



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

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Committee on Advancing Pain Research, Care, and Education; Institute of Medicine

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## Summary<sup>1</sup>

*Acute and chronic pain affects large numbers of Americans, with approximately 100 million<sup>2</sup> U.S. adults burdened by chronic pain alone. The annual national economic cost associated with chronic pain is estimated to be \$560-635 billion. Pain is a uniquely individual and subjective experience that depends on a variety of biological, psychological, and social factors, and different population groups experience pain differentially. For many patients, treatment of pain is inadequate not just because of uncertain diagnoses and societal stigma, but also because of shortcomings in the availability of effective treatments and inadequate patient and clinician knowledge about the best ways to manage pain. Some answers will come from exciting new research opportunities, but changes in the care system also will be needed in order for patients' pain journeys to be shorter and more successful. In the committee's view, addressing the nation's enormous burden of pain will require a cultural transformation in the way pain is understood, assessed, and treated. This report provides recommendations intended to help achieve this transformation.*

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<sup>1</sup>This summary does not include references. Citations for the discussion presented in the summary appear in the subsequent report chapters.

<sup>2</sup> Because of a computational error, the initial publication of the report *Relieving Pain in America* contained an erroneous estimate of the number of adults who experience chronic pain in the United States. A re-analysis of the study by Tsang and colleagues (2008), as well as the independent assessment by Gaskins and Richards (Appendix C), yield an estimate of approximately 100 million U.S. adults who experience chronic pain and not 116 million as stated in the original report. The text of the report has been revised to show this corrected estimate.

Pain is a universal experience. Common chronic pain conditions affect approximately 100 million U.S. adults at a cost of \$560-635 billion annually in direct medical treatment costs and lost productivity. Pain's occurrence, severity, duration, response to treatment, and disabling consequences vary from person to person because pain, like other severe chronic conditions, is much more than a biological phenomenon and has profound emotional and cognitive effects. Pain can be mild and easily handled with over-the-counter medications; it can be acute and recede with treatment; it can be recurrent over months or years; or it can be chronic and debilitating, requiring almost constant attention and accommodation.

Many shortfalls in pain assessment and treatment persist despite humanity's intimate familiarity with pain throughout history, modern appreciation for the complexity of its origins and the diversity of its effects, and the not insubstantial risk that any one person may have serious or chronic pain at some point. In general, these shortfalls arise through gaps in policy, treatment, attitudes, education, and research. Why and how these gaps might be remedied was the focus of the Institute of Medicine's (IOM's) Committee on Advancing Pain Research, Care, and Education.

### **CHARGE TO THE COMMITTEE AND STUDY APPROACH**

Section 4305 of the 2010 Patient Protection and Affordable Care Act required the Secretary, Department of Health and Human Services (HHS), to enter into an agreement with the IOM for activities "to increase the recognition of pain as a significant public health problem in the United States." Accordingly, HHS, through the National Institutes of Health (NIH), requested that the IOM conduct a study to assess the state of the science regarding pain research, care, and education and to make recommendations to advance the field (see Chapter 1 for the committee's statement of task).

This report responds to the committee's charge by providing a blueprint for transforming the way pain is understood, assessed, treated, and prevented. It provides recommendations for improving the care of people who experience pain, the training of clinicians who treat them, and the collection of data on pain in the United States. The report does not provide an exhaustive review of the literature examining the science of pain and its diagnosis and treatment. Nor does the report present a clinical algorithm for the diagnosis and treatment of patients with pain. Rather, it describes the scope of the problem of pain and provides an overview of needs for care, education, and research. The committee's recommendations are based on both scientific evidence and expert judgment.

Several important underlying principles informed the committee's approach to its charge. These principles are presented in Box S-1.

### BOX S-1 Underlying Principles

- ***A moral imperative.*** Effective pain management is a moral imperative, a professional responsibility, and the duty of people in the healing professions.
- ***Chronic pain can be a disease in itself.*** Chronic pain has a distinct pathology, causing changes throughout the nervous system that often worsen over time. It has significant psychological and cognitive correlates and can constitute a serious, separate disease entity.
- ***Value of comprehensive treatment.*** Pain results from a combination of biological, psychological, and social factors and often requires comprehensive approaches to prevention and management.
- ***Need for interdisciplinary approaches.*** Given chronic pain's diverse effects, interdisciplinary assessment and treatment may produce the best results for people with the most severe and persistent pain problems.
- ***Importance of prevention.*** Chronic pain has such severe impacts on all aspects of the lives of its sufferers that every effort should be made to achieve both primary prevention (e.g., in surgery for a broken hip) and secondary prevention (of the transition from the acute to the chronic state) through early intervention.
- ***Wider use of existing knowledge.*** While there is much more to be learned about pain and its treatment, even existing knowledge is not always used effectively, and thus substantial numbers of people suffer unnecessarily.
- ***The conundrum of opioids.*** The committee recognizes the serious problem of diversion and abuse of opioid drugs, as well as questions about their long-term usefulness. However, the committee believes that when opioids are used as prescribed and appropriately monitored, they can be safe and effective, especially for acute, postoperative, and procedural pain, as well as for patients near the end of life who desire more pain relief.
- ***Roles for patients and clinicians.*** The effectiveness of pain treatments depends greatly on the strength of the clinician–patient relationship; pain treatment is never about the clinician's intervention alone, but about the clinician and patient (and family) working together.
- ***Value of a public health and community-based approach.*** Many features of the problem of pain lend themselves to public health approaches—concern about the large number of people affected, disparities in occurrence and treatment, and the goal of prevention cited above. Public health education can help counter the myths, misunderstandings, stereotypes, and stigma that hinder better care.

### THE NEED FOR A CULTURAL TRANSFORMATION IN THE WAY PAIN IS VIEWED AND TREATED

Pain serves a vital function as a warning sign of injury or infection, but once its warning role is over, continued pain is maladaptive. Chronic pain results in many changes in the peripheral and central nervous systems that aid in its per-

sistence. Because of those physiological changes, some types of chronic pain are diseases in their own right.

All people are at risk of chronic pain. It can come about with age (e.g., arthritis), from genetic predisposition (e.g., migraine), as a component of another chronic disease (e.g., cancer, heart disease), as a result of surgery (e.g., severed nerves), or following an injury (e.g., low back pain, neck pain). Pain is a uniquely individual, subjective experience. Why one person suffers an injury and reports modest pain and another with a similar injury reports serious pain depends on many factors: genetic characteristics, general health status and comorbidities, pain experiences from childhood on, the brain's processing system, the emotional and cognitive context in which pain occurs, and cultural and social factors.

Because pain often produces psychological and cognitive effects—anxiety, depression, and anger among them—interdisciplinary, biopsychosocial approaches are the most promising for treating patients with persistent pain. But for most patients (and clinicians), such care is a difficult-to-attain ideal, impeded by numerous structural barriers—institutional, educational, organizational, and reimbursement-related. Costly procedures often are performed when other actions should be considered, such as prevention, counseling, and facilitation of self-care, which are common features of successful treatment. In addition, adequate pain treatment and follow-up may be thwarted by a mix of uncertain diagnosis and societal stigma consciously or unconsciously applied to people reporting pain, particularly when they do not respond readily to treatment.

In the committee's view, remediating the mismatch between current knowledge and its application will require a cultural transformation in the way clinicians and the public view pain and its treatment. Understanding chronic pain as a disease means that it requires direct treatment, rather than being sidelined while clinicians attempt to identify some underlying condition that may have caused it. It also means that health professions education programs should include a substantial amount of learning about pain and its diversity, and that people with chronic pain should be recognized by family, employers, health insurers, and others as having a serious condition. It means that people with chronic pain have an important role to play in managing their disease in an informed, productive way. And finally, it means that the biomedical research community should pursue pain research with the same vigor expended on other serious and disabling chronic conditions.

## FINDINGS AND RECOMMENDATIONS

The findings and recommendations presented in this report revolve around a single conclusion:

*Chronic pain alone affects the lives of approximately 100 million Americans, making its control of enormous value to individuals and society. To reduce the impact of pain and the resultant suffering will require a transformation in how*

*pain is perceived and judged both by people with pain and by the health care providers who help care for them. The overarching goal of this transformation should be gaining a better understanding of pain of all types and improving efforts to prevent, assess, and treat pain.*

The committee's recommendations and the findings that support them fall into four areas that serve to structure the main chapters of the report: pain as a public health challenge, care of people with pain, education challenges, and research challenges.<sup>3</sup>

### **Pain as a Public Health Challenge**

Pain affects millions of Americans; contributes greatly to national rates of morbidity, mortality, and disability; and is rising in prevalence. Substantial disparities exist in the prevalence, seriousness, and adequate treatment of pain that affect the vulnerable populations of traditional public health concern. Pain exacts enormous costs both economically and in the toll it takes on people's lives. Analysis performed for the committee revealed that the annual economic cost of chronic pain in the United States is at least<sup>4</sup> \$560-635 billion. This estimate combines the incremental cost of health care (\$261-300 billion) and the cost of lost productivity (\$297-336 billion) attributable to pain. The federal Medicare program bears fully one-fourth of U.S. medical expenditures for pain; in 2008, this amounted to at least \$65.3 billion, or 14 percent of all Medicare costs. In total, federal and state programs—including Medicare, Medicaid, the Department of Veterans Affairs, TRICARE, workers' compensation, and others—paid out \$99 billion in 2008 in medical expenditures attributable to pain. Lost tax revenues due to productivity losses compound that expense.

***Finding 2-1. Pain is a public health problem.*** Pain is a significant public health problem. Chronic pain alone affects approximately 100 million U.S. adults. Pain reduces quality of life, affects specific population groups disparately, costs society at least \$560-635 billion annually (an amount equal to about \$2,000 for everyone living in the United States), and can be appropriately addressed through population health-level interventions.

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<sup>3</sup> The findings and recommendations are numbered according to the chapter of the report in which they appear. Thus, for example, recommendation 2-1 is the first recommendation in Chapter 2. Note that some of the findings and recommendations are presented here in abbreviated form. The full versions are included in the respective chapters.

<sup>4</sup> The \$560-635 billion range is a conservative estimate because it excludes the cost of pain affecting institutionalized individuals (including nursing home residents and corrections inmates), military personnel, children under age 18, and personal caregivers (such as spouses who miss work while caring for people with pain), as well as the lost productivity of workers younger than 24 and older than 65. The estimate also excludes the emotional cost of pain.

**Finding 2-2. More consistent data on pain are needed.** While it is known that pain affects millions of Americans, the committee acknowledges the lack of consistent data with which to describe the nature and extent of the problem or to identify subpopulations that will benefit most from future interventions. Improvements in state and national data are needed to (1) monitor changes in the incidence and prevalence of acute and chronic pain; (2) document rates of treatment or undertreatment of pain; (3) assess the health and societal consequences of pain; and (4) evaluate the impact of related changes in public policy, payment, and care. Pain data need to be based on standardized questions, preferably using existing international standards, to facilitate comparisons over time and across populations. These data would be useful for a wide range of stakeholders, including policy makers, health care providers, health professions educators, professional licensing authorities, pain advocacy and awareness organizations, and researchers.

**Recommendation 2-1. Improve the collection and reporting of data on pain.** The National Center for Health Statistics, the Agency for Healthcare Research and Quality, other federal and state agencies, and private organizations should improve and accelerate the collection and reporting of data on pain. Data should be collected in the following domains:

- the incidence and prevalence of pain;
- interference with activities of daily living and work, as well as disability, related to pain;
- utilization of clinical and social services as a result of pain;
- costs of pain and pain care, including indirect costs of lost employment and public- and private-sector costs for disability payments; and
- the effectiveness of treatment in reducing pain and pain-related disability, determined through research on the comparative effectiveness of alternative treatments (including in different patient populations), to identify people most likely to benefit (or not) from specific treatment approaches.

Standardized questions, fields, and protocols for surveys and electronic health records should be developed, and pain-related data should be collected at regular intervals.

**Finding 2-3. A population-based strategy for reducing pain and its consequences is needed.** The committee finds that, to effect changes that will reach the millions of American adults living with pain, account for differences in the experience of pain among population groups, and address selected environmental

factors that contribute to the consequences of pain, a population health-level strategy is needed.

**Recommendation 2-2. Create a comprehensive population health-level strategy for pain prevention, treatment, management, and research.** The Secretary of the Department of Health and Human Services should 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. This strategy should

- Describe how efforts across government agencies, including public–private partnerships, can be established, coordinated, and integrated to encourage population-focused research, education, communication, and community-wide approaches that can help reduce pain and its consequences and remediate disparities in the experience of pain among subgroups of Americans.
- Include an agenda for developing physiological, clinical, behavioral, psychological, outcomes, and health services research and appropriate links across these domains (consistent with Recommendations 5-1 through 5-4).
- Improve pain assessment and management programs within the service delivery and financing programs of the federal government.
- Proceed in cooperation with the Interagency Pain Research Coordinating Committee and the National Institutes of Health’s Pain Consortium and reach out to private-sector participants as appropriate.
- Involve the relevant federal agencies and departments (National Institutes of Health, Centers for Disease Control and Prevention, Food and Drug Administration, Centers for Medicare and Medicaid Services, Agency for Healthcare Research and Quality, Health Resources and Services Administration, Indian Health Service, Department of Defense, and Department of Veterans Affairs); private-sector entities (pain advocacy and awareness organizations; health professions associations; health care providers; health professions educators; private insurers; and accreditation, certification, and examination organizations); and state-level entities.
- Include ongoing efforts to enhance public awareness about the nature of chronic pain and the role of self-care in its management.

The development of this strategy should be completed by the end of 2012.



### Care of People with Pain

Currently, large numbers of Americans receive inadequate pain prevention, assessment, and treatment, in part because of financial incentives that work against the provision of the best, most individualized care; unrealistic patient expectations; and a lack of valid and objective pain assessment measures. Clinicians' role in chronic pain care is often a matter of guiding, coaching, and assisting patients with day-to-day self-management, but many health professionals lack training in how to perform this support role, and there is little reimbursement for their doing so. Primary care is often the first stop for patients with pain, but primary care is organized in ways that rarely allow clinicians time to perform comprehensive patient assessments. Sometimes patients turn to, or are referred to, pain specialists or pain clinics, although both of these are few in number. Unfortunately, patients often are not told, or do not understand, that their journey to find the best combination of treatments *for them* may be long and full of uncertainty.

***Finding 3-1. Pain care must be tailored to each person's experience.*** Pain management takes place through self-management, primary care, specialty care, and pain centers. However, the majority of care and management should take place through self-management and primary care, with specialty services being focused on recalcitrant or more complex cases. Accordingly, individualization of pain management is necessary throughout the health care system. Health care providers need to foster pain care that is patient-centered and, when necessary, comprehensive and interdisciplinary. Financing, referral, records management, and other systems need to support this flexibility.

#### **Recommendation 3-1. Promote and enable self-management of pain.**

Health care provider organizations should take the lead in developing educational approaches and materials for people with pain and their families that promote and enable self-management. These materials should include information about the nature of pain; ways to use self-help strategies to prevent, cope with, and reduce pain; and the benefits, risks, and costs of various pain management options. Approaches and materials should be culturally and linguistically appropriate and available in both electronic and print form.

***Finding 3-2. Significant barriers to adequate pain care exist.*** The committee finds that multiple and significant barriers to pain care and management exist in the primary care setting.

- Enhanced continuing education and training are needed for health care professionals to address gaps in knowledge and competencies related to pain assessment and management, cultural attitudes about pain, negative

and ill-informed attitudes about people with pain, and stereotyping and biases that contribute to disparities in pain care.

- Other barriers include the magnitude of the pain problem, including its extremely high prevalence, which makes effective action difficult on a national scale; certain provider attitudes and training, which impede the delivery of high-quality care; insurance coverage, because fully one-third of all Americans are uninsured or underinsured; cultural attitudes of patients, many of whom do not recognize the need to address pain early on; and geographic barriers, which place residents of rural communities at a disadvantage.
- System and organizational barriers, many of them driven by current reimbursement policies, obstruct patient-centered care. Examples of these barriers are minimal capacity for frequent visits when necessary; limited time for conduct of comprehensive assessments; inadequate patient education initiatives; difficulties in accessing specialty care; and lack of reimbursement for needed specialty care services, interdisciplinary practice, psychosocial and rehabilitative services, in-depth patient interviews and education, and time spent planning and coordinating care.
- A comprehensive, strategic approach can succeed in addressing these barriers and help close the gap between empirical evidence regarding the efficacy of pain treatments and current practice.
- Regulatory, legal, educational, and cultural barriers inhibit the medically appropriate use of opioid analgesics.

**Recommendation 3-2. Develop strategies for reducing barriers to pain care.** The population health-level strategy referred to in Recommendation 2-2 should include identifying and developing comprehensive approaches to overcoming existing barriers to pain care, especially for populations that are disproportionately affected by and undertreated for pain. Strategies also should focus on ways to improve pain care for these groups.

**Recommendation 3-3. Provide educational opportunities in pain assessment and treatment in primary care.** Health professions education and training programs, professional associations, and other groups that sponsor continuing education for health professionals should develop and provide educational opportunities for primary care practitioners and other providers to improve their knowledge and skills in pain assessment and treatment, including safe and effective opioid prescribing.

**Recommendation 3-4. Support collaboration between pain specialists and primary care clinicians, including referral to pain centers when appropriate.** Pain specialty professional organizations and primary care professional associations should work together to support the collabora-

tion of pain specialists with primary care practitioners and teams when primary care providers have exhausted their expertise and the patient's pain persists.

**Recommendation 3-5. Revise reimbursement policies to foster coordinated and evidence-based pain care.** Payers and health care organizations should work to align payment incentives with evidence-based assessment and treatment of pain. Optimal care of the patient should be the focus.

**Recommendation 3-6. Provide consistent and complete pain assessments.** Health care providers should provide pain assessments that are consistent and complete and documented so that patients will receive the right care at the right place and the right time.

### Education Challenges

The optimal timing, content, and goals of patient education about pain vary with individual circumstances. Fundamental to treatment is education regarding self-management to minimize flare-ups, decrease day-to-day discomfort, and maximize functioning. In addition, public education about pain can be highly beneficial in promoting

- individual and community actions to prevent injuries,
- advocacy for appropriate acute and chronic pain treatment, and
- support for improved pain prevention and control policies.

Educational programs for the many types of health care professionals who play a role in pain prevention and treatment—nurses, psychologists, physicians, dentists, pharmacists, physical therapists, and complementary and alternative medicine practitioners—vary in the amount and quality of information on pain they contain. In medical education, pain generally has received little attention, which has contributed to the problem of undertreatment. The need for improved education about pain is especially acute for primary care providers—the front-line clinicians for most people's acute or chronic pain problems.

***Finding 4-1. Education is a central part of the necessary cultural transformation of the approach to pain.*** The committee finds that the federal government is in a position to contribute to substantial improvements in patient and professional education about pain.

**Recommendation 4-1. Expand and redesign education programs to transform the understanding of pain.** Federal agencies and other

relevant stakeholders should expand education programs to transform patient and public understanding of pain. In concert with Recommendation 2-2, federal agencies, in partnership with health professions associations, payers, pain advocacy and awareness organizations, and other relevant stakeholders, should develop education programs for patients, the public, and health care providers that are designed to promote a transformation in their expectations, beliefs, and understanding about pain, its consequences, its management, and its prevention.

**Recommendation 4-2. Improve curriculum and education for health care professionals.** The Centers for Medicare and Medicaid Services, the Health Resources and Services Administration, accrediting organizations, and undergraduate and graduate health professions training programs should improve pain education curricula for health care professionals.

**Recommendation 4-3. Increase the number of health professionals with advanced expertise in pain care.** Educational programs for medical, dental, nursing, mental health, physical therapy, pharmacy, and other health professionals who will participate in the delivery of pain care should have increased capacity to train providers who can offer advanced pain care.

### Research Challenges

In recent years, biomedical research has made remarkable strides in understanding of the basic biological and psychological underpinnings of pain. A principal current opportunity may be to use what has been learned across a broad spectrum of fields—from genomic and cellular through behavioral mechanisms—to develop innovative therapies that are simultaneously more targeted to the individual and more comprehensive in meeting patient needs.

From a scientific standpoint, the future of pain research is exciting because of advances in a number of relevant and diverse research fields and the development of new research techniques. This excitement is tempered, however, by knowledge that federal research dollars to address the problem of pain are in short supply and likely to decrease. Pain is a topic of interest to virtually every NIH institute and center, but not a central concern of any one of them. The committee believes one of the existing NIH institutes should be designated the lead institute for pain. The committee further believes that the NIH Pain Consortium needs to take a stronger leadership role in effecting the necessary transformation in how pain research is conducted by fostering coordination across institutes and centers, by ensuring that study section decision making on pain proposals is improved, and by exploring a range of potential public–private initiatives.

Pain research should not be confined to NIH. As this report details, pain-related research is needed across public health entities, involving, for example, the Centers for Disease Control and Prevention's epidemiological and public education expertise, the Agency for Healthcare Research and Quality's quality improvement initiatives, the Health Resources and Services Administration's expertise in professional education and service delivery for vulnerable populations, and the Centers for Medicare and Medicaid Services' research and demonstration programs related to reimbursement policies.

***Finding 5-1. Research to translate advances into effective therapies for pain is a continuing need.*** The committee finds that significant advances have been made in understanding the basic mechanisms of nociception and pain, leading to new potential targets for future pain assessment and treatment strategies. Furthermore, recent advances in the neurosciences, biomarkers, and the behavioral sciences have validated a comprehensive approach to the management of pain that includes the individual's inherent biology, behavior, and psychological makeup and reactions, as well as environmental influences. However, data and knowledge gaps in pain research remain that have prevented such research advances from being translated into safe and effective therapies. Addressing these gaps will require a cultural transformation in the view of and approach to pain research, involving basic, translational, and clinical researchers; federal funding and regulatory agencies; and private organizations. This cultural transformation is reflected in the following recommendations.

**Recommendation 5-1. Designate a lead institute at the National Institutes of Health responsible for moving pain research forward, and increase the support for and scope of the Pain Consortium.**

The National Institutes of Health should designate a specific institute to lead efforts in advancing pain research. At the same time, the National Institutes of Health should increase financial resources and staffing support for and broaden the scope of the Pain Consortium and engage higher-level staff from the institutes and centers in the consortium's efforts. The Pain Consortium should exert more proactive leadership in effecting the necessary transformation in how pain research is conducted and funded.

**Recommendation 5-2. Improve the process for developing new agents for pain control.** Academia and industry should develop novel agents for the control of pain. This does not mean simply recycling current drugs. What is required is basic and clinical science research to discover new classes of pain therapeutics and more efficient ways of developing them. Also required is that regulatory agencies, especially the Food and Drug

Administration, develop new and expeditious ways to evaluate and improve new pain therapies.

**Recommendation 5-3. Increase support for interdisciplinary research in pain.** Federal agencies, such as the National Institutes of Health, Agency for Healthcare Research and Quality, Centers for Disease Control and Prevention, Department of Defense, and Department of Veterans Affairs, as well as private funders of pain research, should increase support for interdisciplinary research and research training—across agencies and professions—on pain-related diseases and the deficiencies noted in Finding 5-1.

**Recommendation 5-4. Increase the conduct of longitudinal research in pain.** Public and private funders should increase support for longitudinal research in pain, including comparative effectiveness research and novel randomized controlled trials, to help ensure that patients receive care that works best in both the short and long terms.

**Recommendation 5-5. Increase the training of pain researchers.** With the support of training grants from the National Institutes of Health, academic institutions should increase the training of basic, translational, behavioral, population, and clinical pain researchers. This training should recognize the interdisciplinary benefits of research on pain and pain management. Agencies such as the National Center for Health Statistics, the Agency for Healthcare Research and Quality, and the Centers for Medicare and Medicaid Services should support the training of researchers interested in secondary analysis of pain-related data collected by these agencies.

## CONCLUSION

With the goal of providing relief for pain in America, the committee concludes this report by offering a blueprint for action toward transforming prevention, care, education, and research (Chapter 6 and Table S-1 below). This blueprint organizes the committee's recommendations into two categories. Recommendations categorized as immediate are those the committee believes should be initiated now and completed before the end of 2012. Recommendations categorized as near-term and enduring build on these immediate actions, should be completed before the end of 2015, and should be maintained as ongoing efforts. The comprehensive population health-based strategy set forth in Recommendation 2-2 should inform actions taken in response to, or consistent with, all of the other recommendations.

**TABLE S-1<sup>a</sup>** Blueprint for Transforming Pain Prevention, Care, Education, and Research

<i>IMMEDIATE: Start now and complete before the end of 2012</i>		
<b>Recommendation</b>	<b>Actors</b>	<b>Key Elements of Recommendation</b>
<b>2-2. Create a comprehensive population health-level strategy for pain prevention, treatment, management, and research</b>	Secretary of Health and Human Services (HHS)	Involve multiple federal, state, and private-sector entities, such as the National Institutes of Health (NIH), Food and Drug Administration (FDA), Centers for Disease Control and Prevention (CDC), Agency for Healthcare Research and Quality (AHRQ), Health Resources and Services Administration (HRSA), Centers for Medicare and Medicaid Services (CMS), Department of Defense (DoD), Department of Veterans Affairs (VA), outcomes research community and other researchers, credentialing organizations, pain advocacy and awareness organizations, health professions associations (including pain specialty professional organizations), private insurers, health care providers, state health departments, Medicaid programs, and workers' compensation programs
<b>3-2. Develop strategies for reducing barriers to pain care</b>	HHS Secretary, AHRQ, CMS, HRSA, Surgeon General, Office of Minority Health, Indian Health Service, VA, DoD, large health care providers (e.g., accountable care organizations)	Key part of the strategy envisioned in Recommendation 2-2
<b>3-4. Support collaboration between pain specialists and primary care clinicians, including referral to pain centers when appropriate</b>	CMS, VA, DoD, health care providers, pain specialists, pain centers, primary care practitioners, pain specialty professional organizations, primary care professional associations, private insurers	The pain specialist role includes serving as a resource for primary care practitioners

TABLE S-1 Continued

Recommendation	Actors	Key Elements of Recommendation
<b>5-1. Designate a lead institute at the National Institutes of Health responsible for moving pain research forward, and increase the support for and scope of the Pain Consortium</b>	NIH	Involve pain advocacy and awareness organizations; foster public–private partnerships
<i>NEAR-TERM AND ENDURING: Build on immediate recommendations, complete before the end of 2015, and maintain as ongoing efforts</i>		
Recommendation	Actors	Key Elements of Recommendation
<b>2-1. Improve the collection and reporting of data on pain</b>	National Center for Health Statistics (NCHS) (part of CDC), AHRQ, CMS, VA, DoD, state and local health departments, private insurers, outcomes research community, other researchers, large health care providers, designers of electronic medical records	Based on Recommendation 2-2; foster public–private partnerships; includes subpopulations at risk for pain and undertreatment of pain, characteristics of acute and chronic pain, and health consequences of pain (morbidity, mortality, disability, related trends)
<b>3-1. Promote and enable self-management of pain</b>	Health professions associations (including pain specialty professional organizations), pain advocacy and awareness organizations, health care providers	Requires the development of better and more evidence-based patient education products
<b>3-3. Provide educational opportunities in pain assessment and treatment in primary care</b>	CMS, VA, DoD, graduate medical education (GME) and continuing medical education (CME) primary care programs (backed by accreditation, licensure, and certification authorities and examiners), nurse practitioner and physician assistant training programs, researchers, health care providers	Improved health professions education requires a stronger evidence base on clinical effectiveness and more interdisciplinary training and care

*continued*



TABLE S-1 Continued

Recommendation	Actors	Key Elements of Recommendation
<b>3-5. Revise reimbursement policies to foster coordinated and evidence-based pain care</b>	CMS, VA, DoD, Medicaid programs, private insurers, health care providers, health professions associations (including pain specialty professional organizations), pain advocacy and awareness organizations	Requires the development of more evidence on clinical effectiveness and collaboration between payers and providers
<b>3-6. Provide consistent and complete pain assessments</b>	Health care providers, primary care practitioners, pain specialists, other health professions, pain clinics and programs, World Health Organization (WHO)	WHO should add pain to the <i>International Classification of Diseases</i> , Tenth Edition (ICD-10)
<b>4-1. Expand and redesign education programs to transform the understanding of pain</b>	FDA, CDC, AHRQ, CMS, Surgeon General, DoD, VA, pain advocacy and awareness organizations, health professions associations (including pain specialty professional organizations), private insurers, health care providers	Focus is on patient education and public education; includes pain prevention
<b>4-2. Improve curriculum and education for health care professionals</b>	CMS, HRSA Bureau of Health Professions, accrediting organizations, <sup>b</sup> undergraduate and graduate health professions training programs (backed by licensure and certification authorities and examiners)	CMS's role is that of payer for GME; include interdisciplinary training
<b>4-3. Increase the number of health professionals with advanced expertise in pain care</b>	Pain medicine fellowship programs and graduate education programs in dentistry, nursing, psychology and other mental health fields, rehabilitation therapies, pharmacy, and other health professions	Requires more effort to attract young health professionals to pain programs; also requires collaboration between educators and clinicians

TABLE S-1 Continued

Recommendation	Actors	Key Elements of Recommendation
<b>5-2. Improve the process for developing new agents for pain control</b>	FDA, NIH, pharmaceutical manufacturing and research industry, academically based biomedical research community, private funders of pain research	Based on Recommendation 5-1; involves developing new and faster ways to evaluate and approve new pain therapies, e.g., novel forms of patient stratification in clinical trials and novel investigative endpoints
<b>5-3. Increase support for interdisciplinary research in pain</b>	NIH, AHRQ, CDC, DoD, VA, pharmaceutical manufacturing and research industry, private funders of pain research, academically based biomedical research community, pain advocacy and awareness organizations	Based on Recommendation 5-1; basic, translational, and clinical studies should involve multiple agencies and disciplines; focus on knowledge gaps
<b>5-4. Increase the conduct of longitudinal research in pain</b>	NIH, AHRQ, CDC, DoD, VA, pharmaceutical manufacturing and research industry, Patient-Centered Outcomes Research Institute, private funders of pain research, academically based biomedical research community, outcomes research community, pain advocacy and awareness organizations	Based on Recommendation 5-1; includes translational, population health, and behavioral aspects of pain care (social and multimodal aspects, not just medications and other single modalities); focus is on real-world situations (comparative effectiveness, not just efficacy); foster public–private partnerships
<b>5-5. Increase the training of pain researchers</b>	NIH, NCHS, AHRQ, CMS, academic medical institutions	Includes more interdisciplinary training

<sup>a</sup> The committee prepared this table based on the recommendations but with a focus on their implementation. The table lists a range of potential actors and key elements of each recommendation.

<sup>b</sup> Accrediting organizations include the Liaison Committee on Medical Education, Commission on Osteopathic College Accreditation, Accreditation Council for Graduate Medical Education, Commission on Dental Accreditation, Commission on Collegiate Nursing Education, National League for Nursing Accreditation Commission, American Psychological Association Committee on Accreditation, Council on Education for Public Health, Council on Social Work Education, and Council for Higher Education Accreditation (Perez et al., 2007).



# Relieving **PAIN** in America

## **A Blueprint for Transforming Prevention, Care, Education, and Research**

Committee on Advancing Pain Research, Care, and Education

Board on Health Sciences Policy

INSTITUTE OF MEDICINE  
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The serpent has been a symbol of long life, healing, and knowledge among almost all cultures and religions since the beginning of recorded history. The serpent adopted as a logotype by the Institute of Medicine is a relief carving from ancient Greece, now held by the Staatliche Museen in Berlin.

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Willing is not enough; we must do.”*  
—Goethe



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This report has been reviewed in draft form by individuals chosen for their diverse perspectives and technical expertise, in accordance with procedures approved by the National Research Council's Report Review Committee. The purpose of this independent review is to provide candid and critical comments that will assist the institution in making its published report as sound as possible and to ensure that the report meets institutional standards for objectivity, evidence, and responsiveness to the study charge. The review comments and draft manuscript remain confidential to protect the integrity of the deliberative process. We wish to thank the following individuals for their review of this report:

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Although the reviewers listed above have provided many constructive comments and suggestions, they were not asked to endorse the conclusions or recommendations nor did they see the final draft of the report before its release. The review of this report was overseen by **Caswell A. Evans** and **Elaine L. Larson**. Appointed by the National Research Council and Institute of Medicine, they were responsible for making certain that an independent examination of this report was carried out in accordance with institutional procedures and that all review comments were carefully considered. Responsibility for the final content of this report rests entirely with the authoring committee and the institution.

## Preface

Protection from and relief of pain and suffering are a fundamental feature of the human contract we make as parents, partners, children, family, friends, and community members, as well as a cardinal underpinning of the art and science of healing. Pain is part of the human condition; at some point, for short or long periods of time, we all experience pain and suffer its consequences. While pain can serve as a warning to protect us from further harm, it also can contribute to severe and even relentless suffering, surpassing its underlying cause to become a disease in its own domains and dimensions. We all may share common accountings of pain, but in reality, our experiences with pain are deeply personal, filtered through the lens of our unique biology, the society and community in which we were born and live, the personalities and styles of coping we have developed, and the manner in which our life journey has been enjoined with health and disease.

The personal experience of pain is often difficult to describe, and the words we choose to describe pain rarely capture its personal impact, whether it is sudden and limited or persists over time. Severe or chronic pain can overtake our lives, having an impact on us as individuals as well as on our family, friends, and community. Through the ages, pain and suffering have been the substrates for great works of fiction, but the reality of the experience, especially when persistent, has little redeeming or romantic quality. The personal story of pain can be transformative or can blunt the human values of joy, happiness, and even human connectedness.

As a physician and a public health professional, we have experienced pain in different ways, but we also share a common bond of experience with those we have cared for professionally or personally. Those experiences shaped the way we approached the request of the Institute of Medicine (IOM) to co-chair a committee to assess the impact of pain in America. Our experiences extend from

the care of individuals to evaluation of health and disease in populations, and we were joined by an outstanding group of individuals with deep knowledge of the biological, psychosocial, ethical, legal, clinical, and deeply personal aspects of pain and suffering. Over an intense 5-month period, we shared facts and figures, perceptions and realities, knowledge and assumptions, and listened carefully to each other and to the dozens of individuals and groups who provided testimony at our public meetings, as well as the thousands who shared their stories, hopes, disappointment, and anger in their written comments and testimonials. Throughout this process, we received extraordinary support from the IOM—especially from Adrienne Stith-Butler and Thelma Cox. We also benefited from the writing skills of Victoria and Neal Weisfeld. We have been enriched by all these experiences and encounters and have tried to respond to the pleas of many for recognition, understanding, and help. While we came to this study with our own expectations, we have recognized as a consequence of our shared efforts that the magnitude of the pain suffered by individuals and the associated costs constitute a crisis for America, both human and economic. We recognize further that approaching pain at both the individual and the broader population levels will require a transformation in how Americans think and act individually and collectively regarding pain and suffering. We believe this transformation represents a moral and national imperative.

Our conclusions are consonant with our individual life journeys. One of us spent decades as a pediatric oncologist and clinical scientist focused on children with catastrophic diseases. Pain and suffering were natural extensions of these disease processes and evoked sympathy and compassion from health care providers, families, and communities. But those experiences also made clear that while pain can often be controlled, it frequently cannot be eliminated, and when that is the case, it becomes more dominant for the individual than her or his underlying disease.

It also became clear that when pain could be ascribed to an underlying disease, such as cancer, it was accepted as real and treated with concern. The validation of disease made the pain socially acceptable, not shunned by the health care system or by families and communities. However, when as a pediatric oncologist one of us also experienced chronic pain in a family member whose underlying disease was less well defined, the cultural perception of and response to the pain by the health care community was dramatically different. Reactions ranged from care and compassion to judgmental opinions that lacked compassion and sometimes devolved into blaming or personalization of responsibility. The lack of a defined disease made the symptoms of pain and suffering less acceptable and more ascribed to overreaction, emotional instability, or worse. Because the pain could not be seen or measured “objectively” or interpreted within the context of the known, it was more likely to be dismissed, diminished, or avoided. The irony is that this pain and suffering, just like that of the patient with a known disease, could be life dominant—a disease in its own right.

As a behavioral scientist, one of us has worked for years with individuals, families, and communities that are trying to manage chronic disease effectively. This personal journey has made clear that for people who must deal with a heart condition, a digestive disease, a rheumatic condition, or a similar problem, pain can be a persistent companion. It can exacerbate depression, produce fatigue, hamper functioning, and diminish quality of life. It can create stress and extract high psychic and material costs in families. It also can lead to the development of unexpected personal strengths and an astonishing capacity to prevail. However, pain is a fearsome way to develop such qualities. Control of pain, and of the disease that often accompanies it, depends on the ability of individuals to garner information and assistance, of family members to give productive help, of clinicians to explore many options, and of communities to create systems to support families and clinicians. Most people living with pain, however, are not cosseted in this way, and we are woefully lacking in understanding how to offer them with the help they need or, when we do understand, in the capacity to provide it.

This is not to say that the medical community is uncaring and unwilling to help people with pain. But health care providers are subject to bias, limitations in knowledge, and differences in the systems in which they work. They are eager for new solutions and new insights, particularly with respect to chronic pain when a defined cause is lacking. Unfortunately, many health care providers lack a comprehensive perspective on pain and not infrequently interpret the suffering of others through their own personal lens. Misjudgment or failure to understand the nature and depths of pain can be associated with serious consequences—more pain and more suffering—for individuals and our society.

Our committee recognizes the need for a transformed understanding of pain. We believe pain arises in the nervous system but represents a complex and evolving interplay of biological, behavioral, environmental, and societal factors that go beyond simple explanation. Knowledge of pain needs to be enriched from the molecular and genetic to the cellular, neural network, and systems levels. It is necessary to understand how the settings and surroundings in which pain occurs and is experienced have an impact on its biology. The committee recognizes the need for new tools and metrics with which to define, diagnose, and monitor pain and its consequences, as well as for new approaches to treatment and prevention that are likely to result from novel and more interdisciplinary approaches to research. We see a need for better ways to develop, evaluate, and make available new approaches to pain management more rapidly and expeditiously. We also see the importance of approaching the individual within the broader domain of cultural diversity and of recognizing the subpopulations that are most affected by chronic pain and develop strategies to address their needs. We believe it is necessary to understand better the link between acute and chronic pain and find ways to break that link. We recognize the need to develop ever more informed health care professionals, working individually and in teams, in rural and urban settings, to address pain in the communities they serve. We believe it is neces-

sary to understand better the true impact of pain on the workforce, our families, and the broader population and seek ways to lessen that impact. Meeting these challenges will require a cultural transformation in the way pain is perceived and managed on both the personal and societal levels.

The committee worked diligently to develop this report in an objective manner based on evidence. In doing so, we became acutely aware of the limitations of existing knowledge and the data on which it is based. We learned from our deliberations that there is crisis in the impact of and response to pain in America. Individually and collectively, we have a moral imperative to address this crisis. It is our hope that this report will help stimulate a concerted response to this crisis.

Philip A. Pizzo, *Chair*  
Noreen M. Clark, *Vice Chair*  
Committee on Advancing Pain Research, Care, and Education

## Acknowledgments

Many individuals and organizations made important contributions to the study committee's process and to this report. The committee wishes to thank these individuals, but recognizes that attempts to identify all and acknowledge their contributions would require more space than is available in this brief section.

To begin, the committee would like to thank the sponsors of this report. Funds for the committee's work were provided by the U.S. Department of Health and Human Services, National Institutes of Health. The committee thanks Amy B. Adams, who served as project officer, for her assistance during the study process.

The committee gratefully acknowledges the contributions of the many individuals who provided valuable input to its work. These individuals helped the committee understand varying perspectives on pain research, care, and education. The committee thanks those who provided important information and data at its open workshops. Appendix A lists these individuals and their affiliations. As part of its work, the committee received written testimony from thousands of individuals and organizations. This testimony helped the committee understand the experiences of persons living with pain and their family members, as well as health care providers, and the perspectives of many stakeholder organizations. Appendix B provides a summary of this input. The committee is grateful for the time, effort, and valuable information provided by all of these dedicated individuals.

The committee would like to thank the authors whose commissioned paper added to the evidence base for this study. These include Darrell J. Gaskin, Johns Hopkins Bloomberg School of Public Health, and Patrick Richard, The George



Washington University School of Public Health and Health Services. Finally, the committee thanks individuals who assisted in its work by providing data. The committee acknowledges Jennifer Madans, Charlotte Schoenborn, Vicki Burt, and colleagues from the National Center for Health Statistics, and Kevin Galloway, Army Pain Task Force.

# Contents

<b>SUMMARY</b>	<b>1</b>
Charge to the Committee and Study Approach, 2	
The Need for a Cultural Transformation in the Way Pain Is Viewed and Treated, 3	
Findings and Recommendations, 4	
Conclusion, 13	
<b>1 INTRODUCTION</b>	<b>19</b>
Study Context and Charge to the Committee, 20	
Study Approach and Underlying Principles, 20	
What Is Pain?, 24	
Who Is at Risk?, 26	
Impact of Pain on Physical and Mental Health, 31	
A Typology of Pain, 32	
What Causes Pain, and Why Does It Sometime Persist?, 34	
The Need for a Cultural Transformation, 44	
Organization of the Report, 49	
References, 49	
<b>2 PAIN AS A PUBLIC HEALTH CHALLENGE</b>	<b>55</b>
Scope of the Problem, 59	
Disparities in Prevalence and Care in Selected Populations, 64	
The Seriousness of Pain, 85	
The Costs of Pain and Its Treatment, 91	
Potential Roles for Public Health, 95	

Findings and Recommendations, 100	
References, 103	
<b>3 CARE OF PEOPLE WITH PAIN</b>	<b>113</b>
Treatment Overview, 115	
Treatment Modalities, 129	
Selected Issues in Pain Care Practice, 137	
Barriers to Effective Pain Care, 153	
Models of Pain Care, 158	
Conclusion, 161	
Findings and Recommendations, 161	
References, 165	
<b>4 EDUCATION CHALLENGES</b>	<b>179</b>
Patient Education, 180	
Public Education, 184	
Physician Education, 190	
Nurse Education, 201	
Other Health Professions Education, 204	
Conclusion, 209	
Findings and Recommendations, 209	
References, 210	
<b>5 RESEARCH CHALLENGES</b>	<b>217</b>
Expanding Basic Knowledge, 220	
Moving from Research to Practice, 224	
Improving and Diversifying Research Methods, 228	
Building the Research Workforce, 238	
Organizing Research Efforts, 239	
Obtaining Federal Research Funding, 244	
Fostering Public–Private Partnerships, 245	
Findings and Recommendations, 250	
References, 254	
Annex 5-1, 259	
<b>6 A BLUEPRINT FOR TRANSFORMING PAIN PREVENTION, CARE, EDUCATION, AND RESEARCH</b>	<b>269</b>
Reference, 271	
<b>GLOSSARY</b>	<b>277</b>

*CONTENTS*

*xvii*

**APPENDIXES**

A	Data Sources and Methods	281
B	Summary of Written Public Testimony	293
C	The Economic Costs of Pain in the United States	301
D	Committee and Staff Biographies	339

<b>INDEX</b>	<b>349</b>
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