



Canadian Consortium
on Pain Mechanisms
Diagnosis and
Management

REPORT

of the Canadian Consortium on Pain Mechanisms Diagnosis and Management

Defining the Research Agenda for Pain in Canada

2001

submitted by:

James L. Henry, Ph.D., Project Leader

Professor of Physiology

Professor of Psychiatry

McGill University

tel. (514) 398-6003

CONTENTS

<u>EXECUTIVE SUMMARY</u>	p. 1 .
<u>1. BACKGROUND</u>	p. 4 .
<u>2. CONCEPT</u>	
p. 6 .	
2.1. Aims and objectives	
2.2. Purpose	
2.3. Keys to success	
2.4. Immediate goals	
2.5. Long-term vision	
<u>3. MARKET ANALYSIS</u>	p. 8 .
3.1. The pain experience in Canada	
3.1.1. The scope of the problem	
3.1.2. Acute pain	
3.1.3. Chronic non-cancer pain	
3.1.4. Cancer pain	
3.1.5. Society and Government Initiatives	
3.1.6. Research initiatives	
3.1.7. Will our past approach be adequate for the future?	
3.2. Why an integrated approach?	
3.2.1. The gate theory.	
3.2.2. Animal models of pain.	
3.2.3. Social and behavioural models	
3.2.4. Clinical Sciences	
<u>4. OPPORTUNITIES</u>	p. 14.
4.1. Genomics, bioinformatics and computational biology	
4.2. Proteomics and cell biology	
4.3 Information technology	
4.4 Non-technological opportunities	
<u>5. ACTION PLAN</u>	p. 17.
5.1. The Consortium has already built some of what is needed	
5.2. The Consortium is currently building other things	
5.3. Other initiatives are also being undertaken	
5.4. Yet, much remains	
5.5. What is needed?	
<u>Appendix I</u> - Activities and achievements of the Consortium	p. 22.

<u>Appendix II</u> - Report of Task Force I – Infrastructure of the Consortium	p. 25.
<u>Appendix III</u> - Report of Task Force II – Pain Research and Management Strategies	p. 29.
<u>Appendix IV</u> - Report of Task Force III – Education and Training Initiatives	p. 32.
<u>Appendix V</u> - Report of Task Force IV - Knowledge Transfer	p. 35.
<u>Appendix VI</u> - Report of Task Force V – Interactions outside the Consortium	p. 39.
<u>Appendix VII</u> - Report of Task Force VI – Societal Issues	p. 42.

Executive Summary

Canadian Consortium on Pain Mechanisms, Diagnosis and Management

MISSION

The mission of this Consortium is to bring together Canada's leaders in this field in order to promote excellence in pain research. It will do so by maintaining permanent Task Forces whose aims will be to promote improved pain research training programs, to facilitate the evolution of improved methods of diagnosis and measurement, to encourage the application of up-to-date techniques of pain management and caregiving, and to provide an in-depth analysis of the specific types of pain impacting Canadians, the efficacy of new pain treatment approaches as they evolve, the effectiveness of health care services in pain throughout Canada and the specific impact of pain on Canadian society and its economy.

BACKGROUND

A Canadian pain research initiative was launched in 1999 through two national meetings in April of that year. This Consortium was one of the outcomes of these meetings. Canadians have traditionally been at the forefront of pain research, diagnosis and management. The pivotal "Gate Control Theory" of pain was co-authored in 1965 by Dr. Ron Melzack of McGill. The current President of the International Association for the Study of Pain is Dr. Barry Sessle, of the University of Toronto. The International Nomenclature Committee is chaired by Dr. Harold Merskey, of the University of Western Ontario. Canada has outstanding, world-class scientists in pain research, Canada is the world leader in treatment of pediatric pain and Canadians have been instrumental in the development of palliative care, neurostimulation, imaging and treatment of neuropathic pain. Efforts to promote research into mechanisms and into improving methods of diagnosis and management are of importance because pain and suffering confront all Canadians and, when unresolved, pain can have major personal, societal and economic costs.

The Consortium set up 6 Task Forces as permanent committees with the following respective mandates:

- I - *Infrastructure of the Consortium*, to oversee continuance of the Consortium,
- II - *Pain Research and Management Strategies*, to promote our identified strengths in pain research,
- III - *Education and Training Initiatives*, to broaden and strengthen training programs in the field of pain research,
- IV - *Knowledge Transfer to Pain Management*, to assemble information on pain research and management facilities in Canada and to circulate this information as widely as possible,
- V - *Interactions Outside Consortium*, to partner with other stakeholders in quality of life issues and to promote technology transfer in the field of pain,
- VI - *Societal Issues*, to promote epidemiological studies on pain in Canada and to apply the knowledge gained to health care and to policymaking at all levels.

Each Task Force has one or two chairpersons and a membership of 8-10 participants.

ACCOMPLISHMENTS DURING THE FIRST YEAR

The first Annual Meeting of the Consortium was held 13-15 November, 1999, in Montreal, with 36 members of the Consortium attending. Each Task Force drew up a specific list of recommendations. The detailed reports are found as appendices to this report.

The Consortium Executive Office set up a web site, www.curepain.ca, a listserv, curepain@lists.mcgill.ca, and an e-mail address, curepain@med.mcgill.ca, for information exchange. This Office also raised over \$70,000 in additional funds from industry partners to carry out its programs for the future. Two organizational meetings of the Task Force leaders were held, one 4-5 February, in Toronto, the other 14 May, in Calgary.

The investment by CIHR in establishing this Consortium resulted directly or indirectly in a number of other initiatives. Several collective grant applications were submitted, including two to the Canada Foundation for Innovation (both successful), and one grant to Parke-Davis (funded at \$120,000) to hold a meeting on neuropathic pain. Because of the early successes achieved by this Consortium a successful application was submitted by one of the members (Dr. Mary Lynch) to create the Canadian Consortium for the Study of Cannabinoids in Human Therapeutics. In addition, a proposal has been approved by the International Association for the Study of Pain to hold a satellite symposium in Montreal in association with the 2002 International Pain Congress in San Diego. This year has also seen the establishment of the Centre for the Study of Pain at the University of Toronto as well as the first steps to create a Centre for Research on Pain at McGill. The Quebec Pain Research Initiative has been established and a Canada-wide group has been struck, creating the National Strategy for Pain Management, to establish national programs including clinical research and trials as well as to establish a video-telecommunications network. Collectively, members of the Consortium hold a total of over \$13 million in annual research funds. There are more than 230 trainees in research groups of members, with a total income of over \$1.3 million annually. Members also attract almost \$1 million in team grants funds, over \$700 thousand in career awards programs and this year have obtained \$6.7 million in equipment grants.

IMMEDIATE FUTURE PROJECTS

For the second year of operation, in addition to the Annual Meeting of the Consortium, two Workshops are being planned, one on promoting technology transfer in the field of pain research, the other to set in place mechanisms to interact with industry to develop projects of common interest through shared expertise. A Travelling Speaker programme will be launched and initial work on developing a pain database has commenced. There will also be at least one organizational meeting of the Task Force Leaders to assess and assure progress on the spectrum of other projects being pursued.

MAJOR RECOMMENDATIONS

It was recognized that Canada has an exemplary international reputation in pain research. Yet, a number of common themes emerged from the individual reports of the six Task Forces. These are detailed in the Appendices to this report. This report reveals a number of strengths and weaknesses in pain research, diagnosis and management in Canada. While some additional work is required, Canada is generally strong in research on pain mechanisms and in generating biotechnology companies developing drugs and procedures to minimize pain. Canada is weak in setting, carrying out and monitoring standards of management, in epidemiology of pain and in promoting clinical trials on analgesics.

The Consortium members identified a number of ways in which pain research can be significantly improved in Canada, building on established strengths and buttressing areas of weakness. The deliberations did lead to a principal conclusion, that pain research in Canada is on a solid footing and that it operates from a number of important institutional frameworks. Canada has many world-renowned scientists working in the field, and it has produced and is still producing important contributions to the understanding of the problems associated with pain - medical, social, and economic. But a great deal more can be done. Our aim is to produce a truly multi-faceted approach to pain research involving a series of independent yet mutually reinforcing institutional frameworks in the interests of stimulating, supporting and encouraging the community.

Some of the needs identified by the various Task Forces can be met by institutions which already exist to serve the pain research community. However, an important structural weakness was identified, one which must be corrected if the long-term vision in this document is to be realised: *a central body must be created which is capable of promoting research into priority areas, which is capable of providing enhanced funding to support the training of new personnel and seed-funding for preliminary results in new, cross-cutting fields of pain research, and which is capable of taking the lead in coordinating the various interactions undertaken by the pain research community internally and externally.*

THE REPORT

This document is organized into a main text and a series of appendices. The main text serves to outline the vision of where the future of pain research lies – what new institutional frameworks are required, what coordination needs to be done, where operating procedures may need to be changed. *Appendix 1* provides a detailed summary of the Consortium's activities since its inception, the milestones which have been achieved, and the groundwork which has been laid for milestones to be achieved in the next twelve months. *Appendices 2-7* are the Reports prepared by the 6 permanent Task Forces which were struck by the Consortium to study and make recommendations upon broad-ranging areas relating to pain research. Each of these Reports includes a detailed set of recommendations of what is needed to advance their respective objectives in the short- and medium-terms.

1. BACKGROUND

The Canadian Consortium on Pain Research, Diagnosis and Management was formed as a result of a series of meetings held in the spring of 1999, to discuss ways in which research on pain and pain-related matters could be advanced in Canada. From these meetings, a plan emerged which laid the groundwork for a truly comprehensive strategy for optimizing prevention and management of pain in Canadian society in the interest of enhancing the health and quality of life of Canadians, and minimizing the impact of pain on the Canadian economy.

The first stage in this process was an application submitted in July 1999 under the CIHR Opportunities Program. The purpose was to bring together a broad cross-section of those interested in pain research to create a consensus vision of where we, collectively, should be heading to address the needs of Canadians for improved control of pain and prevention of its destructive consequences. This application was funded in October 1999, and a series of meetings, programs, and electronic communications resulted over the ensuing twelve months. A summary of these activities and the Consortium's achievements in the past year is presented in Appendix 1. Details of this vision are outlined in this document.

Six Task Forces, each with a specific, on-going and evolving mandate, were established by the Consortium. These are as follows:

- ◆ Task Force I - Infrastructure of the Consortium: The general purpose of this Task Force was to set up mechanisms to promote the exchange of ideas within the pain research, diagnosis and management community. This Task Force will be a coordinating committee with ongoing responsibility for integration of the Consortium, ensuring continuity of effort. Its recommendations are summarized in Appendix 2 to this Report,
- ◆ Task Force II - Pain Research and Management Strategies: The general purpose of this Task Force was to foster identified strengths in pain research, measurement and clinical management, which are collectively identified as such, and to set in place mechanisms to promote the further development of these strengths. Its recommendations are summarized in Appendix 3 to this Report,
- ◆ Task Force III - Education and Training Initiatives: The general purpose of this Task Force was to establish a broadly-based training and exchange program for graduate students and postdoctoral fellows among member laboratories and to establish a competitive awards program for graduate students and postdoctoral fellows. Its recommendations are summarized in Appendix 4 to this Report,
- ◆ Task Force IV - Knowledge Transfer to Pain Management: The general purpose of this Task Force was to introduce concrete mechanisms to facilitate the transfer of knowledge concerning pain-related matters to target audiences of various types. Its recommendations are summarized in Appendix 5 to this Report,

- ◆ Task Force V - Interactions Outside Consortium: The general purpose of this Task Force was to consider the many and varied interactions which the Canadian pain research community engages in and to set in place mechanisms which would facilitate those interactions. These would include interactions with government, established pain groups and organizations, the Canadian public at large and the corporate sector. This Task Force will, in particular, focus on helping to establish an effective Technology Transfer Program for the pain research community. Its recommendations are summarized in Appendix 6 to this Report, and

- ◆ Task Force VI - Societal Issues: The general purpose of this Task Force was to establish a program in epidemiological research to identify the unique needs of Canadians regarding pain and its specific impact on Canadian society and the economy. Its recommendations are summarized in Appendix 7 to this Report.

The main text of this Report sets the background, defines the problem being addressed, sets out the global vision of the current status of pain research in Canada and where we need to be, defines the current opportunities which present themselves to the pain research community, lays out a specific action plan to address the problem in terms of the vision vs. the opportunities, and details some initiatives already being undertaken.

2. CONCEPT

2.1. Aims and objectives

The aims and objectives of the Consortium are to enhance the health of Canadians by promoting Canada's world-recognized strengths in research that focuses upon our understanding of pain, its mechanisms, its diagnosis and its management, as well as setting in place concrete steps to translate the knowledge base being generated to have an impact on the broader socio-economic context.

2.2. Purpose

The purposes are to establish and maintain a permanent think-tank of leaders in the field of pain research:

- ◆ to provide on-going assessment of the strengths of the pain research community in Canada,
- ◆ to provide assessment of the adequacy of pain diagnosis and management in Canada,
- ◆ to oversee dissemination of information about pain and about pain treatment facilities to the Canadian public, and
- ◆ to provide input to policy-making decision mechanisms to prevent pain and to bring about the best possible management of pain in the health care domain.

2.3. Keys to success

Our keys to success lie primarily in the investigators already in place in Canadian pain research. Canadians have traditionally been at the forefront of pain research, diagnosis and management. The pivotal "Gate Control Theory" of pain was co-authored in 1965 by Dr. Ron Melzack, of McGill. The current President of the International Association for the Study of Pain (IASP) is Dr. Barry Sessle, of the University of Toronto. The International Nomenclature Committee of IASP is chaired by Dr. Harold Merskey, of the University of Western Ontario. Two Councillors of IASP are in Canada. Canada has outstanding, world-class scientists in pain mechanisms research: Canada is the world leader in treatment of pediatric pain, and Canadians have been instrumental in the development of palliative care, neurostimulation, imaging and treatment of neuropathic pain.

Six members of the Consortium have university endowed chairs. Seven are personally funded with national salary awards. Four are Fellows of the Royal Society.

2.4. Immediate goals

Immediate goals are defined in the mandates of six Task Forces which have been set up and which are defined in the proposal below:

- I - *Infrastructure of the Consortium,*
- II - *Pain Research and Management Strategies,*
- III - *Education and Training Initiatives,*
- IV - *Knowledge Transfer to Pain Management,*
- V - *Interactions Outside Consortium,*
- VI - *Societal Issues.*

2.5. Long-term vision

Long-term objectives will be to continue to strengthen and integrate the already strong research base through the Research and Management Program which is the nucleus of the Consortium and which will be sustained by Task Forces I-IV.

Also, mechanisms will be formalized to apply this knowledge base to the broader community through the eventual establishment of two additional programs.

A commonly-held opinion among those in the field is that far too much pain is going untreated or is inadequately managed, with significant social and economic cost. Thus, one of these additional programs is the "**Outreach Program**", which will have the following mandates: (i) to promote public awareness of new developments and rights to optimal management of pain, for example through patient groups and clinics, (ii) to establish, ensure participation and evaluate implementation of continuing education programs for professionals involved in pain management so that knowledge transfer is more effectively and wisely delivered to health professionals managing patients in pain, (iii) to formalize means of communication with the media, and (iv) to initiate and maintain interaction with policy-makers concerned with legislation, standards and guidelines in the field. This Outreach Program is focussed specifically on reducing the direct and indirect cost and impact of chronic pain on the lives of Canadians.

The second program is what we are naming the "**Technology Transfer Program**". Canada has already seen a number of patent applications and the emergence of several start-up companies based around analgesics and other strategies to treat chronic pain, and it is anticipated that this Program will be a timely addition to the field. Thus, the mandates of this Program will be (i) to interact with members of the research base in the search for knowledge of potential commercial value, (ii) to work with the respective home universities, clinics and institutes of the members of the Consortium to facilitate protection of intellectual property and to promote establishment of start-up companies, and (iii) to promote collaborative interaction with industry.

3. MARKET ANALYSIS

3.1. The Pain Experience in Canada

3.1.1. The scope of the problem

Pain afflicts us all. Pain is the most common symptom for which Canadians seek help from health professionals. Unrelieved pain has been identified as a problem for people with acute pain, cancer pain, and persistent non-cancer pain. It is estimated that 80% of physician office visits involve a pain-related component. For the fortunate this is simply a necessary complement of adaptive processes, promoting survival of the individual. For the less fortunate, chronic pain can be a nightmare, an all-consuming distraction which in extreme cases can lead to suicide. Uncontrolled pain continues to be the single most common cause of disability that impairs the quality of life in Canada.

Characteristically daily pains are managed by the so-called NSAIDs, the non-steroidal anti-inflammatory drugs, such as aspirin. Yet an estimated 30,000 deaths occur in North America each year as a result of gastric lesions produced by aspirin. Post-surgical analgesia is typically opioid, and many who have experienced post-surgical pain can attest to the fact that such treatment is often less than sufficient. The problems of tolerance and dependence hang like a pall over the prescription of opiates for chronic or severe pain.

One of the significant factors which prolongs hospital stay is pain: generally, the last 2-3 days of hospital stays are due to pain. One Canadian study has shown that infants whose pain is not treated are more likely to have more difficult recovery from surgery. Even everyday procedural pain in the neonatal intensive care unit can result in subsequent development of chronic pain. Surprisingly, Canadian infants in intensive care units experience 3-14 untreated painful events daily.

What is now coming to be recognized is that if transient, or acute, pain is not managed adequately, chronic pain can ensue. Given this, it is imperative that health care professionals be made aware that acute pains must be adequately managed from the beginning - if it is not, it may develop into permanent, or chronic pain. A concrete example is the 10-12 % of patients who suffer a debilitating neuropathic pain for the rest of their lives as a result of damage to anterior intercostal nerves during open-chest surgery.

3.1.2 Acute pain

Acute pain, which was traditionally seen as temporary is now envisioned as the initiation phase of an extensive, persistent nociceptive and behavioural cascade of reactions triggered by tissue injury. Within minutes of trauma, phenotypic changes are observed in primary afferent as well as spinal cord and brain nociceptive neurons, and these changes are the basis for long-term sensitization. Moreover, adults and infants with greater pain

after surgery have been found to have more complications such as infections, longer hospital stays, and greater disability after being discharged home. Conversely, a Montreal study of 2415 randomly selected hospitalized patients revealed that early pain management reduced the duration of pain and shortened the hospitalization time.

Canadian researchers have documented the problem of inadequate acute pain management in several settings with infants, children, and adults. Daily procedural pain in the neonatal intensive care unit can result in subsequent development of chronic pain, and infants in Canadian intensive care units have experienced many untreated painful events each day. Pain assessment with adults, infants, and children who are unable to verbalize their pain experience is a challenge. A considerable effort in this regard has been made by Canadian pain experts who are internationally recognized for their work in developing pain measures particularly for infants and children. Adult surgical patients have continued to report poorly-controlled pain and inadequate management with analgesic medications. In a large Canadian urban study, most patients undergoing coronary bypass artery graft surgery received minimal pain relief methods including analgesic medication despite having considerable pain. Research has also demonstrated that both health professionals and patients hold misbeliefs about opioids and addiction, that are significant barriers to adequate acute pain management. Further research is needed to determine strategies to narrow the gap between what we know about pain management and current practices.

3.1.3. Chronic non-cancer pain

The National Population Health (NPH) Survey of 1996-1997 indicated that 3.9 million Canadians (17%) over the age of 15 have chronic pain. For 70% of these, pain is rated as moderate to severe enough to interfere with normal daily activities. In long-term care facilities, 70 to 80% of people have considerable pain that interferes with their daily functioning. Chronic pain can cause tremendous disruption to individual and family functioning and can lead to work loss and social disability. The NPH Survey found that, compared to the population at large, people reporting considerable pain had more disability days off work in the previous 2 weeks (2.2 to 3.2 days versus 0.6 days), spent more days in hospital in the past year (3.9 days versus 0.7 days), and had more frequent physician contacts in the past year (12.9 visits). Of these chronic pain patients, an estimated 64% have pain of unexplained etiology. Some types of pain remain refractory to medical treatment, such as certain types of neuropathic and inflammatory pains, fibromyalgia, and idiopathic pains.

Persistent non-cancer pain is a very costly problem. The Nuprin Pain Report, commissioned in 1985 to study the impact of chronic pain in the U.S., revealed that people with chronic pain had reduced capacity to work and enjoy life. The annual number of lost days at work was estimated at 4 billion, or 23 days for every adult. In Canada, the total economic burden of illness in 1993 was estimated at \$157 billion. Although chronic pain was not specifically categorized, musculo-skeletal pain conditions and injuries which have pain as a major component, ranked second and third overall with total costs of \$17.8 billion and \$14.3 billion respectively. Also, painful musculo-skeletal

conditions were the leading cause of long term disability in Canada accounting for over one-third of all long-term disability costs (\$13.5 billion). The economic impact in terms of lost work, clinic and hospital visits and out-of-pocket medication costs is estimated to be \$9,723 to \$14,744 per person each year. To this are added the impact on the quality of life for the patient as well as the emotional strains on immediate family; these costs cannot be given a monetary value. These financial and quality of life costs can be reduced significantly by promoting research on all aspects of pain and by promoting the transfer of knowledge to patients, health care professionals and policy-makers.

3.1.4. Cancer Pain

More than 70% of patients with cancer develop significant pain at some time during the course of their illness. Many patients receive inadequate treatment for their pain despite the fact that most cancer pain can be treated effectively. Inadequate understanding of the principles of cancer pain therapy contributes greatly to this undertreatment; efforts to change this situation are both a therapeutic and ethical imperative. Most patients with advanced cancer often have multiple causes and sites of pain. Pain can be caused by direct tumour involvement of nerves (65-85%). Pain can also result from cancer therapy such as chemotherapy, surgery, or radiation treatment (15-25%). Between 3 and 10% of cancer patients can even have pain from non-cancer problems. Despite established data that 85% of cancer pain can be controlled by opioids, severe pain can be difficult to manage, particularly when a person is dying.

Economic constraints have dramatically changed the Canadian health care system resulting in reduced hospital stays for both the diagnostic and treatment phases for cancer patients. Many people and their families deal with cancer-related pain at home, with little knowledge of optimal pain relief strategies. Further research is needed to support effective pain management across the complex trajectory of cancer treatments. During the last 10 years there have been major advances overall in the assessment and management of cancer pain. Recognition of the multidimensionality of cancer pain has led to an improvement in available management therapies including opioids. However, a remaining challenge includes educating health professionals to include these advancements in their pain practices.

3.1.5. Society and Government Initiatives

Undertreatment of pain continues despite almost 30 years of educational efforts with health professionals, patients, and the public about pain and its treatment. During the last decade, professional organizations have worked toward improving pain management. The Canadian Pain Society has published a position paper on pain relief to increase health professionals' awareness of effective pain practices. Existing standards have been based on the assumption that health professionals have the knowledge and commitment to apply them. The CPS paper makes explicit the key principles underlying effective pain management and does so in clear and simple statements, understandable to both health professionals and patient-families.

Only recently has the monitoring of pain practices been included in accreditation standards. The revised standards from the Canadian Council on Health Facilities Accreditation (CCHFA) now contain components requiring documentation of pain assessment and management, including patients' responses to treatment for pain. The accreditation evaluation also includes documentation of the interpersonal care process involved in symptom management. The Canadian accreditation standards give clear direction to Canadian hospitals that ongoing assessment of the effectiveness of pain management is expected and a component of the CCHFA evaluation. However, traditional patterns of professional practice are difficult to change. Health care organizations and institutions need to address the problem of a lack of accountability for quality pain management. Therefore, research is critical to examine the contextual issues involved in managing pain, including the impact of the accreditation changes on patients' pain outcomes.

3.1.6. Research Initiatives

Until recently there has been nothing in place in Canada to link the expertise and initiatives of the pain research community. Despite the large number of internationally recognized pain experts in Canada, progress to date has been accomplished largely by individual effort. In an attempt to link our existing strengths for maximum gain in research, an initiative to establish a Canadian network of basic and clinical pain scientists was begun in April, 1999. A meeting was held in Toronto on the 6th of April and was attended by Drs. Yves De Koninck, James L. Henry (as Chair), Michael Salter and Barry J. Sessle. A second meeting was held in Toronto on the 17th of April and was attended by Drs. Clark (Dalhousie), Crook (McMaster), Davis (Toronto), De Koninck (McGill), Dray (AstraZeneca), Henry (McGill), Katz (Toronto), McGrath (Dalhousie), Salter (as Chair; Toronto) and Sessle (Toronto).

The result was a successful application to the Canadian Institutes for Health Research for funding under the Opportunities Program to form the Canadian Consortium on Pain Mechanisms, Diagnosis and Management, the activities of which for the last year are summarized in Appendix 1.

3.1.7. Will our past approach be adequate for the future?

A consensus among those involved in pain research, diagnosis and management is that many patients receive inadequate treatment for their pain. There is a monumental, unmet need in Canada for improved methods for the treatment of both acute and chronic pain. This problem will only worsen with the complex demands of an increasingly older population. Thus, significant changes in the way in which pain is treated in Canada must be found to avoid a critical impact on our health care system in the future.

In addition, a new emphasis must be placed on improved coordination and delivery of patient treatment. There is also a critical shortage of training of highly qualified personnel in this field. For example, in a recent survey, PharmaVision Quebec estimated that in the pharmaceutical and biotechnology industries alone, the demand for highly

qualified people is increasing by about 30% per year over current levels. However, this study found that the current rate of increase is only 3%, a situation which, were it to continue, would have serious implications for these industries in Canada. Among the recommendations is one to increase funds available for training programs and awards, in order to attract the best young investigators to the field.

3.2. Why an integrated approach?

Pain transmission and perception have multiple physiological, psychological, and social dimensions. Thus, only an integrated, interactive research program that embraces all aspects of pain, from its cellular and molecular bases to its social, societal and economic manifestations will yield the required information to establish effective and comprehensive therapeutic strategies for adequate and universal management of pain in Canada.

3.2.1. The Gate Theory

The Gate Control Theory was proposed in 1965 by British physiologist, Dr. Patrick Wall, and Canadian psychologist, Dr. Ronald Melzack. Although derived from basic research data, this theory provided a model to explain the diverse nature of pain and, in addition to being of direct benefit to basic research for this reason, it also gave pain care professionals a framework within which to conceptualize what they were experiencing in the clinic.

As a derivative of this, it became apparent to these professionals that pain was indeed a diverse phenomenon and as a result pain clinics began to emerge. Unfortunately, despite this knowledge, few cities have pain clinics to which patients can go for treatment by an integrated team of specialists. New clinics are being developed albeit slowly. An increased focus on the importance of pain as a distinct health care problem should lead to a dramatic change in this situation.

The newly perceived need for further integration of effort led to the formation of the International Association for the Study of Pain in 1974, and its First World Congress on Pain in Florence in 1975. As a point of note, Canada was the first country to have hosted 2 of the now regular tri-annual World Congresses. Presidents of the IASP serve three-year terms, and two have been from Canada. Subsequent to the founding of IASP, each country has been urged to set up a national chapter. Canada's has been in place since 1975 and its activities are described below.

3.2.2. Animal models of pain

As a result of the Gate Control Theory scientists were attracted to the field because they now had a specific conceptual model to test. This increase in scientific investigation in turn has led to new animal models of acute and chronic pain, the latter including models

which closely exhibit the complement of symptoms described by neuropathic patients, by arthritis patients, by patients experiencing visceral pain, by late-stage cancer patients with metastatic bone pain, etc.

Data from these models are becoming increasingly important to pain care professionals, as evidenced by the increasing number of interdisciplinary sessions at annual meetings of the Canadian Pain Society and at World Congresses.

Basic science concepts which have changed management of pain include:

- the concept of central sensitization,
- intracellular signal transduction mechanisms mediating excitation in central pain pathways,
- phenotypic changes deriving from acute pain that lead to chronic pain,
- the identification of specific chemical mediators of synaptic transmission in pain pathways,
- the demonstration, through functional imaging studies, of the diffuse nature of pain.

3.2.3. Social and Behavioural Sciences

Recognition that the neurophysiological systems for pain evolved for protective purposes – warnings of danger, motivating avoidance or escape from physical harm – has led to studies of sensory psychophysics, perceptual and cognitive mechanisms, affective and motivational processes, and adaptive coping mechanisms. The importance of social and communication processes is reflected in the need for pain to have overt expression if other persons are to intervene on behalf of the suffering person, the complexity of diagnosing sources of pain, particularly when disease or trauma has impaired the capacity for self-report, and the key role of caregiver expectations and beliefs in the delivery of care. The large number of Canadians suffering persistent or recurrent pain that does not respond to current health care intervention necessitates development of evidence-based programs to care for these people.

3.2.4. Clinical Sciences

Traditional approaches to the management of acute and chronic pain have been generally uni-dimensional with specialty groups and health care providers approaching therapy from their own training and expertise (e.g. anaesthesiology, dentistry, neurology, neurosurgery, physiotherapy, psychology, rheumatology, etc). The multidimensional nature of pain calls for a broadly based approach, especially for chronic pain, although this principle is in fact true for all pain, whether in the elderly or young, chronic or acute, and in cancer. This is the primary guiding principle of the CPS, the IASP and multidisciplinary pain centres; however, most health care providers managing pain do not use this broadly-based approach. This potentially leads to the undermanagement of all aspects of pain with the consequence of continued acute pain leading to chronic pain, increased costs to the health care system and society supports (ie unemployment, social agencies, etc), with diminished quality of life for the sufferers and an increasing burden of responsibility on their families. There is also a stark need for an increased transfer of

knowledge to and enhanced education of health care providers, along with advocacy of evidence-based standards and clinical randomised trials into the efficacy of traditional and broadly based approaches to the management of pain.

4. OPPORTUNITIES

4.1. Genomics, bioinformatics and computational biology

Knowledge of the human genome and the genetic basis of disease is offering the potential to understand acute and chronic pain in new and unanticipated ways. As we embark on the post-genome era, pain, like other complex biological phenomena, is starting to be studied at the level of the gene. With the great strides made recently in molecular biological technology, cloning, mapping, and sequencing of genes can now be done much more rapidly than even just a few short years ago. Already examples of single gene mutations have been linked to pain conditions in humans (e.g. the so-called congenital insensitivity to pain and an inherited form of migraine) and the search is on for new linkages of single genes to pain. Undoubtedly the major genetic contributions to pain are poly- rather than mono-genic. Thus, understanding which cohort of the 30,000 or so mammalian genes is involved in the mediation and modulation of pain represents a major goal in the field. Once pain-relevant genes are known it will be important to establish the role of genetic polymorphisms in naturally occurring variations in responses to painful stimuli, pain pathophysiology and analgesic drug responsiveness.

The understanding of pain-relevant genes will come about through the concerted efforts in and the interplay between studies in animals as well as in humans. Studies in model organisms from worms to mice are already providing the means for targeted manipulation of individual known genes in order to study the role of these genes in nocifensor responses. There is great expectation that the newly emerging genome-wide mutagenesis screens in mice will identify, in an unbiased way, genes that could not be predicted *a priori* to be involved in pain. Human studies will allow for linkage analysis of complex pain traits and will be the ultimate test of whether a particular gene is pain-relevant. All of this will require the full power of *bioinformatics* and the next generation of pain geneticists will be well-positioned to benefit greatly from the advances in *computational biology* that are now on the horizon.

4.2. Proteomics and cell biology

The ultimate manifestation of disorders, even for those diseases that are gene-based, is through the dysfunction of proteins and of protein-signalling networks. As the various genome projects are being completed new information is becoming available about protein products of genes. Understanding how proteins interact, are modified and how they function in protein-signalling networks is central to future advances in biological sciences.

The importance of the area of proteins has already sparked the creation of “proteome” projects aimed to identify the complete set of proteins and of protein-protein interactions in cells. The ultimate impact of such efforts on the field of pain will be profound. Once pain-relevant genes are known we will then be in a position to determine how the products of these genes work and interact to effect changes in cellular, and in the end organismic, function.

There are a number of clinical benefits that are likely to follow from understanding the genes and gene products involved in pain. The most obvious is that the gene products identified may be targets for pharmacological therapy. Thus the discovery of novel genes that are pain-relevant, in particular, will undoubtedly spur efforts towards targeted drug-discovery. A second benefit may be the identification of genetic variations, ie. polymorphisms or mutations, which produce altered proteins or changed protein expression levels, that render particular individuals with varied sensitivity to painful stimuli or to pharmacological intervention. Because of this one can envisage the day when drug therapies are targeted not only at particular gene products but are individually tailored to the polymorphisms expressed by a particular person. This type of molecular medicine approach may maximize drug effectiveness and minimize side effects. Finally, inherent in understanding of pain-relevant genes and gene products will be sorting out the ultimate causes in the tangled web of pain cause and effect.

4.3. Information technology

A host of opportunities have opened up for the pain research community. Computational systems allow the assembly of complex data sets into a single, searchable database, allowing researchers to conduct queries rapidly and effectively. These systems are flexible and allow for a wide variety of studies, from basic through clinical to societal, to be conducted in an efficient and cost-effective fashion. The changes in available "IT" resources have also allowed increasingly powerful imaging tools to be brought to bear at the molecular and cellular levels, allowing researchers to conduct investigations that were previously impossible. Innovations of this type are likely to continue to be developed as creative and highly-trained personnel adapt existing tools to suit new needs or innovate new technologies to fit novel needs.

Opportunities also abound for using these new technologies as a means of disseminating research findings amongst members of the pain community and as a means in which the knowledge obtained by their research may be transmitted to other populations, including the medical community, policy makers and patient groups. Finally, the increasing broad-band capacity that is being created for the Internet opens new ways in which research data and results may be shared between research groups. Real time transmission of large video and other imaging files will speed up the research process, allowing their sharing to happen in minutes instead of the days or weeks of yesterday.

4.4. Non-technological opportunities

The nature of what and how research is conducted has changed dramatically in the last two decades. Many of these changes have already been embraced, in whole or in part, by the pain research community. Overall, they need to be integrated into all aspects of how this community operates. With the creation of the Canadian Institutes of Health Research and the Canada Foundation for Innovation, new funding opportunities for members and groups in pain research are emerging. These new opportunities need to be explored

thoroughly by our researchers and mechanisms need to be put in place to be able to optimize meeting the bases for these new opportunities. We also need to work more closely with these and other funding stakeholders to dovetail the community's needs and the funding agencies' objectives and resources.

Multidisciplinary research is being strongly encouraged within this new climate of funding. This force has created new collaborations between members within our pain research community and there has been a noticeable increase in the number of collaborative and team grant applications submitted. This has also occurred between our members and those in other sectors of research, both nationally and internationally. The potential that these collaborations bring to medical research has been significant, but pain research is placed in a particularly advantageous position within this new climate, because the belief is broadly held that pain is multidimensional and thereby requires a multidisciplinary approach. Thus, it has been natural for collaborations to occur between pain researchers of various expertise, and these are expected to flourish within this new climate.

5. ACTION PLAN

Demographics, genomics, proteomics, informatics and key personnel provide exceptional opportunities to improve the quality of life and health care in Canada. This is a far-reaching ambition to capitalize upon these opportunities to enable Canada to maintain its world-recognized role as a leader in research on pain mechanisms, diagnosis and management, and to set the international standard for a health care system which is constantly being refreshed as new knowledge is becoming available and integrated into practice. Yet there is also every reason to believe that this ambition can be fulfilled.

5.1. The pain research community has already built some of what is needed nationally

The Canadian Pain Society, a chapter of the IASP, was founded in 1975. The membership is comprised of health professionals and researchers from many disciplines, it has an Executive Office in Ottawa, and an Executive Committee whose members are turned over regularly by election. The membership currently stands at over 500 and the aims of the Society are to foster and encourage research on pain mechanisms and pain syndromes, to promote education and training in the field of pain and to promote and facilitate the dissemination of new information about pain. There is a quarterly newsletter sent to members and a web site posts relevant information to all interested parties. The Society has a peer-reviewed journal, *Pain Research and Management*, which publishes research and review articles on all aspects of pain on a quarterly basis. In conjunction with both industry partners and CIHR, it sponsors 4 doctoral and post-doctoral fellowship awards across Canada.

The Canadian Pain Foundation was set up as a registered charity by members of the Society in 1985 to promote public awareness of the magnitude of the problem which pain causes in Canada and to foster medical research that will help bring about its final resolution. The Foundation serves the pain research community by public awareness campaigns and through targeted fund-raising drives to help finance research into pain-related issues. Its Executive Committee meets annually.

The Canadian Consortium on Pain Mechanisms, Diagnosis and Management is considered healthy, as this report is intended to show. Its members intend that it remain a permanent part of the Canadian pain research community, serving as a consultative group, an advisory group, and as a lobby group aimed at decision makers, the general public and the pain research community itself. The Consortium is intended to be self-sustaining through a dynamic funding plan which targets multiple sources and types of funds for its various programs. The Consortium has set up a website, www.curepain.ca, for communication with the public; although in its infancy, with several important issues remaining to be finalized about its future, it is intended that this web site become self-sustaining through contributions and through funds generated by advertising. A listserv, curepain@lists.mcgill.ca, has also been established, initially for communication within

the Consortium. However, this is envisaged long-term as becoming open to all those in Canada who have a direct interest in pain-related research, thus expanding involvement beyond what can be served by the Society, by the Foundation or by the Consortium.

5.2. The Consortium is currently launching other initiatives

A specific proposal has come forward from Drs. John Clark and Patrick McGrath, members of the Consortium, to establish a Network of Pain Research and a national database of all the human capital involved in pain research at all levels. This initiative was discussed at the meeting of the Consortium Task Force Leaders, held in Calgary in May, 2000, and the mechanisms to have this initiated and maintained by a commercial venture as well as raising the necessary funds to provide this service have been set in place. While run independently of the Consortium, activities will be overseen by the Consortium.

An initiative is also underway by Dr. David Goldstein to establish a National Data Link in which data on management and efficacy can be entered from bedside into a central database, which is then available to all those needing this information in the treatment of pain patients. Long-term this will be expanded to the international level, so as to interact with similar databases established in other countries.

Symposia in the pain field are also occurring across Canada, organized by members of the Consortium. Dr. Patrick McGrath is organizing one in Halifax on pediatric pain issues. Dr. David Goldstein is holding a national meeting of acute pain physicians in Kingston. Dr. Angela Mailis is collaborating with Parke-Davis Pharmaceuticals in arranging a think-tank meeting in Toronto of 30 national and international experts on neuropathic pain. Dr. Andre Dray is organizing one in Montreal on G-protein receptors and their involvement in models of pain in August 2001.

The initial meeting of the consortium helped crystalize the formation of the Canadian Consortium for the Investigation of Cannabinoids in Human Therapeutics, lead by Dr. Mary Lynch at Dalhousie University. This consortium has also been funded under the CIHR Opportunities Program. This consortium proposes the development of a multicentre interdisciplinary consortium who will pursue basic science work regarding spinal and supraspinal mechanisms of cannabinoid actions and clinical trials investigating cannabinoids as therapeutic agents in relief of human suffering.

5.3. Other initiatives are also being undertaken at local levels

Pain research centres are being formed independently at Dalhousie, McGill, Toronto, Western and UBC. Pain management centres and clinics are being formed at McGill, the Toronto Western Hospital, the Vancouver Hospital and at various hospitals and academic

centres across Canada. These research and clinical investigation units are pursuing the major challenges of pain at all levels of investigation, including the basic neurosciences, applied clinical, health systems and services, and societal and cultural levels.

A recent research initiative was inspired by evidence of unnecessary suffering, medical complications, social problems and economic burden as a result of pain in Canadians unable to effectively communicate their distress. These include infants and children with significant neurological impairment and adults and seniors with intellectual disabilities, brain damage, or senile dementia. An Interdisciplinary Health Research Team, including Drs. Ken Craig and Tim Oberlander at the University of British Columbia, Thomas Hadjistavropoulos at the University of British Columbia, Bonnie Stevens at the University of Toronto, and Patrick McGrath and Allen Finley at Dalhousie, have submitted a CIHR proposal for research on pain assessment and management in persons with a limited capacity to communicate. A letter of intent was approved and the full proposal has been submitted and is presently under review.

Faculty in the Humanities, Social Sciences and Medicine, led by Dr. Judy Segal in the UBC Department of English, have been successful with a Tri-Council Workshop/Networking Program application to explore "Pain and Suffering and the Health of Canadians". About 25 scholars and scientists will explore multidisciplinary perspectives on the theme in January, 2001, in the interests of bringing innovative perspectives from the humanities and social sciences to bear on problems that traditionally have fallen in the medical domain. The expectation is that collaborative, interdisciplinary research will arise from the workshop

On-going training awards are also being put in place by industry support. AstraZeneca offers two post-doctoral fellowships in Pain/Anaesthesia each year, named after Canadian pain researcher, Dr. Ronald Melzack. Each fellowship includes a stipend allowance as well as a research allowance, for a total of \$50,000 per year. This sum can be increased by another \$12,500 by the Canadian Institutes of Health Research, as decided by its Fellowship Committee.

In addition the Canadian Pain Society, in conjunction with Parke-Davis, has just introduced an annual Research Award in Chronic Pain which is peer reviewed by the Research Committee of the Society. The Society has also introduced a new Fellowship program at the pre-doctoral level in conjunction with Janssen-Ortho Inc. A post-doctoral fellowship will be offered through the Partnership Program of CIHR, which will provide equal funding. A further fellowship will be offered, on a peer review basis, by the Society and Janssen-Ortho Inc.

The pharmaceutical industry has also recently installed pain research facilities in Canada. AstraZeneca has a pain research centre in Montreal and a smaller pain unit has been set up by Merck.

Currently, many of our basic researchers are receiving grant or contract funds from industry, including AstraZeneca, Monsanto/Searle, Boeringer-Ingelheim, Medtronic, Parke-Davis/Warner-Lambert, Pfizer Corp., Eli Lilly Corp, Merck Frosst, Janssen-Ortho Inc, PurdueFrederick, Roxane Laboratories, and USPA.

5.4. Yet, much remains

We have no epidemiological study on pain in Canada. Today we still do not know whether we are more like Americans in this respect or whether we resemble the Scandinavians.

How many Canadians seek pain treatment of a non-conventional type, and what drove them to try alternative therapies? How successful are these other types of treatment? How many patients remain with a non-conventional therapy?

There is no study on the specific family, social or economic cost of pain in Canada, whether acute or chronic. What would be the cost savings for every investment dollar put into bringing Canadian pain research to the leading edge of the wave?

We have yet to gather reliable information on the efficacy of the treatments that are already in place in pain clinics today. Also alarming is the fact that essentially no information of this type is available for treating pain outside recognized pain clinics.

No formal mechanism is in place for getting information on pain treatment facilities to those in pain.

Despite the burgeoning of information on new methods to treat pain there is no formal mechanism to get this information to those who dispense pain treatment.

Canada is proud of its cultural diversity. It has nothing in place to identify appropriate pain management techniques for cultural differences.

Recognition of gender differences in the direct or indirect impact of pain is essentially nonexistent. Similarly, gender differences in the management of pain are nonexistent.

What is Canada's policy with regard to age differences when it comes to treatment of pain?

5.5. What is needed?

A vision of the future of pain research was generated communally at the November, 1999, meeting of the Canadian Consortium on Pain Mechanisms, Diagnosis and Management. In addition, the subsequent deliberations of the six Task Forces came up

with specific recommendations to achieve this vision.

The first step is to set up a large-scale mechanism to infuse monies into all aspects of the pain field, from basic research, to training highly qualified personnel, to the diffusion of information broadly, to transferring the knowledge base to development and commercialization, to ensuring the participation of pain researchers in health care policy so that it is concordant with the needs of pain patients in Canada. Some of these need larger sums of money, others, smaller amounts. However, what is clearly needed is the establishment of a central coordinating mechanism.

What has been created is self-sustaining and therefore does not require any additional funds. What is needed, though, is a mechanism to directly promote research efforts in priority areas. Funds are also required to promote training of highly qualified personnel, whether in basic research, in diagnostic research or in research on improving pain management. Funds are needed to promote the translation of the knowledge base to health care professionals, to patients, to support groups. A formal mechanism co-ordinating links between pain-related groups in Canada is also needed, to ensure optimum integration of the efforts of, for example, the Society, the Foundation, the Consortium, the different groups organizing symposia and professional development courses. There also needs to be one central organization co-ordinating links with other pain-related organizations outside Canada, such as the recently-formed Danish Pain Consortium, the American Pain Society, etc. A co-ordinating body is also needed to promote and support the development of new technologies and to facilitate bringing new technology to commercialization; this could be envisaged as being able to provide seed funds, to provide expertise on protecting intellectual property, working as a liaison with the Health Protection Branch in securing Investigational New Drug classification, facilitating the setting up of clinical trials and other steps in the process toward commercialization.

A central co-ordinating body will also be able to promote the efficient distribution of funds from other sources. For example, in its 1996-1997 annual report, the Canadian Association for the Drug Industry reported that in 1995 the pharmaceutical industry had invested \$624M in research and development, a growth of 11.2% with respect to the \$524M in 1994 and a growth of 506% with respect to the \$103M invested in 1987. In the PMAC Update of June, 1998, it was reported that \$768M was invested in 1996 and \$825M in 1998. With the growing interest of industry in analgesics and other methods of managing pain, it is expected that funding by industry of the full spectrum of pain research, diagnosis and management will continue to increase in the future. Accordingly, it would be in the interests of Canadians and of Canada to have a co-ordinating body to work with industry to ensure the most efficient appropriation of these funds, as determined by industry and those directly involved in research on basic mechanisms, diagnosis and management of pain.

Appendix I

Impact and Activities of the Consortium

Calendar of Activities - Year 1

April 1999	- Two <u>meetings</u> held, early and late April, in Toronto to start organization process of Consortium
May - July 1999	- Preparation of CIHR Opportunities Program <u>application</u> and other fundraising in support of November meeting
August-October 1999	- <u>Administrative</u> preparations for November meeting, establishment of basic infrastructures (web page, listserv, formation of Task Force Teams) for the Consortium's organizational needs.
November 13-15, 1999	-First <u>annual meeting</u> of the Consortium held in Montreal. Topic: Directions for the Pain Community in the 21 st Century.
November-January 2000	-Respective <u>Task Forces</u> correspond by email in order to elaborate plans discussed in November.
February 04-05, 2000	- <u>Meeting</u> of the Task Force Leaders in Toronto. Topic: First drafts of the Task Force Reports; start of integrative Final Report
February-April 2000	- Respective <u>Task Forces</u> continue to elaborate on their reports by email exchanges. Task Force Leaders continue to work on Final Report by email.
May 14, 2000	- <u>Meeting</u> of Task Force Leaders in Calgary (following the CPS Annual Meeting). Topic: Final drafts of Task Force Reports and in-depth discussion of first draft of Final Report
May-August, 2000	- Task Force Leaders complete <u>Final Report</u> by email. Report is disseminated to all Consortium members for comments.
September, 2000	- Comments from Consortium members integrated into Final Report prior to its submission to CIHR

Other spin-offs and accomplishments

In addition to preparing the required report for CIHR, the Consortium has undertaken the following initiatives:

- ◆ Organized a symposium on neuropathic pain in Toronto, 16-19 November, 2000
- ◆ Established Consortium infrastructure needs including a listserv, email address, web page and initial work on a database for use by the Canadian pain community.
- ◆ Started a fundraising campaign aimed at Industry in support of Consortium activities. A total of five sponsors have signed-on to date, representing funds received or pledge in excess of \$60,000Cdn.
- ◆ Conducted information campaigns to explain the Consortium's aims, objectives and

proposed relationship to established pain community institutions (such as the Canadian Pain Society and the Canadian Pain Foundation). These include presentations to the annual CPS meeting and notices in the CPS newsletter and in *Pain Research and Management*, the professional journal of the Canadian pain community.

- ◆ Started work on needs of the pain community which the Final Report identified, most particularly starting the long process of preparing for an application for funding under the NCE program.

Indirect initiatives/activities

Members of the Consortium have also been responsible for the following initiatives for the pain community:

- ◆ University of Toronto Centre for the Study of Pain established (Michael W. Salter, Director, Karen Davis, Jonathon Dostrovsky, Joel Katz, Angela Mailis, Barry Sessle, Bonnie Stevens and Judith Watt-Watson)
- ◆ Establishment of the “Reseau FRSQ en santé buccodentaire” and a Québec Pain Consortium, both via Gilles Lavigne
- ◆ Creation of a Centre for Research on Pain at McGill (James L. Henry, Director, Cathy Bushnell, Yves de Koninck and Gilles Lavigne)
- ◆ CFI grant awarded, summer, 2000 - Montreal (Yves de Koninck, Leader, Cathy Bushnell, Manon Choiniere, Terence Coderre, James L. Henry, Celeste Johnston, Gilles Lavigne, and Alfredo Ribeiro-da-Silva)
- ◆ CFI grant awarded, summer, 2000, to Dr. David Goldstein.
- ◆ IHRT application submitted on Pain Assessment in Patients with Limited Ability to Communicate (Kenneth Craig, Patrick McGrath, Bonnie Stevens)
- ◆ Valorisation - Recherche Québec - application for personnel support for core research facilities (Letter of Intent accepted, Oct., 2000, full application submitted Nov., 2000)
- ◆ Canadian Consortium for the Study of Cannabinoids in Human Therapeutics (CCIC), Halifax May 25-26 2000 , (Mary Lynch, Project Leader, A. John Clark, James L. Henry and Judith Watt-Watson)
- ◆ Application prepared for submission to CFI program, “National Strategy for Pain Management”; (James L. Henry, Project Leader, A. John Clark, Kenneth Craig, Yves De Koninck, Mary Lynch, Michael Salter, Jana Sawynok, Barry J. Sessle, Bonnie Stevens, Judith Watt-Watson)

Awards and Recognition to Consortium Members since Application

Honours and Awards:

- ◆ Canadian Pain Society, Millennium Distinguished Career Award: James L. Henry
- ◆ IASP Special Interest Group on Pain in Children, Young Investigator Award: Bonnie

Stevens

- ◆ Signy Hilary Eaton Chair of Nursing Research, Toronto Hospital for Sick Children: Bonnie Stevens
- ◆ MRC/PMAC Research Chair, McGill University, A. Claudio Cuello
- ◆ CIHR/SSHRC/NHRDP Senior Investigator Award: Kenneth Craig

Major Competitive Grant Competitions:

- ◆ MRC Operating Awards, March 2000 Competition: A. Claudio Cuello (2nd MRC), Celeste Johnston (2 awards), Joel Katz, Alfredo Ribeiro-da-Silva, and Bonnie Stevens.
- ◆ CIHR Operating Awards, June 2000 Competition: Cathy Bushnell, Ken Craig, Jonathon Dostrovsky, James L. Henry (2nd CIHR), Patrick McGrath, Greg Ross and Michael W. Salter (2nd CIHR).

Appendix 2

TASK FORCE I - INFRASTRUCTURE OF THE CONSORTIUM

Task Force Participants

Task Force Leaders: Ken Craig, James L. Henry

Task Force Members: Cathy Bushnell, A. John Clark, Andy Dray, David Goldstein, Chris Loomis, Harold Merskey, Mary Ellen Jeans, Celeste Johnston, Carl von Baeyer

Background

The general purpose of this Task Force was to set up mechanisms to promote the exchange of ideas within the pain research, diagnosis and management community. This was to be done through (i) an annual meeting coupled with regional meetings, (ii) a web page with information on the consortium as well as on individual members of the consortium, their curricula vitae, lists of recent publications and grants from external agencies and industry, (iii) promotion of similar web pages for the pain research centres and pain clinics across Canada, and establishing links between these, (iv) a centralized listserv for collection of information and for dissemination to members of the consortium as well as to the web site for general access, and (v) a speaker exchange program, including speakers internal to the consortium as well as speakers of international reputation from outside the Consortium to keep Canadian pain researchers and clinicians abreast of advances in pain research, diagnosis and management made by Canadians and others. This Task Force was envisioned as being a coordinating committee with ongoing responsibility for integration of the consortium, ensuring continuity of effort.

Recommendation 1 - Role:

- ◆ that the Consortium be organized as a permanent player in the Canadian pain community, regardless of whether it is ultimately funded by Canadian Institutes for Health Research (CIHR), by other granting agencies, or by private sources of funds,
- ◆ that the Consortium be limited to the roles of a consultative group, an advisory group and a lobby group. For the Consortium to run a scientific program in addition to that already run by the Canadian Pain Society (CPS) would be repetitive and would not contribute to the most important objective, namely cooperation amongst the key stakeholders in the Canadian pain community.

Recommendation 2 – Structure and Organization of the Consortium:

- ◆ that within a period of two years the role of Task Force I be assumed by an executive group answerable to a Board of Directors,

- ◆ that the Executive Group oversee the programs and general activities of the Consortium,
- ◆ that the Board of Directors should be constituted of but not be restricted to the following: a lay representative, a representative from the business community, representatives from the Canadian Pain Society and the Canadian Pain Foundation, a lawyer, the Project Leader and one or more Task Force Leaders,
- ◆ that Project Leader should serve a term of 3 years, renewable once. This would ensure evolution of the guiding vision and avoid concentration of decision-making processes. Candidates for Project Leader would most likely come up through the ranks of the Consortium,
- ◆ that the selection of Task Force Leaders should be on the basis of their ability to represent and to lead their respective peers. Participants would be those demonstrating excellence and leadership,
- ◆ that the Consortium will require an Administrative Coordinator to organize its activities and generally conduct its day-to-day business. During the initial start-up period, a half-time position was thought sufficient to meet the Consortium's needs,
- ◆ that the basis for membership in the Consortium must balance the twin needs to a) provide suitable representation from all parts of the Canadian pain community and b) not grow so large that it becomes unwieldy for the roles enumerated in Recommendation 1. While no formal size limitations are recommended, to provide flexibility to the Consortium so that it can respond to needs as they arise, membership in the Consortium should be restricted to leaders in the various fields, and in particular to those who have proven themselves to be both representative and active.

Budget: \$53,000/annum

- Half-time administrative coordinator and benefits – \$25,000 per year
- Office expenses – network connection, long distance, FAX charges, copying, etc. – \$4,000 per year
- Two Task Force Leaders meetings/year – \$12,000 per year
- Two Board of Directors meetings/year – \$12,000 per year

Recommendation 3 - Future meetings of the Consortium:

- ◆ that scientific sessions should stay the domain and mandate of the Canadian Pain Society,
- ◆ that the Consortium as a whole should meet as a satellite to the Annual Meeting of the Canadian Pain Society, both as a means of containing travel costs and to encourage participation in the Society's program by all members of the Consortium,

- ◆ that the purpose of Consortium meetings be to review, in the broadest possible way, those areas which are of greatest short- and long-term concern to the pain community as identified by the respective Task Forces, to collectively update progress on all initiatives of the Consortium and to reassess priorities for the future.

Budget: \$36,000/annum

- One full Consortium meeting/year (40 participants) – \$36,000 per year
(Costs include air fare, hotel, meals, room rental)

Recommendation 4 - External relations and liaison:

- ◆ that good relations and cooperation with existing stakeholders in the Canadian pain research community, in particular with the CPF and the CPS, are essential to the Consortium's purpose. The spirit that should enlighten the relationship between the Consortium and other stakeholders should be one of partnership and not competition. It was recognized that many of the Consortium's programs will either be carried out in cooperation with the CPF (fundraising, scholarship programs, etc.) or with the CPS (lobbying, policy issues, education, etc.) and thus close ties would be essential to the successful outcome of its objectives,
- ◆ that connections with lay groups, such as those covering migraine, other chronic pain groups, the North American Chronic Pain Association or the Canadian equivalent be established as and when possible,
- ◆ that while the Consortium should develop strong links with CIHR, it should also develop ties to other funding bodies including private industry, private foundations and lay groups which support research into pain issues. The essential point is that the Consortium develop the broadest possible base for its funding needs. To realize this mandate, the Consortium should dedicate resources and personnel to this purpose,
- ◆ that the Consortium needs to establish an effective public relations program in conjunction with other stakeholders to educate the Canadian public on pain related issues and to raise the profile of the many noted successes which those in the pain community have achieved.
- ◆ that the Consortium needs to develop an effective lobby presence so that it can communicate its message to public policy makers more effectively. It was noted that several important recent decisions relating to the healthcare of Canadians -- eg. the Senate Report on End of Life Care -- were lacking a pain component even though one was clearly relevant.

Budget: \$40,000/annum

- Office expenses: copying, long distance, FAX - \$4,000 per year
- Travel to meetings with other groups - \$6,000 per year
- Communications - \$2,000 per year
- Information retrieval regarding lay groups, funding opportunities, etc. - \$16,000 per year
- Secretary assistance, half-time, and benefits - \$12,000 per year

Recommendation 5 - Infrastructure needs:

- ◆ that the Consortium web page should continue to develop along the lines which were originally established, namely as a source of information on the Consortium, its members, and as a means of linking together relevant stakeholders in the pain community. The critical point is that the Consortium website should become a starting point for those in the pain community to reach others,
- ◆ that the Consortium web page and similar information technology endeavours eventually become self-financing through partnerships with the private sector,
- ◆ that the Consortium listserv should continue to function as a tool for disseminating information of import to Consortium members and for notices of an administrative nature,
- ◆ that a separate, more open listserv be established wherein those in the pain community could discuss scientific matters,
- ◆ that a web-based forum be created which would allow lay persons with questions on pain related matters to connect with those with expertise in the appropriate field.

Budget: \$39,000

- Web hosting services - \$14,000 per year
- Design (\$2,000) and maintenance (\$1,000) of website and listserv - costs are per year
- Information retrieval on prevalence of pain and its social and economic impact - \$10,000
- Secretary assistance, half-time, and benefits - \$12,000 per year

Appendix 3

TASK FORCE II – PAIN RESEARCH AND MANAGEMENT STRATEGIES

Task Force Participants

Task Force Leader: Michael W. Salter

Task Force Members: Frances Abbott, Robin Cohen, Joan Crook, Gilles Lavigne, Angela Mailis, Patrick McGrath, Brian Milne, Dwight Moulin, Greg Ross, Jana Sawynok, Peter Soja, Lewis Slotin

Background

The general purpose of this Task Force was to foster current identified strengths in research, measurement and clinical management, which are collectively identified as such, and to set in place mechanisms to promote the further development of these strengths, such as the means of attracting research funds from government, non-governmental agencies, charitable foundations, patient-oriented groups and industry.

Potential areas of fruitful research opportunity include:

- ◆ Research themes - common to cross-cutting areas: genetics of pain; molecular/cellular/neural systems of nociceptive transmission and modulation; development of nociceptive and modulatory systems; human somatosensory physiology, psychophysics and imaging; validation of experimental models; clinical trials; epidemiology; pain economics; dissemination/changing clinical practice (evidence-based guidelines);
- ◆ Cross-cutting areas – bridging research themes: pain in neonates and children; neuropathic/neurogenic pain; musculoskeletal pain; visceral pain; orofacial pain; acute pain/postoperative pain/prevention of chronicity; cancer pain; pain and gender; pain and aging; pain and sleep; pain in patients with limited ability to communicate;
- ◆ Emerging areas/new targets/new technologies: diagnostic tools – molecular imaging; pain genomics/pharmacogenomics; proteomics; stem cell technologies; bio-informatics; advanced health care delivery systems; alternative/complementary therapies.

Recommendation 1 - Role of the Consortium in Research:

- ◆ that the role of the Consortium should be to help guide and facilitate research but not to mandate specific research directions. The overall research framework in Canada must be kept dynamic, progressively evolving as new discoveries and insights are made. The fundamental objective is to develop a framework for achieving meaningful research goals that will ultimately lead to changes in pain management and other practices that will

improve the health of Canadians suffering with pain,

- ◆ that the Consortium be a “pain resource” for funding agencies for advice on strategic directions, expert reviewers for grant panels, members of council, institute boards, etc,
- ◆ that the Consortium serve as a source of information and advice to those interested in developing new multi-investigator research programs in Canada and to those interested in developing research programs with the private sector,
- ◆ that the Consortium encourage and help establish new partnerships between key interest groups – lay, industry, government – in the development of research programs.

Recommendation 2 – The Principle of Peer Review:

- ◆ that peer review be entrenched as a basic principle in all relevant Consortium activities,
- ◆ that the Consortium encourage all grant and training programs, regardless of funding source, to be awarded on merit, as judged by rigorous and high quality scientific peer review. To avoid conflicts of interest, these peer-review committees should be set up to run independently of the organization funding the program.

Recommendation 3 – Databases on Pain-related Information:

- ◆ that an integrated database of pain management facilities in Canada be developed which would serve as a focal point for the collection and dissemination of information on the impact of pain on the life of Canadians which would then be used to educate key policy makers and the general public about pain related issues,
- ◆ that an integrated database of pain research facilities in Canada be developed which would identify areas of opportunity under CIHR and other granting programs, such as the National Centres of Excellence (NCE) and the Canadian Foundation for Innovation (CFI), which would be of interest to members of the pain community,
- ◆ that these databases be managed by a single organization so that efforts can be coordinated in the collection and dissemination of information.

Budget:

- Administrative: \$4,000 per year
- Database development: \$25,000 (one time cost)
- Database maintenance: \$10,000 per year

Recommendation 4 - Research Agenda:

- ◆ that multi-investigator pain initiatives be promoted to take advantage of the latest research potentials offered by cross-cutting techniques and the synergy potential of the pain community in Canada.
- ◆ that more young investigator programs be developed to ensure good career progression opportunities to those in the pain community and to encourage those interested in science to consider pain research as an attractive option.
- ◆ that, with the increased competitiveness of major operating grant programs, financial seed support be made available to fund novel experimental approaches to provide the preliminary evidence demanded by granting panels.

Budget:

- Grants program - Current research grant funds from all sources, awarded to members of the Consortium, total more than \$13,000,000 per year. The total funds currently supporting all pain research in Canada cannot be estimated presently.

- Trainee awards program - At present there are 230 trainees in the research groups of the members of the Consortium. Stipends from all sources for these trainees total more than \$1,300,000 per year. The total funds currently supporting all trainees in pain research in Canada cannot be estimated presently.

- Team grants program - Possibly as a result of the interdisciplinary nature of pain research, members of the Consortium are highly interactive with other researchers. The total team grant support coming to members total more than \$960,000 per year.

- Career awards program - As indicated elsewhere in this document, Canadian pain researchers comprise a distinguished group. Twelve of the members of the Consortium receive their salary as an award for a total of more than \$700,000 per year. In addition, six members have endowed chairs from their respective universities.

- Equipment grants program - World-class research requires use of state-of-the-art equipment. Funds coming from all sources to members of the Consortium for the purchase of equipment total more than \$6,700,000 this fiscal year, \$6,200,000 from the Canada Foundation for Innovation, \$500,000 from CIHR and \$60,000 from other sources.

Appendix 4

TASK FORCE III – EDUCATION AND TRAINING INITIATIVES

Task Force Participants

Task Force Leaders: Yves de Koninck, Judy Watt-Watson

Task Force Members: Manon Choinière, Jonathan Dostrovsky, Alex Jadad, Mary Lynch, Patricia McGrath, Gary Rollman, Bonnie Stevens

Background

The general purpose of this Task Force was to promote cross-training and interdisciplinary sharing, and to disseminate information about training opportunities. Pain research, despite its importance at both clinical and cellular levels, is currently underdeveloped. Canadians are leaders amongst the eminent scientists in this field in the world. However, their contribution to science and education needs to be more formally recognized by the creation of a database of established centres and programs. Current training opportunities need to be identified, evaluated, and developed further. Problems identified in attracting applicants to pain-related training opportunities have included inadequate financial incentives and career support, little or no articulation between programs and minimal marketing of available opportunities and of unique centre interests.

Recommendation 1 - Canadian Pain Training Database:

- ◆ that a survey be conducted of Canadian University Health Science Departments and associated Campuses/ Hospitals/ Agencies/Laboratories and related Societies (e.g. CPS, specialty societies with pain interest groups/ standards e.g. oncology, anaesthesia, cardiology) to determine:
 - a. current opportunities for basic and clinician scientist trainees,
 - b. pain-related areas of research activities and expertise,
 - c. evaluation methods of adequacy and relevance,
 - d. possible connections with other centres/programs/researchers,
 - e. the degree to which Centres or individuals need trainees or would welcome trainees,
 - f. the roster of suitable senior mentors available to be resources for interested trainees,
 - g. funding sources for existing trainee programs at all levels, including faculty entry-level,

- ◆ that this information, once gathered, be assembled into an integrated database which will be used to improve existing programs and to identify gaps in training which may currently exist,
- ◆ that this database also be used to provide a centralized mechanism to disseminate information about training programs, research programs, research mentors, and funding to the pain community and other relevant groups.

Budget:

- Administrative: \$4,000 per year
- Database development: \$25,000 (one time cost)
- Database maintenance: \$10,000 per year

Recommendation 2 - Evaluation of Existing Training Programs:

- ◆ that an evaluation mechanism for existing training programs be established. Accreditation processes currently being utilized need to be included (e.g. academic, professional, associations/ societies), and existing programs need to be reviewed to ensure that they include:
 - a. purpose, scope, priorities of training (e.g. clinical and/or basic scientist),
 - b. description of standards and criteria used in determining eligibility of trainees,
 - c. level and type of trainee (e.g. undergraduate, graduate, postdoctoral, medicine, nursing, dentistry),
 - d. residency requirements for specialties (e.g. anaesthesia, surgery, oncology etc.: liaise with Royal Colleges for residency standards),
 - e. focus of research related to pain,
 - f. type and duration of exchanges between centres/ programs,
 - g. other components of training programs such as ethics, clinical management, clinical effectiveness, research dissemination, etc.,
 - h. role of other societies (e.g. Canadian Medical Association, Canadian Pain Society),
 - i. relationship with existing clinical training fellowships (e.g. MRC/CIHR, NHRDP, Heart & Stroke),
 - j. funding/ resources/ partnerships,
- ◆ that following this analysis, and through the use of program adequacy and relevance data, gaps and inconsistencies in existing pain education training programs be addressed in order to develop the pain community's research capacity.
- ◆ that this evaluation, once complete, be used as a model for developing new training programs in areas where gaps have been identified.

Recommendation 3 - National Pain Training Program:

- ◆ that a National Training Program be established to circulate the names and area of specialization of pain researchers to potential trainees, to serve as a resource for orientation of young scientists interested in the field and to create a fellowship program with the potential for matching funds from organizations such as Health Canada and private foundations,
- ◆ that this program include but be not limited to the following aspects:
 1. links and information exchange between training programs and member laboratories and the development of joint programs,
 2. the development of interdisciplinary training programs, training grants for regional research groups, and the promotion of cross-training amongst the community,
 3. the development of exchange programs for trainees involving various experts, i.e short-term laboratory exchanges to develop a research component with related experts, whether this be within a discipline or amongst closely related disciplines,
 4. the creation of additional competitive awards and support programs to attract the highest quality graduate students, post-doctoral fellows, and career scientists within all disciplines. The target for these programs should be a total of nine per category (PhD, Post-Doc, Medical), allowing for a three-year tenure of each award with three awards per category being awarded each year.

Budget:

- Administrative coordinator (half-time) to carry out all the programs: \$25,000 per year
- Administrative costs as above: \$4,000 per year
- Research and analysis: \$20,000 (one time cost)
- Database development: \$25,000 (one time cost)
- Database maintenance: \$10,000 per year

Appendix 5

TASK FORCE IV – KNOWLEDGE TRANSFER

Task Force Participants

Task Force Leaders: A. John Clark, Patrick J. McGrath

Task Force Members: Manon Choinière, Terence Coderre, Yves De Koninck, Jonathan Dostrovsky, Gilles Lavigne, Mary Lynch, Angela Mailis, Dwight Moulin, Alfredo Ribeiro-da-Silva, Gary Rollman, Bonnie Stevens, and Judy Watt-Watson

Background

The main goal of the Consortium is to promote and facilitate research about pain.

The targets for knowledge transfer include practitioners, researchers (basic and clinical scientists), policy makers (professional bodies, government, funding agencies, health facilities), patients/public, administrators, regulatory bodies, industry and undergraduate/postgraduate students.

The steps in knowledge transfer will vary, depending on whom the transfer is occurring between. As an example, several levels occur from the basic sciences to patient care. These include the basic scientist to the clinical scientist, and thence to tertiary care, to primary care, and subsequently to the media and the public. There are major differences and variances in how different groups obtain and assimilate information.

The Consortium should facilitate effective transfer of information that results in an improvement in pain-related research. Success in this respect includes having pain assessment as a part of the hospital accreditation process in Canada, which would be comparable to a recent decision to have pain recognized as a 5th vital sign in the US.

There are numerous resources available for the dissemination of information including the print media, internet, centres of learning, continuing and professional development (CPD), clinical fellowships and clinical/research fellowships, and undergraduate/postgraduate training programs/positions.

The Consortium will work in partnership with other groups to promote knowledge transfer. For some issues the Consortium will lead; in others it will be supportive. For example, the Consortium will be a source of information to develop guidelines/position papers on outcome measures, but it is more appropriate that professional bodies take the lead in their establishment. However, it should be noted that research into effective knowledge transfer is a central part of the mission of the Consortium.

Recommendation 1 - Canadian Pain Research Database:

- ◆ that the Consortium develop a database of all centres and individuals conducting pain research in Canada. This database will serve as the basis for identifying individual interests and expertise and will help to establish networking opportunities amongst established groups in areas of emerging cross-cutting research,
- ◆ that a standard web-based system be developed so that members of the pain community can register their particular interests and research programs with the database,
- ◆ that this database also be designed in a sufficiently broad manner so that access to populations that might be of interest to other researchers would be included.

Budget:

- Database development: \$15,000 (one time)
- Database maintenance: \$12,000 per year
- Administrative costs: \$2,000 per year

Recommendation 2 -- Development of Common Outcome Measures:

- ◆ that a consensus conference to define the types of outcome measures and the methods for selecting outcome measures across different types of pain or populations be held. The resulting consensus statement will guide development of sets of common outcome measures in specific areas,
- ◆ that the Consortium encourage and promote consensus conferences, requests for proposals (RFPs) and other methods to promote the development of common outcome measures in specific areas.

Budget:

- Consensus conference costs: \$50,000 (one time)
- Administrative and maintenance costs: \$2,000 per year
- Costs associated with generation of a Position Statement on Outcome Measures - \$12,000.

Recommendation 3 - Health Systems Research:

- ◆ that the Consortium promote health systems research including outcomes research, dissemination research, practice utilization research, and patterns of practice research through a series of bottom up and top down methods. Individuals will be brought

together at Consortium meetings and at a yearly joint workshop on health systems research to be held in conjunction with the Canadian Pain Society,

- ◆ that a clearing house on opportunities through CIHR, CHSRF and other sources of available funding for health systems research be established for the pain community. This clearing house should be established in the form of a readily accessible web-based user interface database,
- ◆ that lobby efforts be undertaken so that pain will be included in calls for targeted funding for health systems research.

Budget:

- Joint Workshop: \$25,000 per year
- Database development: \$20,000 (one time)
- Database maintenance: \$10,000 per year
- Administrative costs: \$2,000 per year
- Costs associated with a Position Statement on Health Systems Research - \$12,000.

Recommendation 4 - The Pain Community:

- ◆ that the formation of multi-centre groups for the development of randomized clinical trials and other types of multi-site studies must be encouraged and supported,
- ◆ that Topic Interest Groups should be encouraged to form,
- ◆ that programs to cover infrastructure support costs for these groups be developed,
- ◆ that workshops on Good Clinical Practice for the training of personnel must be established,
- ◆ that the Consortium assist these efforts by providing information on existing opportunities through its database, technical expertise and professional advice on establishing programs and trials, and by lobbying for increased sensitivity towards the need of infrastructure support costs in the critical start-up phase.

Budget:

- Administrative expenses, database maintenance and lobbying: \$10,000 per year
- Workshops on Good Clinical Practice - two each at \$12,000 - total \$24,000 per year

Recommendation 5 - Development of Treatment Guidelines:

- ◆ that Evidence Based/Best Practice Clinical Treatment Guidelines be developed and updated in light of the latest available data,

- ◆ that the Consortium work in conjunction with other key stakeholders, eg. the CPS, to develop a Canadian depository of relevant practice guidelines. The major role of the Consortium will be to advocate the use of appropriate mechanisms to develop and evaluate guidelines.

Budget:

- Database development: \$15,000 (one time)
- Database maintenance: \$12,000 per year
- On-going research and analysis: \$20,000 per year
- Administrative costs: \$2,000 per year

Recommendation 6 - Public Education:

- ◆ that the dissemination of information about pain research to the public is essential to achieve the long-term goal of improving the healthcare of Canadians,
- ◆ that workshops on how to effectively use the media to communicate a message are essential to address a lack of expertise in this area amongst the Canadian pain community,
- ◆ that these workshops should be run in conjunction with other community activities such as the CPS Annual Meeting, Consortium Meetings or similar events,
- ◆ that a clear public relations plan and public education strategy be developed for the pain research community in Canada. These should take into account the various levels -- general public, policy makers, lay groups -- which must be targeted individually or in tandem,
- ◆ that the dissemination of information about pain treatment to patient groups is a vital part of the pain community's strategy to improving the healthcare of Canadians. Mechanisms should be established to improve the flow of information concerning the latest recommended treatment methods and clinical trials to patient populations.

Budget:

- Media workshops: \$10,000 per year
- Public relations: \$50,000 per year

Appendix 6

TASK FORCE V : INTERACTIONS OUTSIDE CONSORTIUM

Task Force Participants

Task Force Leaders: Andy Dray & Barry Sessle

Task Force Members: Cathy Bushnell, Robin Cohen, James L. Henry, Celeste Johnston, Chris Loomis, Harold Merskey, Brian Milne, Michael W. Salter, Jana Sawynok, Lewis Slotin, Peter Soja

Background

The general purpose of this Task Force is (i) to set in place mechanisms for identifying specific needs of the community of pain researchers and managers, (ii) to foster interaction with already established pain groups and organizations, such as the Canadian Pain Society, the Canadian Pain Foundation and the *Journal of Pain Research and Management*, for mutual benefit, (iii) to establish a system to promote the dissemination of information to the community at large, (iv) to promote technology transfer to and interaction with the commercial sector and (v) to pass on visions of future priorities to policy-makers at the political level. This Task Force is the precursor to the Technology Transfer Program which the Consortium will develop in concert with other stakeholders over the next few years.

It was recognized that the role of this Task Force is not to set priorities for pain research, education or training needs, but that it is to develop the mechanisms which the Task Forces will require to implement their mandates. Establishing these mechanisms is essential to the long-term objectives of the Consortium as outside buy-in and committed support (CIHR, industry, insurance companies, pain foundations and support groups, etc) are vital to the pain community.

Recommendation 1 - Pain Research Community:

- ◆ that it clearly identify and inventory the needs, capabilities and current interactions of the pain research community as a preliminary measure,
- ◆ that this evaluation, once complete, should be compiled as an integrated database, evaluated, and the strengths and weaknesses of the community be identified,
- ◆ that other research tools -- such as the Cochrane data-base for world wide trials and clinical research -- be employed in concert with this analysis to assemble a strategy for the pain community in its dealings with external bodies.

Recommendation 2 - Lay Groups:

- ◆ that a systematic analysis of those lay groups which are connected with, or which might become connected with, pain research be undertaken. Particular attention must be devoted to patient and support groups which have an immediate relation to pain, but other groups, such as consumer associations, retired peoples associations and similar pressure groups should not be overlooked,
- ◆ that following this analysis, steps be taken to strengthen, or in some cases develop, ties with the identified bodies, listening to their concerns, and finding common ground upon which a mutually beneficial relationship might be developed,
- ◆ that in all of these measures the Consortium work in close tandem with other key stakeholders, in particular the Canadian Pain Society and the Canadian Pain Foundation.

Recommendation 3 - Industry:

- ◆ that interactions with Industry be considered of special importance as Industry could be both sponsor of and user of the information and expertise in the pain research community,
- ◆ that an education program be established for the pain research community which would include workshops on what Industry needs are from partnership agreements, negotiation of technology transfer agreements and patent requirements, and similar matters,
- ◆ that opportunities for scientific and social interactions between Industry and the pain research community be increased,
- ◆ that mechanisms should be established which would encourage mutually beneficial collaborations between Industry and the pain research community, including such likely partnership areas as:
 1. animal and clinical modelling of pain states for evaluation of analgesics,
 2. database construction on preclinical pain research facilities in Canada,
 3. database on basic and clinical pain research training facilities,
 4. database construction on pain management facilities,
 5. database on the epidemiology of pain, including a geographical breakdown,
 6. clinical trials information, design and performance,
 7. co-operative intellectual property development
 8. gathering and sharing of socio-economic information on the burden of poorly treated pain,
 9. improved methods of pain diagnosis (genomics and proteomics methods) with the

long term view of personalized treatment of pain.

Recommendation 4 - Policy Makers:

- ◆ that the pain research community needs to develop a more effective lobbying strategy to ensure that pain issues are reflected in all relevant public policy decisions,
- ◆ that information sessions on how the policy making process works and how it can be influenced be held for interested members of the pain research community,
- ◆ that the pain research community work in concert with lay groups and other NGOs to achieve common objectives.

Recommendation 5 - Public Education:

- that a comprehensive plan be developed to educate the general public on pain research-related issues and on what the pain research community in Canada is doing to help pain sufferers,
- that in pursuit of this policy, strong links with the media be established to ensure that the pain research community's message is effectively communicated,
- that a series of public events on pain research-related matters be organized on both a regional and national level to raise the profile of the pain research community in Canada. Special note should be made that events such as a Travelling Speaker's Program would provide forums in which to combine target audiences -- Industry sponsorship of such programs would simultaneously increase mutually beneficial communications between the pain research community and Industry and it would also achieve its public education aims.

Budget:

- Administrative costs: \$4,000 per year
- Database design and research: \$20,000 (one time)
- Database maintenance: \$10,000 per year
- Coordination and lobbying: \$15,000 per year
- Workshops & information sessions: \$20,000 per year
- Travelling Speakers Program: \$15,000 per year (5 speakers)
- Other Public Education programs: \$10,000 per year

Appendix 7

REPORT OF TASK FORCE VI: SOCIETAL ISSUES

Task Force Participants

Task Force Leaders: Mary Ellen Jeans, Patricia McGrath

Task Force Members: Alex Jadad, Frances Abbott, Joan Crook, David Goldstein, Greg Ross, Carl Von Baeyer

Background

The general purpose of this Task Force is to develop a framework for identifying and addressing the societal issues relevant to understanding and treating the pain problems of all Canadian citizens, recognizing that there are unique pain problems for different subgroups of the diverse population. Studies from many countries have shown that the prevalence of different types of acute, recurrent, and chronic pain varies by age, by sex, and perhaps by ethnic background. Differences in pain problems may reflect subtle differences in underlying mechanisms, sensitivities, or environmental risk factors. Yet, few population-based studies have been conducted in Canada so we lack important data about the unique pain problems of all Canadians. In particular, we lack data on the impact and burden of pain for individuals, society, the health care system and the economy.

In addition, all Canadians should have informed access to the rapidly increasing variety of drug, physical, psychological, and complementary therapies required to treat pain. The Task Force recognized that there has been a continuous increase in the need for pain relief across society combined with an unprecedented explosion in knowledge and development of information technology available to the public so that the public is increasingly involved in health and health-related decisions. Yet, there is evidence of wide gaps in society in terms of access to knowledge, technology and pain services. Information on treatment efficacy should be based on evidence from relevant study populations and disseminated efficiently in an understandable format to the public.

Recommendation 1 - Epidemiological Research to Identify the Unique Needs of Canadians:

There have been excellent individual efforts in Canada and abroad to study the prevalence of different types of pain. However, methodological differences and lack of coordination among investigators has produced data of limited value to guide pain research and specific clinical or policy decisions. Generally the efforts of academic groups have been cross-sectional and intensive, while those of government agencies have been longitudinal but not as intensive.

The Task Force recommends that resources be allocated to assess the magnitude and impact of pain as a problem for Canadian society. Specific recommendations include the following.

- ◆ that a database be created with data about researchers, projects and datasets in relation to pain in Canada,
- ◆ that identification be undertaken of priorities, questions, variables, formats and criteria to judge the value of existing datasets,
- ◆ that a database of existing and needed connections among researchers, datasets and producers of pain-related data in Canada,
- ◆ that sources and opportunities for funding be identified for new epidemiological studies (ideally longitudinal and deep) and for mining existing databases,
- ◆ that a core set of items be created to enable collaborative efforts to study the epidemiology of pain in Canadian society,
- ◆ that “The Canadian Pain Study” be undertaken as a large, prospective, longitudinal, epidemiological study of the presence and impact of pain throughout Canadian society. Efforts should be made to promote independent but integrated studies, and to piggyback epidemiological studies to other existing, planned or ongoing initiatives.

Recommendation 2 - Considerations within the Health Care System:

- ◆ An extensive study and evaluation should be undertaken on three levels: the “micro” level, which includes patients, families, providers, care givers or individual members of the public; the “meso” level, which includes communities, health care institutions or health authorities; the “macro” level, which includes the national economy or the health care system as a whole.
- ◆ Included in this study should be outcomes as varied as the impact of pain on the Gross National Product, on the health budgets, on health service allocation, on well-being and on quality of life.
- ◆ Assessment of the decision-making process about the diagnosis and treatment of pain at all levels within the health care system must also be included.
- ◆ This study must also integrate societal attitudes, knowledge and skills about pain and its management at all levels, as a means of understanding their impact on pain and suffering as well as on pain relief.
- ◆ Mechanisms and processes should be recommended to evaluate the appropriateness of decisions about pain and its management at all levels.
- ◆ It is important that the data collected are representative of all Canadians. For example, some groups may require special attention during any epidemiological study. They could be identified using different approaches such as, selection according to demographic characteristics (e.g., age, gender, SES, literacy levels, cultural background, employment status), the etiology of the pain (e.g., cancer, work-related) or co-morbidity (e.g., people with cognitive impairment, depression, etc.). It was identified as essential to ensure that the needs of special groups be discussed during the design of epidemiological studies, building bridges to connect research groups with common and complementary interests.

Recommendation 3 - Assessment of Pain Services:

In association with representatives from organizations such as the Canadian Institute for Health Information, accreditation bodies and the International Association for the Study of Pain (IASP), the Consortium should develop a feasible system for assessing the quality of pain services in Canada.

- ◆ Using acute pain as a model, it is necessary to learn more about the assessment of pain services in general and draw on these efforts to assess other types of health services within and outside Canada.
- ◆ It is necessary to identify and validate measures of the appropriateness of staff and facilities across different settings, the attitudes of payers about the services, and the level of continuity of care across settings and groups of providers.
- ◆ It is important and relevant to identify elements that are likely to increase the effectiveness and efficiency of different types of service, as well as predictors of failure (e.g., lack of continuity).
- ◆ Potential barriers to change must also be identified.

Recommendation 4 - Ethical Issues:

The Task Force recognized that many important ethical issues in pain research, education, and management are facing society. In collaboration with the Canadian Pain Society and professional ethicists, the Consortium should facilitate research and education on ethics in pain.

- ◆ Special concerns in conducting animal research must be addressed (e.g., the impact on animals of chronic pain models, criteria for the use of anaesthesia and LD50 for research, the need for appropriate integration of clinical management and research protocols).
- ◆ The unique challenges of clinical research on pain must be identified and assessed (e.g., regulatory issues that promote clinically irrelevant studies, the design of efficacy vs. effectiveness trials, issues related to equipoise, informed consent).
- ◆ Accurate and evidence-based information on diagnosis and treatment must be promoted (e.g., the use of strong analgesics to hasten death, the use of opioids and other psychotropic drugs in an “opio-phobic” society).

Recommendation 5 - Immediate Promotion of Pain Awareness:

- ◆ Awareness about the existence and goals of the Consortium must be raised and promoted. This could be achieved through an immediate press release directed to the Canadian Institutes for Health Research, universities, media and the public.
- ◆ The issue of pain as a significant socioeconomic factor in society must be promoted in priority-setting at academic institutions: The Consortium could act as a catalyst to persuade universities of the importance of the study of pain and to motivate the creation of professorial chairs and graduate programs to promote the study of pain.

- ◆ Collaborations among and across groups should be encouraged. The Consortium is in a privileged position to facilitate strong links among groups with common interests operating throughout Canada.
- ◆ The Consortium is also uniquely positioned to foster strong proposals for submission to major funding agencies, contributing to the allocation of adequate levels of funding to the right type of studies. It is important to capitalize on opportunities to encourage increased funding for pain research at all levels, through programs such as Requests for Proposals.

Recommendation 6 - Collaborative Liaisons:

- ◆ Those in the pain research community should be encouraged to attend to current trends outside the traditional realm of epidemiological pain research (e.g., changes at WHO, emphasis on quality of life, views on health that go beyond illness).
- ◆ Opportunities should also be explored to interact with international efforts led by Canada that relate to pain (e.g., research funded by the Canadian International Development Agency on landmines),
- ◆ Efforts must also be made to facilitate the collection and analysis of documents on pain produced by Canadian professional organizations (e.g., reports by the Canadian Nurses Association).
- ◆ Strong links should be established with consumer (e.g., Consumers Association of Canada, Arthritis Society, Canadian Cancer Society) and professional organizations (e.g., Victorian Order of Nurses) interested in the societal impact of pain in Canada.

Budget

Administrative costs: \$12,000 per year

Epidemiological research development: \$20,000 (One time cost)

Personnel support for leader (to devote 10 - 15% of time to project): \$15,000 per year