrative Healthcare (www.imconsortium.org/)
Federation of State Medical Boards (www.fsmb.org/)
International Association for the Study of Pain (www.iasp-pain.org/)
LifeSource (www.yourlifesource.org/)
LIVESTRONG Foundation (www.livestrong.org/)
Mayday Fund (www.maydayfund.org/)
National Alliance for Hispanic Health (www.hispanichealth.org/)
National Community Pharmacists Association (www.ncpanet.org/)
National Fibromyalgia and Chronic Pain Association (www.fmcpaware.org/)
National Medical Association (www.nmanet.org/)
National Patient Advocate Foundation (www.npaf.org/)
National Pharmacists Association (www.npha.com/)
National Quality Forum (www.qualityforum.org/)
National Vulvodynia Association (www.nva.org/)
Pain and Policy Studies Group – University of Wisconsin (www.painpolicy.wisc.edu/)
People's Health Movement (www.phmovement.org/)
The American Geriatrics Society (<http://www.americangeriatrics.org/>)
TMJ Association (www.tmj.org/)
Western Pain Society (www.westernpainsociety.org/)

Appendix C

- What initiatives is YOUR organization currently conducting to address the IOM Report, *Relieving Pain in America*?
- Are you aware of other meaningful programs or initiatives in response to the Institute of Medicine's (IOM) Report, *Relieving Pain in America*?
- Are you aware of the Pain Action Alliance to Implement a National Strategy (PAINS) that was initiated in response to the IOM report?
- In your opinion, what are the barriers and challenges to moving the IOM recommendations forward?
- What public policies have thwarted more effective pain treatment? How can they be overcome?
- What government agencies are most likely to drive change in this area?
- Is there currently an effective model of integrative pain management, either in the public or private sector?
- In what way will the shift toward patient-centered, outcomes-based care facilitate a shift in the way chronic pain is treated?
- Has public policy regarding diversion and abuse opioids stifled a research-driven debate about pain among medical professionals? How can this be addressed?
- Based on the success of other public health initiatives, do you think a national campaign would be effective in educating the public?
- What is at the root of the cultural stigma/dismissive attitude toward individuals who suffer from chronic pain? And how can this be addressed?
- How can PAINS help to advance the "transformation in the way pain is perceived, judged and treated" called for in the IOM report?
- What key strategies would facilitate more pain research?
- Do you believe that an alliance that will convene and facilitate work to improve the treatment of pain is necessary and/or helpful to a social transformation in this area?
- Do you have any recommendations for the sequence of milestones that PAINS should aim for?
- What needs and interests would be important for you or your organization to realize during your participation?

Appendix D

The Pain Action Alliance to Implement a National Strategy (PAINS)

The Pain Action Alliance to Implement a National Strategy (PAINS) is an alliance of leaders in professional societies, patient advocacy organizations, policy groups, consumers, payers and the private sector working together toward a common vision and mission. It began in response to the Institute of Medicine Report, *Relieving Pain in America*, which was submitted to Congress on June 29, 2011.

PAINS will:

- develop a strategy to tell the stories of chronic pain sufferers that is compelling and tap into the emotional core of the issues involved to influence voters.
- support the development of multiple models of care.
- work with state primary care associations to integrate chronic pain treatment into medical homes.
- promote the replication of successful community-based programs such as Don't Take It Lying Down in Victoria, Australia, the DEA's Nationwide Prescription Drug Take-Back Day, Utah's Use Only as Directed, and LifeSource's Zero Unintentional Deaths.
- provide a mechanism and an infrastructure through which organizations committed to this common goal can work together to maximize the impact of their individual organizational efforts, engage in projects and initiatives too large for any one organization to assume, and combine strength in order to address and influence common concerns.

Collectively, participants of PAINS will:

- use their collective influence to engage governmental agencies (both state and federal) to respond to the IOM recommendations.
- educate the American public about the findings and recommendations in *Relieving Pain in America* and to engage them in reforming pain care.
- promote additional biomedical and social research regarding chronic pain.

Recognizing the tremendous changes that are transpiring in healthcare, PAINS is working to integrate bio-psychosocial pain care into efforts to create patient-centered medical homes and accountable care organizations. PAINS is also reaching out to other national coalitions and alliances involved in healthcare reform to encourage them to integrate improved pain care into their efforts and to learn how to support their work as well.

PAINS and many of those involved in this initiative believe that a new policy framework is necessary to improve care for those who live with chronic pain. Individuals who work in pharmaceutical companies and other corporate entities, including medical device companies, and third-party payers are involved with PAINS. The majority of those involved with PAINS, however, come from professional societies, patient advocacy groups, policy organizations, academic institutions and other organizations that are not-for-profit. PAINS is based on the belief that all those involved in the treatment of chronic pain must be "at the table" but that no group or organization will be allowed to have more influence or a stronger voice than do others.

Given the coming trends of an enormous influx of patients, the aging Baby Boomer generation and physician shortage, combined with the urgent and growing social and economic costs of chronic pain, the healthcare system is on a course set for implosion. Therefore, the PAINS strategy must be far-reaching. PAINS proposes to improve patient and public understanding of pain, federal agencies and other stakeholders through education programs, with an aim to foster an understanding among patients, the public, and healthcare providers that there are complex biological and psychosocial aspects to pain. PAINS will develop educational materials about the nature of pain, ways to use self-help strategies to prevent, cope with, and reduce pain, and about available treatments.