

**Arthritis isn't a big deal...
...until you get it.**

Ask 4 million Canadians.

Report from the

**Summit on Standards for
Arthritis Prevention and Care**

**November 1 – 2, 2005
Ottawa, Ontario, Canada**

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Executive Summary

Arthritis is everywhere. Arthritis destroys lives – young and old alike.

Four million Canadians have arthritis today. Arthritis knows no age limits. Children and adults of all ages get arthritis. Arthritis comprises over 100 different conditions and is the leading cause of deformity and long-term disability in Canada. It is one of the major reasons why people over 65 years of age visit their family physician. The burden of illness in the population due to arthritis is increasing due to increased longevity, reduced physical activity, increased obesity and lack of access to timely health care to mitigate disability.

Arthritis is costly to society. The inability to work and/or live independently and lost opportunities have a devastating impact on the lives of four million Canadians. Strategies must be developed to reduce the burden of arthritis in our population. Unless these strategies are developed immediately, it is anticipated arthritis will place an even greater stress on the health care system over time and will continue to destroy lives.

The impact of arthritis on Canada's Aboriginal communities

Arthritis is up to two-and-a-half times as common in the Aboriginal community living off reserve (Public Health Agency of Canada, 2003) as in non-Aboriginal Canadians. Overall, 27% of Aboriginal people living off reserve have arthritis compared with 16% of the general Canadian population. However, arthritis receives little attention as a significant health issue within the Aboriginal community.

Cost is a significant barrier for people with arthritis to receive appropriate medications and other treatments.

Canadians with arthritis from coast-to-coast do not have consistent or equitable access to the best evidence-based treatments available today. Where you live can be more important in determining treatment than how sick you are. Provincial, territorial and private drug plans vary considerably in their coverage of prescription medications for arthritis, in particular those medications that are the most costly to patients. There are also regional variations in availability of chronic illness self-management strategies, rehabilitation services and surgery.

Canadians with arthritis make up the lion's share of those on joint replacement wait lists.

Over 90% of people who undergo hip or knee replacement surgery have arthritis – fewer than 10% undergo this procedure for other conditions, such as hip fracture. Of those who have hip or knee replacement surgery for arthritis, approximately 95% have osteoarthritis (Hawker 1998, Katz, J. N. 2001).

Wait times for joint replacement surgery in Canada have been identified as unacceptable. According to the 2002 *Fraser Institute Waiting Times Survey* (Esmail & Walker 2002), waits for consultation with orthopaedic surgeons, and waits from decision to proceed with joint replacement to time of surgery exceeded all other waiting times in Canada (median wait from General Practitioner to surgeon 12.7 weeks; median wait from decision to surgery 19.3 weeks). The number of patients who wait more than a year for surgery has grown exponentially, and continues to grow. In 2001, approximately 20% of patients waited more than a year for a first hip replacement, and almost 30% waited this long for a first knee replacement. Hip and knee replacement surgeries help people return to work and get on with their lives: strategies to reduce these unacceptable wait times are urgently needed. Several approaches are currently being evaluated across Canada. Although the focus of attention has been on hip and knee joint replacement surgery, attention is also needed to the prolonged wait times for other orthopaedic surgeries people with arthritis frequently require.

The arthritis community is united.

In 2002, arthritis community stakeholders came together to form the Alliance for the Canadian Arthritis Program (ACAP) to work towards changing the inequities that exist across Canada in arthritis prevention and care.

More than 20 organizations make up ACAP. While each group continues its own specialized work, ACAP provides a central focus for national arthritis-related initiatives.

Importantly, the forming of ACAP means the many voices of the arthritis community are united and deliver to government one consistent set of key messages.

The Summit on Standards for Arthritis Prevention and Care makes health care policy history.

In 2005, ACAP determined its focus would be to take action on the lack of arthritis prevention strategies and the widely prevailing disparities in arthritis diagnosis, treatment, and care for Canadians with arthritis by convening a Summit on Standards for Arthritis Prevention and Care.

The Summit marked the first time in history an entire disease community united to gather research evidence and establish acceptable, achievable standards to improve arthritis prevention and care across Canada.

A key objective of the Summit was to build on work done to date in the arthritis community to improve awareness, prevention and care for people living with the disease, including strengthening the *Arthritis Bill of Rights* developed in 2001 (The Arthritis Society 2001).

The Summit was the culmination of "*Rock This Joint 2005 – Bringing Together Arthritis Knowledge and Action*," an ACAP initiative that saw eight days of high-level arthritis meetings in Ottawa from October 27 to November 3, 2005.

The arthritis community develops actionable standards for arthritis prevention and care.

The Summit generated consensus across the entire spectrum of the arthritis community: consensus on standards that need to be implemented now; standards that need further refinement and development; areas where more research is needed before moving forward, and action plans for each.

Most importantly, the Summit generated consensus, leading to the point where the many voices of the arthritis community (consumers, professionals and stakeholders of all kinds) are agreed on the steps that must follow.

This report lays out the work accomplished. Already, the Summit organizers are hard at work on the next steps. These include: identifying from the volumes of work completed the "early wins" that can be implemented immediately; and working with all the partners, including people with arthritis, government, health care providers, health researchers, policy makers and industry, to improve the lives of Canadians living with arthritis.

Arthritis Partners:

Dr. Elizabeth Badley, Arthritis Community Research & Evaluation Unit
Ms. Angelique Berg, Canadian Orthopaedic Foundation
Mr. Emidio DeCarolis, Pfizer
Ms. Louise Desjardins, Institute of Musculoskeletal Health and Arthritis,
Canadian Institutes of Health Research (CIHR)
Mr. Jean-Francois Dicaire, Abbott Laboratories Limited
Ms. Anne Dooley, Canadian Arthritis Patient Alliance
Dr. Ciaran Duffy, Canadian Paediatric Rheumatology Association
Dr. John Esdaile, Arthritis Research Centre of Canada
Mr. John Fleming, The Arthritis Society
Dr. Cy Frank, Institute of Musculoskeletal Health and Arthritis, CIHR
Dr. Gillian Hawker, Rheumatologist / Researcher – Member at Large
Ms. Catherine Hofstetter, Canadian Arthritis Patient Alliance
Ms. Cheryl Koehn, Arthritis Consumer Experts
Mr. Jean Legare, Patient Partners in Arthritis
Ms. Sydney Linekar, Arthritis Health Professions Association
Ms. Jennifer Lothian, Amgen Canada Inc.
Ms. Anne Lyddiatt, Patient Partners in Arthritis
Dr. Dianne Mosher, Rheumatologist – Member at Large
Ms. Erynn Peters, Institute of Musculoskeletal Health and Arthritis, CIHR
Dr. Robin Poole, Canadian Arthritis Network
Ms. Ann Qualman, Canadian Arthritis Patient Alliance
Mr. John Riley, Canadian Arthritis Network
Mr. Michel Therriault, Merck Frosst
Dr. Peter Tugwell, Cochrane Collaboration
Mr. Gordon Whitehead, Consumer Advisory Board
Ms. Hazel Wood, Bone and Joint Decade
Dr. Michel Zumner, Canadian Rheumatology Association

Arthritis Standards for Prevention and Care:

1. Every Canadian must be aware of arthritis.
2. Every Canadian with arthritis must have access to accurate information and education on arthritis that meet a defined set of criteria and are appropriate to their age and stage of disease.
3. Participation in social, leisure, education, community and work activities must be an integral measure used to evaluate outcomes by health professionals, educators, policy makers and researchers.
4. Every Canadian must be informed about the importance of achieving and maintaining a healthy body weight, and actively encouraged to engage in physical activity to prevent the onset and worsening of arthritis.
5. All relevant health professionals must be able to perform a valid, standardized, age appropriate musculoskeletal screening assessment.
6. Inflammatory arthritis must be identified and treated appropriately within four weeks of seeing a health care professional.
7. Health care professionals must recognize osteoarthritis as a significant health issue and treat it according to current treatment guidelines (Jordan 2003).
8. Bone mineral density testing must be offered free to all women > 65 years, all men and women with low trauma fracture after age 40, and every Canadian of any age with risk factors for osteoporosis, according to current prevention and treatment guidelines (Brown 2002).
9. Every Canadian with arthritis must have timely and equal access to appropriate medications.
10. Post-approval evaluation of arthritis medications must be part of drug approval.
11. Patient preferences, including risk-benefit trade-offs, must be incorporated into regulatory decision making and prescribing of arthritis medications.

12. Every Canadian requiring joint surgery must wait no longer than six months from the time the decision to have surgery is made by the patient and physician.

Provisional Standards Requiring Additional Research

13. To prevent arthritis, every Canadian must understand and implement prevention strategies to reduce sport and recreation injuries.
14. Every Canadian with arthritis must have timely access to appropriate integrated health care, appropriate to their age and disease stage.
15. Every Canadian with arthritis will be enabled to participate in life roles that are important to them.

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SECTION 1

BACKGROUND

The Alliance for the Canadian Arthritis Program (ACAP), formed in 2002, brought together arthritis health care professionals, researchers, funding agencies, government, voluntary sector agencies, industry, and most importantly, representatives from arthritis consumer organizations from across Canada. ACAP was established to create a single voice for the four million Canadians with arthritis and bone disease. The common goal was to improve the lives of Canadians with arthritis by working as one to: improve access to care and treatment; to increase educational initiatives for to the arthritis community, the public, and health policy makers; and increase arthritis research efforts.

In January 2004, the ACAP steering committee asked, "What can be done by the ACAP community that will have the greatest impact on the lives of Canadians with arthritis?" ACAP recognized that if arthritis was to be prevented and the health of Canadians with arthritis improved, one of the most pressing needs was the establishment of standards for arthritis prevention and care. A Summit was proposed to develop standards that would build on the earlier Supporting Evidence (Appendix 1) and *The Arthritis Bill of Rights*. A Planning Committee was created with broad input from all stakeholders. The Planning Committee promptly determined the largest group attending the Summit would be people with arthritis – chosen to represent differing ages, genders, races/ethnicities, and geographic locations. Furthermore, all attending would be chosen because they brought a special perspective or skill to the planning process.

1.1 The Summit on Standards for Arthritis Prevention and Care Planning Process

The Summit Planning Committee brought together representatives from across the broad arthritis community, and for the first time in the history of national arthritis initiatives, the majority represented people living with arthritis.

Organizations represented on the Committee included:

Arthritis Community Research & Evaluation Unit
Arthritis Consumer Experts
Arthritis Health Professions Association
Arthritis Research Centre of Canada
Bone and Joint Decade
Canadian Arthritis Network
Canadian Arthritis Patient Alliance
Canadian College of Family Physicians
Canadian Orthopaedic Association
Canadian Orthopaedic Foundation
Canadian Osteoporosis Patient Network
Canadian Paediatric Rheumatology Association
Canadian Rheumatology Association
Children's Arthritis Foundation
Cochrane Collaboration
Consumer Advisory Council of the Canadian Arthritis Network
Consumer Advisory Board of the Arthritis Research Centre of Canada
Health Canada
Industry Representatives
Institute of Musculoskeletal Health and Arthritis
Patient Partners in Arthritis
The Arthritis Society
Youth with Arthritis

To conduct its work, the Summit Planning Committee met in person for three full-day planning sessions, as well as frequently between these meetings by teleconference.

To begin their work, the Planning Committee embarked on a process to identify the key issues facing Canadians with arthritis and their caregivers. The key issues were then grouped into three themes: Arthritis Awareness, Arthritis Prevention and Arthritis Management.

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SECTION 2

KEY ISSUES

2.1 Arthritis Awareness

There is a lack of awareness of arthritis among the public, government, employers, educators, health care providers and people at risk for and affected by arthritis. Indeed, arthritis is frequently perceived as a normal part of aging. This is particularly true for osteoarthritis. Although musculoskeletal (MSK) conditions represent up to one-fifth of all visits to primary care practitioners, there is a lack of confidence (including a lack of knowledge and skills) among primary care physicians in performing an arthritis screening assessment. This results in under-diagnosis and under-management of arthritis in the community. Reliable and valid screening tools exist but have not been introduced in Canada.

Musculoskeletal conditions also comprise the largest practice area for Canadian physical therapists and occupational therapists. Despite this, MSK conditions are under-recognized in the professional certification examinations. There are no minimum level practice standards or core curricula specific to arthritis/MSK in Canadian occupational therapy and physical therapy training programs and content varies across universities.

Delivering accurate information and high-quality educational programs is important to aid in the goals of changing attitudes and health behaviours. These programs need to target multiple groups: the general population, government policy makers, health care providers, people with arthritis, and their families, caregivers, teachers, etc. Strategies are also needed to ensure core competencies among health professionals about arthritis.

Arthritis affects participation in broad roles and societal activities such as employment, education, social involvement, personal relationships, and leisure activities. These roles are part of people's identity, current and future goals and aspirations such that participation, or lack thereof, impacts on life satisfaction and quality of life. Restrictions in participation are associated with emotional distress that may persist over time. Participation needs and goals will change across the lifespan. Assessment and intervention should therefore reflect these lifespan-related shifts, from childhood through adulthood and into the retirement years. A broad range of personal and contextual factors will also influence participation.

In spite of its importance, participation is under-evaluated as an important outcome to measure in clinical practice and clinical research, and by employers, educators and policy makers. The impact of difficulties in participation is under-evaluated.

The impact of interventions designed to improve participation has been under-studied. It needs to be recognized that facilitating change in participation will require the wide-ranging input and cooperation of many groups, including people with arthritis themselves, their clinicians, family, employers and policy makers.

2.2 Arthritis Prevention

Obesity is a recognized risk factor for both the development and progression of osteoarthritis. Attaining and maintaining a healthy weight, and weight reduction where appropriate, are therefore important prevention strategies for osteoarthritis. Physical activity is necessary to achieve and maintain healthy body weight, thus physical activity may indirectly prevent osteoarthritis. However, the type and dose (frequency and intensity) of physical activity that will assist in the prevention of osteoarthritis is not known. Furthermore, implementation of recommendations for physical activity is complex, involving consideration of many factors. These include: personal motivation and available time; costs and community access to facilities; promotion of activity by health care providers; provision of information and education; behavioural and social approaches; environmental approaches; and public policy.

At high levels of physical activity, as in organized sport, the potential for injury must also be considered. Lower extremity injuries account for more than 60% of all sport injuries in adolescents, with most common being knee and ankle injuries. Sports-related injuries result in dropout from sport (i.e. decreased physical activity leading to increased risk for obesity). Injuries are a leading cause of osteoarthritis in later life, in particular fractures and knee (meniscus and/or anterior cruciate ligament injuries), ankle, hip and foot injuries. Despite this, there is inadequate injury surveillance in sport (in particular child and adolescent sport), and inadequate knowledge of the risk factors for, and outcomes following, injury.

In people with arthritis and osteoporosis, physical activity has a beneficial effect on bone and joint health (physical and psychosocial functioning). However, as for prevention, the optimal 'dose' (i.e. frequency and intensity) and type of physical activity for persons with different types and severity of arthritis is not known. The lack of explicit guidelines for physical activity (i.e. a physical activity prescription) in people with arthritis or osteoporosis poses a significant barrier to increasing physical activity among these groups. Additional identified barriers to physical activity include: lack of motivation to exercise; arthritis-related fatigue; lack of sustainability; cost; lack of community accessibility; inappropriateness to age and disease status; lack of clarity regarding how best to deliver information about physical activity to parents, caregivers, children, and health providers; and lack of knowledge about appropriate physical activity among persons who deliver/prescribe physical activity and sports.

There is a need for evidence-based, cost-effective prevention and control strategies to be implemented in child and adolescent sport in order to prevent premature dropout from sport due to injury, and to enable Canadians to remain actively engaged in physical activity throughout their lives.

2.3 Arthritis Management

The current model of care delivery to people with arthritis is inadequate to meet the current and future (growing) population needs. There are not enough arthritis health professionals. (rheumatologists, orthopaedic surgeons, anaesthetists, nurses, occupational and physical therapists, primary care physicians, etc.). Furthermore, available arthritis health professionals are not being used efficiently (e.g. orthopaedic surgeons spend only one third of their clinical practice in the operating room). As a result, waiting times for consultation for conditions requiring specialist care (e.g. new onset inflammatory arthritis and orthopaedic surgery) are unacceptably long, resulting in suboptimal clinical outcomes, increased costs to the health care system and society, and reduced quality of life for people with arthritis. There is inadequate monitoring of wait times for essential arthritis services in Canada.

Guidelines exist for the diagnosis and management of osteoarthritis (*American College of Rheumatology Subcommittee on Osteoarthritis Guidelines, 2000*) and osteoporosis (Brown 2002), yet these guidelines are not being followed. Furthermore, self-management approaches have been used successfully in arthritis, but are currently underutilized.

Despite the establishment of a Common Drug Review process in Canada, there is unacceptable inequity in access to proven, cost-effective therapies for arthritis and osteoporosis for patients with similar diagnoses and severity of disease. There is inadequate post-marketing surveillance for adverse effects of approved medications. The preferences of people with arthritis are not currently considered in the drug review and approval process in Canada.

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SECTION 3

THE NINE TOPICS FOR STANDARD DEVELOPMENT

Once the three key themes were identified, distinct areas for standards development were outlined. They included the following nine topics:

3.1 Arthritis Awareness

1. Consumer and Public Awareness
2. Health Professional Education
3. Participation

3.2 Arthritis Prevention

4. Physical Activity
5. Injury Prevention

3.3 Arthritis Management

6. Access to a Diagnosis
7. Manpower and Models of Care
8. Access to Medications
9. Access to Surgery

Following the identification of the nine priority standards development topics, teams were formed to begin work on each topic. Team leaders were appointed for each team, and charged with the responsibility of developing a multi-disciplinary, multi-perspective team (Appendix II). Each team included at least one member of the public living with arthritis.

A standard was defined as an authoritative statement of minimum level of acceptable performance. The teams were charged with developing a small number of workable standards that were:

- *Evidence-based*
- *Concrete*
- *Pragmatic*
- *Actionable*
- *Responsive to the needs of people with arthritis*

A template for each standard was developed that included:

- *Key issues and needs for a standard*
- *The proposed standard*
- *Supporting evidence for the standard*
- *Outstanding research gaps and needs*
- *Barriers to implementation and strategies for implementation*
- *Potential measures for assessing implementation of the standard*

The teams met frequently by conference call. Team leaders met by conference call and twice in person to review the status of the standards of all the teams. The draft standards were sent out to the broader community, and the final draft version was presented and discussed at the Summit itself.

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SECTION 4

THE SUMMIT ON STANDARDS FOR ARTHRITIS PREVENTION AND CARE NOVEMBER 1-3, 2005

Two hundred Summit delegates met for two days, November 1-2, 2005 in Ottawa, Ontario. On the first day, the standards from the nine topics were reviewed and modified during two sessions attended by approximately 20 delegates. On the second day, the potential barriers to, and facilitators of, standard implementation were similarly discussed twice. Thus, every delegate reviewed two topics for the standards and two for implementation. Experienced facilitators from Health Canada assisted the discussions.

Over the two days, delegates heard keynote speeches by Dr. Matthew H. Liang of the Harvard Medical School, The Hon. Dr. Carolyn Bennett, Minister of State (Public Health), The Hon. Stephen Owen, Minister of State (Sport), and The Hon. Senator Pat Carney. Dr. Liang addressed the need for standards in a modern health care system, Dr. Bennett called for Summit delegates to bring forward solutions, Minister Owen noted the urgency of the fitness agenda and Senator Carney noted the power of a united group to effect change in a complex world.

Finally, an action plan was put forward that included, as a first step, the development of this report and its approval by ACAP.

Subsequent to the Summit, the team leaders carefully reviewed transcripts of their team's standard workshops and, where appropriate, made modifications to their standard(s) to ensure everyone's comments had been considered. These summaries provided the foundation for this report, which has been reviewed in its entirety by the Summit Planning Committee, all Standards Team Members and ACAP.

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SECTION 5

THE STANDARDS FOR ARTHRITIS PREVENTION AND CARE

5.1 Definitive Standards

1. Every Canadian must be aware of arthritis.
2. Every Canadian with arthritis must have access to accurate information and education on arthritis that meet a defined set of criteria and are appropriate to their age and stage of disease.
3. Participation in social, leisure, education, community and work activities must be an integral measure used to evaluate outcomes by health professionals, educators, policy makers and researchers.
4. Every Canadian must be informed about the importance of achieving and maintaining a healthy body weight, and actively encouraged to engage in physical activity, to prevent the onset and worsening of arthritis.
5. All relevant health professionals must be able to perform a valid, standardized, age appropriate musculoskeletal screening assessment.
6. Inflammatory arthritis must be identified and treated appropriately within four weeks of seeing a health care professional.
7. Health care professionals must recognize osteoarthritis as a significant health issue and treat it according to current treatment guidelines (Jordan 2003).
8. Bone mineral density testing must be offered free to all women > 65 years, all men and women with low trauma fracture after age 40, and every Canadian of any age with risk factors for osteoporosis, according to current prevention and treatment guidelines (Brown 2002).
9. Every Canadian with arthritis must have timely and equal access to appropriate medications.
10. Post-approval evaluation of arthritis medications must be part of drug approval.
11. Patient preferences, including risk-benefit trade-offs, must be incorporated into regulatory decision making and prescribing of arthritis medications.

12. Every Canadian with arthritis requiring joint surgery must wait no longer than six months from the time the decision to have surgery is made by the patient and physician.

Provisional Standards Requiring Additional Research

13. To prevent arthritis, every Canadian must understand and implement prevention strategies to reduce sport and recreation injuries.
14. Every Canadian with arthritis must have timely access to appropriate integrated health care appropriate to their age and disease stage.
15. Every Canadian with arthritis will be enabled to participate in life roles that are important to them.

SECTION 6

ACTION PLAN FOR STANDARDS IMPLEMENTATION

1. Standard: Every Canadian must be aware of arthritis.

Action Steps

- Take an inventory of existing public information sources on arthritis
- Develop a contact list of arthritis community members and a systematic approach to disseminate information to all members
- Develop partnerships with government and non-arthritis groups
- Capacity-build within the health professionals community to ensure demand from raised public awareness can be met
- Using a multi-media approach, create and launch a public awareness campaign with a few key messages targeting all age groups, cultures, and geographic regions

Facilitators

- Easy access to information
- Willingness of all groups to work together
- Keeping the message simple, real, unique (e.g. a memorable slogan)
- Fine tuning the standard to make it very clear, simple and provocative
- Existing government health website

Potential Barriers

- Cost
- Technological barriers
- Human resources (expertise, skill, capacity)
- Target group very large and geographically widely dispersed
- Varied languages, cultures
- Lack of public appeal of "arthritis"
- Pre-conceived myths, beliefs about arthritis, e.g. "only old people get arthritis"

2. Standard: Every Canadian with arthritis must have access to accurate information and education on arthritis that meet a defined set of criteria and are appropriate to their age and stage of disease.

Action Steps

- Establish a working group to facilitate the development of "quality standards" against which all arthritis information and educational materials can be judged

- Ensure input from all stakeholder groups, both nationally and internationally, in developing the “quality standards” to encourage international buy-in and use
- Establish a plan to build capacity for stakeholder review of publicly available arthritis information, which may include development of a national strategy for the delivery of accurate information about arthritis to the public at large, and high-quality educational programs to people with arthritis

Facilitators

- Consensus and buy-in among all groups involved, including international groups
- Credibility of the message bearers
- Willingness of all groups to work together
- Setting reasonable and achievable standards for information/education quality
- Information standardization model already exists in diabetes and in other disease settings

Potential Barriers

- Differing organizational needs
- Lack of resources (costs)

3. Standard: Participation in social, leisure, education, and community and work activities must be an integral measure used to evaluate outcomes by health professionals, educators, policy makers and researchers.

Action Steps

- Governments must invest urgently in continued development and testing of measures to evaluate participation across all ages and types of arthritis
- Incorporate evaluation of participation in clinical assessment of people with arthritis (across all age groups and types of arthritis)

Facilitators

- Recognition by arthritis organizations and funding agencies that participation in life roles matters as a health outcome
- Incorporation of evaluation of participation in clinical assessment of people with arthritis

Potential Barriers

- Lack of available valid and reliable measures of participation, applicable for all ages and stages of arthritis

4. Standard: Every Canadian must be informed about the importance of achieving and maintaining a healthy body weight, and actively encouraged to engage in physical activity, to prevent the onset and worsening of arthritis.

Action Steps

- Need for standardized quality, accessible, adaptable community-based programs/facilities
- Incorporation into a public awareness campaign – the strong message that physical activity and healthy weights are beneficial for arthritis (may prevent arthritis and reduce symptoms once arthritis is established)
- Incorporate arthritis into the Public Health Agency's (Health Canada) Physical Activity agenda

Facilitators

- Increased primary care physician awareness of prevention and treatment of osteoarthritis
- Integration of this message with current "physical activity" and "healthy weights" agenda

Potential Barriers

- Inadequate communication between primary care and specialist care
- Inadequate time
- Weight management programs largely unfunded
- Preventive care largely unfunded

5. Standard: All relevant health professionals must be able to perform a valid, standardized, age-appropriate musculoskeletal screening assessment.

Action Steps

- Validate a screening tool appropriate for use in clinical practice
- Develop plan to teach/disseminate
- Test students for acquisition/retention

- Review patient outcomes
- Develop core group of educators to implement above steps

Facilitators

- Buy-in of all health professionals' training bodies

Potential Barriers

- Lack of awareness that effective arthritis treatments exist

6. Standard: Inflammatory arthritis must be identified and treated appropriately within four weeks of seeing a health care professional.

Action Steps

- Develop, test, and then implement a clinical tool, intended for use in primary care practice and by other relevant health care professionals, to assist in the recognition of inflammatory arthritis
- Incorporate this arthritis screening "tool" into the training of all relevant health care professionals
- Establish maximum acceptable wait times for time-from-referral to consultation with rehabilitation health professionals for various arthritic conditions
- Increase continuing medical education and health professional directed knowledge translation activities regarding the diagnosis and management of inflammatory arthritis
- Develop incentives (and remove disincentives) for health care professionals to attend arthritis continuing medical education activities
- Increase awareness of arthritis among public (increase attention paid to new symptoms, demand diagnosis and treatment) and all primary care providers (Getting a Grip project)
- Guidelines appropriate for the context of primary care
- Empower people with arthritis to seek/demand care

Facilitators

- Involvement of government, people with arthritis and relevant health professionals in developing clinical tools
- Endorsement of the "tool-kits" by government, consumer organizations and health professional bodies

- Allow direct referral of people with possible inflammatory arthritis from all arthritis health professionals to rheumatology specialists
- Funding to allow for the assessment of alternative models of arthritis care that reduce wait time for consultation with arthritis specialists
- Funding of strategies to increase public and health professional awareness of arthritis

Potential Barriers

- Cost
- Differences across provinces regarding access to various arthritis health care providers
- Lack of sensitive, specific and feasible tests to diagnose some forms of inflammatory arthritis
- Capacity (human health resources, including training programs)
- Potential resistance among arthritis health care professionals to accept alternate models of arthritis care delivery

7. Standard: Health care professionals must recognize osteoarthritis as a significant health issue and treat it according to current guidelines.

Action Steps

- Ensure valid and reliable screening tool for arthritis incorporates identification of people with possible osteoarthritis
- Develop incentives (and remove disincentives) for health care professionals to attend arthritis continuing medical education activities
- Modify existing guidelines for osteoarthritis care such that they are appropriate for use in the primary care setting

Facilitators

- Increased public awareness that OA can be treated (demand care from physicians/other health care providers)
- Endorsement of the guidelines and practical tools by government, consumer groups and health professional bodies
- Empower people with arthritis to seek/demand care

Potential Barriers

- Cost

- Lack of perceived importance of osteoarthritis relative to other health conditions among health care providers and public (e.g. osteoarthritis is thought of as a normal part of aging)

8. Standard: Bone mineral density testing must be offered free to all women >65 years, all men and women with low trauma fracture after age 40, and every Canadian of any age with risk factors for osteoporosis, according to current prevention and treatment guidelines.

Action Steps

- Disseminate "tool kits" to support evidence-based diagnosis and management of osteoporosis for primary care professionals
- Develop incentives (and remove disincentives) for health care professionals to attend arthritis continuing medical education activities

Facilitators

- Continued strategies to increase awareness of osteoporosis

Potential Barriers

- Lack of perceived importance of osteoporosis relative to other health conditions among health care providers and public
- Geography (availability of bone mineral density testing within reasonable distance)
- Lack of understanding among health professionals and people with severe osteoporosis that effective treatments exist

9. Standard: Every Canadian with arthritis must have timely and equal access to appropriate medications.

Action Steps

- Determine which arthritis medications can be considered "life-saving" or "quality of life saving"
- Determine current access to available effective therapies for arthritis
- Develop a proposal for the development of a national drug program to ensure rapid and equal access to life-saving and quality-of-life saving medications
- Pilot-test a limited expanded access program

Facilitators

- Increased awareness of the “costs” (lost employment, inability to live independently or care for others, informal care giver costs, etc.) associated with untreated or under-treated arthritis

Potential Barriers

- High drug costs
- Delay in getting drugs from approval to market
- Variability across provinces regarding drug coverage
- Canada Health Act does not include medications

10. Standard: Post-approval evaluation of arthritis medications must be part of a drug approval.

Action Steps

- The federal government must mandate post-marketing surveillance to provide real-world safety and effectiveness information on all drugs

Facilitators

- Buy-in from the pharmaceutical industry

Potential Barriers

- Under-reporting of adverse events by health care professionals and people with arthritis

11. Standard: Patient preferences including risk-benefit trade-offs, must be incorporated into regulatory decision-making and prescribing of arthritis medications.

Action Steps

- Arthritis consumer organizations demand inclusion in all health policy decision-making processes regarding medication review

Facilitators

- Arthritis consumer organizations provide volunteers to serve on relevant committees and boards

Potential Barriers

- Undervaluing of input from the public

12. Standard: Every Canadian with arthritis requiring joint surgery must wait no longer than six months from the time the decision to have surgery is made by the patient and physician.

Action Steps

- Support research to identify, test and implement more efficient, integrated, alternative models for arthritis care that take into consideration the shortage of arthritis health professionals
- Develop and disseminate appropriateness criteria for total joint replacement (and for other orthopaedic surgeries) – for primary care providers, rheumatologists, people with arthritis
- Promote “active” waiting rather than current passive waiting i.e. pre-surgery education, rehabilitation, etc. during waiting period
- Identify strategies to expand training, recruitment and retention of orthopaedic surgeons

Facilitators

- Where possible, establish regional rather than hospital based wait list registries

Potential Barriers

- Insufficient health professional manpower
- Growing number of people requiring surgery, as well as the backlog of patients already on the list
- Cost

Standards requiring more research

13. Standard: To prevent arthritis, every Canadian must understand and implement prevention strategies to reduce sport and recreation injuries.

Action Steps

- Governments must invest urgently in research to evaluate risk factors for sport and recreation injury, with subsequent development and testing of interventions designed to ameliorate identified risk factors

Facilitators

- Better communication between sports medicine and orthopaedic surgery disciplines
- Dissemination of existing information on prevention strategies for public education sports programs and community activities

Potential Barriers

- Dependence on volunteers to coach and/or supervise recreational sport

14. Standard: Every Canadian with arthritis must have timely access to appropriate integrated health care, appropriate to their age and disease stage.

Action Steps

- Governments must invest urgently in designing and testing new models of integrated health care that take into consideration limited existing and future health professional resources

Facilitators

- Studies to test the feasibility, costs and effectiveness of alternative models of arthritis care

Potential Barriers

- Provincial health plans largely cover physician services; inadequate and variable funding of other arthritis health professionals' services

15. Standard: Every Canadian with arthritis will be enabled to participate in life roles that are important to them.

Action Steps

- Public awareness and health professional education

Facilitators

- Information and resources from consumer advocacy organizations, self-management programs, public information from The Arthritis Society
- Emerging and increased research publications focused on participation

Potential Barriers

- Limited attention to enabling participation in the arthritis community

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SECTION 7

OUTSTANDING RESEARCH QUESTIONS

7.1 Arthritis Awareness at the Government, Consumer/Patient and Public Levels

- What is the best way to deliver information and educational programs to Canadians with arthritis? To the general public? What helps and hinders access to information and education?
- What is the current level of awareness of Canadians about arthritis? What is the best strategy to improve Canadians' awareness of arthritis across the lifespan?
- What should be the minimal acceptable standard for quality and accuracy of information and educational programs? How do existing programs stand up to these standards?
- Which benchmarks should be used to evaluate the success of interventions to increase public and consumer awareness of arthritis?

7.2 Medical/Health Professional Education

- What is the reliability and validity of commonly-used arthritis screening assessment tools, including the Gait, Arms, Legs, Spine tool (GALs), for the detection of synovitis (joint inflammation)? Joint derangement? In children and adults?
- Will training of primary care/community care practitioners in the performance of reliable and valid screening tools for arthritis in children, adolescents and adults increase the number of arthritis evaluations performed? Reduce time to diagnosis and institution of effective treatments?
- What should be the "core competency" required of entry and advanced-practice levels in physical therapy and occupational therapy? Other relevant health professional disciplines?
- What are the current knowledge and skills of entry and advanced-practice levels of occupational therapists and physical therapists?
- What is the efficacy and cost-effectiveness of arthritis interventions delivered by various occupational therapist/physical therapists? What about complimentary and alternative therapies?
- What strategies delivered by occupational therapists and physical therapists have the greatest impact on arthritis progression?

7.3 Participation

- How should “participation” be defined in order to differentiate it from other concepts and constructs?
- How does participation relate to other patient outcomes, including quality of life, mood, and physical and psychosocial function?
- Are existing measures suitable as core measures of “participation” for all people with arthritis? If not, should new measures be developed?
- Will improvements in arthritis care lead to improvements in participation?
- Will attention to participation as a key outcome in arthritis lead to improvements in participation in life roles (for children and adults)? Will this lead to improved treatment of people with arthritis?
- How do we align treatment practice with participation goals as well as traditional arthritis outcomes?
- What is the impact of the following community factors on participation: built environment; self-management/coping abilities; assistive devices; diet; and complimentary and alternative therapies?
- How do participation expectations change in relation to the life span, individual differences (e.g. culture, race/ethnicity, personal resources) and geographical region?
- How can we apply existing theories and models to facilitate behaviour change and maintenance in an effort to improve participation?

7.4 Physical Activity

- What is the type and dose (frequency and intensity) of physical activity that is optimum for joint health of children and adults?
- Does physical activity prevent osteoarthritis? Are there specific types of physical activity that increase risk for, or progression of, arthritis?
- What is the type and dose (frequency and intensity) of physical activity that is optimum for therapeutic exercise in people with established arthritis (osteoarthritis, inflammatory arthritis in children, adolescents and adults) and osteoporosis?
- What types of recreational physical activity are appropriate for persons with established arthritis or osteoporosis?
- Which approach is most likely to result in sustained, whole population participation in physical activity?
- What are the requirements (minimum competency level) for persons who implement physical activity and sports programs for persons with disability?
- Does maintaining a healthy body weight prevent osteoarthritis?

7.5 Injury Prevention

- What is the risk associated with intrinsic factors (i.e. body size differential ability, equipment (i.e. shin guards), environment (i.e. ice conditions, field conditions, shoe/playing surface interface) and rules of play (i.e. contact in hockey, penalties, refereeing standards) in adolescent sport?
- How accurate (comprehensive) are current sports injury surveillance programs? What is the cost-effectiveness of developing a national/provincial registry for sports injury?
- What are the optimal sport-specific prevention strategies in other adolescent and recreational populations? Which will have the greatest public health impact? Which is most cost-effective?
- What is the impact of sport-specific prevention strategies on sports performance, drop out from sport, long-term outcomes such as obesity, mortality? What is the knowledge uptake following implementation of such programs?
- What would be the impact/cost-effectiveness of a global, multifaceted, school-based injury-prevention program?
- What are the short-and longer-term outcomes associated with various sports injuries?
- What is the level of knowledge among coaches and assistant coaches regarding sports injury prevention? What level of compliance can be expected from them in supporting injury prevention strategies?

7.6 Management and Models of Care

7.6.1 Access to Diagnosis/Manpower and Models of Care for Individuals of All Ages with Arthritis

- What is the effectiveness (cost-effectiveness) of current models for arthritis care – in particular for early inflammatory arthritis, OA and orthopaedic care for arthritis? What are the barriers to delivery of effective arthritis care? Is there differential effectiveness for patients of different age, racial/ethnic background, geographic region, or gender?
- What are the current wait times for consultation with a rheumatologist for new onset inflammatory arthritis? What are the current outcomes of care?
- What alternate/new models of care delivery are associated with improved outcomes (e.g. time to initiation of disease modifying anti-rheumatic drug for inflammatory joint disease, wait times for surgery) for patients? What are the barriers and facilitators to implementing these models?

- Is online technology effective (and cost-effective) as a means of providing information and management support for people with arthritis and their caregivers? What about for primary care practitioners?
- What are the barriers and facilitators to implementing a model of patient-initiated care (self-management) that is suited to local needs?
- What are the characteristics and needs of people with arthritis who can successfully self-manage?
- What are the consequences of delayed diagnosis in osteoarthritis?
- How should "early osteoarthritis" be defined in clinical practice? In clinical research? What are the implications of various definitions?
- Does early intervention in OA alter the course of the disease?
- What should be the model for the management of osteoarthritis prior to need for total joint replacement surgery?
- What therapeutic modalities are associated with improved outcomes in arthritis? When and how should they be used?
- What are the arthritis health professional manpower needs, assuming the existing model of care delivery, versus alternate models of care?
- Are the information and practice needs of rural physicians different from those of urban physicians? If so, how?
- What is the evidence to support the use of the various arthritis orthopaedic surgical procedures?

7.6.2 Access to Medications

- What is the best method by which to monitor drug safety once drugs become available?
- What is the adequacy of existing administrative databases for post-marketing surveillance for drug safety? What are the limitations? For example, how does *MedEffect* (Health Canada 2006) market itself to consumers and health care professionals? How does *MedEffect* reporting translate into government action, and within what time frame?
- What are the barriers to equitable access to proven cost-effective therapies in Canada? What strategies might reduce current inequities in access to proven cost-effective therapies for arthritis and osteoporosis? What would be the impact of equal access across provinces and territories on specific arthritis therapies (e.g. office and emergency room visits, hospitalization rates and hospital length of stay, home care demands and long term care needs)?
- How might pragmatic clinical trials methodology be utilized to examine the safety and effectiveness of various arthritis treatment strategies?

- How should the “cost-effectiveness” of arthritis drugs be evaluated? Which costs and which effects should be measured?
- Would more equitable and timely access to medications result in improved employment and employment satisfaction among people with arthritis?

7.6.3 Access to Surgery

- What is the effect of waiting time on patient outcomes (survivorship, pain, physical functioning, satisfaction, participation etc.) after joint replacement surgery? Other orthopaedic procedures?
- What are patient expectations regarding access to surgery (acceptable waiting times for consultation and orthopaedic surgery)?
- What is the role of rehabilitation prior to joint replacement surgery? Does pre-operative rehabilitation change post-operative outcomes following total joint replacement?
- Can we use computer simulation models to identify the key process variables that explain waiting times (rate-limiting steps)?
- What is the best approach to urgency rating of patients on the waiting list for joint replacement surgery?
- What is the current distribution and characteristics (including case-mix for surgeons) of full-time-equivalent orthopaedic surgeons/anaesthetists/operating room nurses, nationally?

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SECTION 8

NEXT STEPS

On January 24th 2006, ACAP's Steering Committee met in Toronto to determine "next steps" for implementation of the standards. Each standard was reviewed and discussed with respect to its importance to people living with arthritis (i.e. potential to reduce the burden of arthritis in our population) and the feasibility of implementing the standard in Canada to make a discernible difference to their lives within one to two years. Consideration was also given to the ongoing activities of each of the stakeholder arthritis organizations and what was unlikely to happen without the collective energy of the arthritis community behind it.

Based on these daylong discussions, the following three standards were identified as requiring immediate attention.

1. ***Every Canadian must be aware of arthritis.***
ACAP, through its member organizations, will undertake a number of strategies to increase Canadians' awareness of arthritis. This will include a social marketing campaign directed at the Canadian public and the development and implementation of an "Arthritis 101" program directed at elected officials and government health policy makers.
2. ***All relevant health professionals must be able to perform a valid, standardized, age-appropriate musculoskeletal screening assessment.***
The "Access to Diagnosis" Team will formally evaluate the reliability and validity of various arthritis screening tools in order to determine the optimal candidate tool or tools. Once the tool(s) is determined, key leaders within the arthritis community will liaise with medical and allied health professional schools to encourage training of relevant health professionals in performance of the screening assessment. They will also liaise with the professional licensing bodies to encourage that evaluation of competency in performance of the assessment be incorporated into the accreditation process. Continuing medical education strategies will be used to disseminate the tool(s) to relevant health providers in established practice. Links with the Canadian Medical Association to assist in this dissemination will be sought.
3. ***Every Canadian with arthritis must have timely and equal access to appropriate medication.***
A sub-committee of ACAP will be established to examine the current situation in Canada with respect to access to medications currently recommended for the management of arthritis and osteoporosis. This sub-committee will also assess the scientific evidence to support the "life-saving" or "quality-of-life saving" effects of these medications. Once this information has been assembled, the

sub-committee will make recommendations to ACAP regarding the next steps, including whether or not there is evidence to support the need for a federally-funded drug plan for so-called life-saving medications for arthritis.

The initial focus of attention for ACAP will be on these three standards. However, all stakeholder organizations are encouraged to consider the priorities for standards development identified through the Summit process when developing their own organizations' strategic plans. Once these standards have been implemented, ACAP will turn its attention to each of the remaining standards in turn, according to feasibility and relevance.

The areas that have been identified as requiring additional research have been provided to the relevant arthritis funding bodies (The Canadian Arthritis Network, the Institute for Musculoskeletal Health and Arthritis (IMHA) within the Canadian Institutes of Health Research, and The Arthritis Society). Priority setting within the many identified research questions was also established. There was general consensus among the arthritis stakeholder groups that the first and foremost priority for research is to develop and test alternate models for arthritis care. Only through innovative new models can we ultimately achieve many of the identified benchmarks for arthritis care in Canada.

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APPENDICES

APPENDIX I – Supporting Evidence

1. Consumer and Public Awareness

- Educational interventions have been shown to be effective in improving knowledge levels about arthritis (Barlow & Wright 1998, Moll & Wright 1972, Niedermann 2004) and promoting behaviour change in people with arthritis (Karlson 2004, Warsi 2004).
- There is no current evidence that Canadians have accurate arthritis information. Research has shown that the lay public is not as well informed about arthritis as people with arthritis are (Price 1983).
- There is evidence the quality of information in arthritis resources available on the internet is poor (Maloney 2005, Suarez-Almazor 2001).
- Only 28% of elderly people were found to have a home computer and only 39% of these people looked for information on the internet (Tak 2005).

2. Health Professional Education

- Musculoskeletal issues are common in the daily practice of primary care physicians, representing up to 20% of daily practice (Dequeker & Rasker 1998).
- Primary care physicians report less confidence and abilities completing musculoskeletal assessments compared with other clinical encounters (Glazier 1996 and 1998, Myers 2004).
- Musculoskeletal conditions make up the largest area of practice for Canadian physiotherapists (Canadian Alliance of Physiotherapy Regulators 2005). Yet, undergraduate physiotherapy programs were found to have significant variation in rheumatology instructional hours and limited opportunities for clinical skills development (Westby 1999).
- Arthritis history and physical assessment skills were found to be limited in entry-level physiotherapists and occupational therapy students (Moncur 1985).

3. Participation

- Arthritis affects participation in broad roles and societal activities such as employment, education, social involvement, personal relationships and leisure activities (Adam 2005, Backman 2004, Carr 1999, Desrosiers 2005, Dieppe 2000, Fex 1998, Gignac 2000, Katz & Yelin 2001, Lacaille 2004,

Neugebauer & Katz 2004, Reisine 2003, Strine 2004, Van Jaarsveld 1998).

- Participation is linked to people's identity, goals, aspirations and to emotional well-being (Desrosiers 2005, Gignac 2000, Katz & Yelin 2001, Perenboom & Chorus 2003, Strine 2004, Wilkie 2004 and 2005).
- It is important to not only look at the disease but also what makes people healthy (World Health Organization 2001). With few exceptions, current treatment focuses on symptoms of the disease, personal care, and functional activities such as walking, but largely ignores participation (Cardol 1999, Wilkie 2005).

4. Physical Activity

- Obesity is a recognized risk factor for osteoarthritis of the knee, the hip and the hand (Carman 1994, Felson 1988 and 2004, Gelber 1999, Lievens 2002). There is some agreement that increased load on the joint is one mechanism contributing to the development of osteoarthritis (de Jong, O. R. 2004, Olsen 2003, Schoster 2005). Weight loss has been identified as an important prevention strategy for osteoarthritis (Felson 1992 and 2000, Powell 2005).
- Physical activity is necessary to achieve and maintain healthy body weight, and can be a preventative measure for the development of osteoarthritis (Provincial Health Services Authority 2005, Public Health Agency of Canada 2003).
- Physical activity can have a beneficial effect on bone and joint health, as well as physical and psychosocial functioning of individuals with joint disease (Hurley 2003, Imundo & Klepper 2005, Sharma 2003). Certain types of recreational physical activity are appropriate for persons with rheumatoid arthritis and osteoarthritis (Brosseau 2003, de Jong, Z. 2004, Han 2004).
- Therapeutic exercises, including functional strengthening, general physical activity, and whole body, low-intensity exercises, are effective in managing arthritis (Ottawa Panel 2004).

5. Injury Prevention

- Sport is a leading cause of injuries in adolescents requiring medical attention and emergency department visits (Bienfeld 1996, Emery 2003, King 1998, Statistics Canada 1997). Injuries of the lower extremity, primarily knee and ankle, are most common, making up greater than 60% of sporting injuries (Abernethy & MacAuley, Bienfeld 1996, Emery 2003 and 2005, King 1998, Statistics Canada 1997).

- Eight per cent of adolescents drop out of sport each year due to injury (Grimmer 2000). Drop out from sport will lead to physical inactivity and resultant health problems related to obesity and illness (Blair 1993, 1995, Jebb & Moore 1999, Paffenbarger 1994).
- Injuries such as fractures or injuries of the knee, hip, ankle and foot can lead to increased risk of development of osteoarthritis later in life. Recent findings showed that > 50% of people who have a knee injury will develop osteoarthritis within 12-20 years (Roos 2005).
- Some studies have identified risks for injuries, such as decreased strength, endurance and balance in adults and adolescents (Cahill & Griffith 1978, Emery 1999 and 2005, Emery & Meeuwisse 2001, Jones 1993, Lysens 1984, Meeuwisse 1991, Pinto 1999, Tropp 1984). Injury prevention strategies in sport have been shown to have some beneficial impact (Bahr 1997, Caraffa 1996, Emery 2003 and 2005, Janda 1993, MacKay 2001).
- Valid and sustainable injury surveillance in child and adolescent sport is limited (Hagel 2003, Meeuwisse 2002, Meeuwisse & Love 1997, Schick 2003, van Mechelen 1997).

6. Access to a Diagnosis

- Guidelines recommend early consultation with an arthritis specialist to confirm diagnosis and treatment (American College of Rheumatology Subcommittee on Rheumatoid Arthritis Guidelines 2002, Ontario Musculoskeletal Therapeutics Review Panel 2000).
- Early DMARD (disease modifying anti-rheumatic drug) intervention slows the progression of structural joint damage and improves long-term outcomes, as well as overall patient quality of life. Delays of three months or more in instituting DMARDs can lead to worse physical disability and joint damage (Eltringham 2003, Fries 1996, Lard 2001, Pincus 1984).
- There are recommended guidelines that support the management of osteoarthritis using both pharmacologic therapy and non-pharmacologic interventions, such as exercise, education, joint protection and assistive devices (American College of Rheumatology Subcommittee on Osteoarthritis Guidelines 2000, Jordan 2003). Strategies for guideline dissemination result in modest to moderate improvements (Grimshaw 2004).
- Bone mineral density is the best predictor of fracture risk (Brown 2002, Consensus Development Conference on Osteoporosis 1991).

7. Manpower and Models of Care

- There are human resources shortages in health professions such as rheumatology and orthopaedic surgery, and geographical variation reported in the availability of health professionals (Public Health Agency of Canada 2003, Rumble & Kreder 2004, Shipton 2004).
- There is supporting evidence for the effectiveness of multidisciplinary team care for arthritis (Vliet Vlieland & Hazes 1997, Vliet Vlieland 2004).
- There is evidence to support the effectiveness and, in some cases, cost-effectiveness of emerging models of care, such as the use of specialized nurses or rehabilitation therapists working in extended clinical roles (Campos 2001 and 2002, Hill 1997 and 2003, Li 2005, Temmink 2001, Tjihuis 2002, van den Hout 2003).
- Models designed to improve knowledge of primary care physicians in screening and referrals have resulted in positive outcomes, such as reduced wait times for rheumatologists (Ahlmén 2005, Boonen & Svensson 2003, Glazier 2005, Schulpen 2003).

8. Access to Medications

- The use of DMARDs in people with severe arthritis can impact quality of life, may maintain work productivity, and reduce the need for surgery due to joint damage (Pope 2002).
- New biological therapies for the treatment of inflammatory arthritis may also lessen joint destruction (Eltringham 2003, Fries 1996, Lard 2001, Pincus 1984). They are also more expensive therapies.
- Studies typically evaluate effectiveness of drugs in "ideal" patients. The design of many studies is often inadequate to assess safety under real-world conditions for reasons such as small numbers of study patients and short duration of follow-up (Sokka & Pincus 2003, Wolfe 2004).
- Patients in clinical trials are often not representative of patients who receive drug therapies, because patients are often excluded from studies if they have other conditions (Zimmerman 2004).
- Ongoing monitoring of drug utilization and outcomes in the form of post-marketing surveillance is considered crucial to enhance safety, effectiveness and cost-effectiveness (Laupacis 2002).
- Patients place importance on being involved in decision-making with their physicians about their health care (Wensing 1998).

9. Access to Surgery

- Total joint replacement is a cost saving both to the health care system and to patients and their caregivers (Hawker 2004).
- There is significant suffering and significant loss in quality of life, possibility of joint damage, and reduced mobility for patients who wait greater than six months for surgery (Mahon 2002).
- Worse arthritis status prior to surgery predicts poorer outcomes in patients following their surgery (Fortin 2002).
- The recommended standard is consistent with other national and international benchmarks regarding access to care (Rumble & Kreder 2004).

Appendix II – Participants and Teams

Co-chairs

- Dr. John Esdaile – Rheumatologist / Researcher, University of British Columbia
- Dr. Gillian Hawker - Rheumatologist / Researcher, University of Toronto
- Ms. Cheryl Koehn – Person with Rheumatoid Arthritis / President, Arthritis Consumer Experts
- Dr. Dianne Mosher – Rheumatologist, Dalhousie University

Planning Committee

- Elizabeth Badley – Epidemiologist / Researcher, University of Toronto
- Kathleen Bell-Irving – Family Physician, Canadian College of Family Physicians / University of British Columbia
- Angelique Berg – Executive Director, Canadian Orthopaedic Foundation
- Claire Bombardier – Rheumatologist / Researcher, University of Toronto
- Sheila Brien – Person with Osteoporosis, Canadian Osteoporosis Network
- Wyncel Chan – Youth with Arthritis, British Columbia
- Andrea Crowe – Youth with Arthritis, Nova Scotia
- Marie DesMeules – Public Health Agency of Canada (advisory role)
- Paul Dieppe – Rheumatologist / Researcher, University of Bristol, England
- Ciarán Duffy – Paediatric Rheumatologist / Researcher, McGill University

- John Fleming – President and C.E.O., The Arthritis Society
- Cy Frank – Orthopaedic Surgeon / Researcher, University of Calgary
- Joyce Greene – Person with Arthritis, Canadian Arthritis Network, Consumer Advisory Council
- Martha Hall – Public Health Agency of Canada (advisory role)
- Catherine Hofstetter – Person with Arthritis, Canadian Arthritis Patient Alliance
- Claudia Lagacé – Public Health Agency of Canada (advisory role)
- Jean Légaré – Person with Arthritis, Patient Partners in Arthritis
- Matthew Liang – Rheumatologist / Researcher, Harvard Medical School
- Sydney Lineker – Physical Therapist, Arthritis Health Professions Association
- Robin Poole – Researcher, McGill University
- Bill Rennie – Chair, Alliance for the Canadian Arthritis Program and Orthopaedic Surgeon, University of Manitoba
- Johnathan Riley – Managing Director, Canadian Arthritis Network
- Rayfel Schneider – Paediatric Rheumatologist, University of Toronto
- Pam Sherwin – Parent of Child with Arthritis, Children's Arthritis Foundation
- Peter Tugwell – Rheumatologist / Researcher, University of Ottawa
- Gordon Whitehead – Person with Arthritis, Arthritis Research Centre of Canada, Consumer Advisory Board
- Hazel Wood – Project Coordinator, Bone and Joint Decade
- (Rotating) Pharmaceutical Industry Representatives

Teams

Team 1 – Physical Activity

Juliette (Archie) Cooper * – Occupational Therapist / Researcher, University of Manitoba
Cameron Blimkie – Kinesiologist / Researcher, McMaster University
Lucie Brosseau – Physical Therapist / Researcher, University of Ottawa
Janice Butcher – Physical Education / Researcher, University of Manitoba
Sandra Curwin – Physical Therapist / Researcher, University of Alberta
Maureen Dunn – Person with Osteoporosis, Ontario
Jacqueline Lukas – Person with Arthritis, Ontario
Lydia Makrides – Physical Therapist / Researcher, Dalhousie University
Patti-Jean Naylor – Physical Education / Researcher, University of Victoria
Samantha Stephens – Paediatric Researcher, Hospital for Sick Children

Team 2 – Injury Prevention

Carolyn Emery* – Assistant Professor, University of Calgary
Phil Groff – Director, Research & Evaluation, Smartrisk, Ontario
Margaret Herbert – Public Health Agency of Canada
Donna MacIntyre – Associate Professor, University of British Columbia
William Stanish – Orthopaedic Surgeon, Dalhousie University
Hazel Wood – Bone and Joint Decade

Team 3 – Access to a Diagnosis

Sasha Bernatsky* – Rheumatologist / Researcher, McGill University
Jolanda Cibere – Rheumatologist / Researcher, University of British Columbia
Pierre Dagenais – Rheumatologist / Researcher, University of Montreal
Robert Eaton – Family Physician, Central Ottawa Family Health Network
Carol Hitchon – Rheumatologist / Researcher, University of Manitoba
Diane Lacaille* – Rheumatologist / Researcher, University of British Columbia
Anne Lyddiatt – Person with Arthritis, Ontario
Morris Markentin – Family Physician, Saskatchewan
Suzanne Ramsey – Paediatric Rheumatologist, Nova Scotia
Gordon Whitehead – Arthritis Research Centre of Canada Consumer Advisory Board

Team 4 – Manpower and Models of Care

Elizabeth Badley* – Epidemiologist / Researcher, University of Toronto
Claire Bombardier – Rheumatologist / Researcher, University of Toronto

Michel Brazeau – Royal College of Physicians and Surgeons of Canada
Ciarán Duffy – Paediatric Rheumatologist / Researcher, McGill University
David Hawkins* – The Association of Faculties of Medicine of Canada
Mary Kim – Person with Arthritis, Ontario
Linda Li* – Physical Therapist / Assistant Professor, University of British Columbia
Sydney Lineker – Physical Therapist, Arthritis Health Professions Association
Crystal MacKay – Physical Therapist / Researcher, University of Toronto
Dianne Mosher – Rheumatologist, Dalhousie University
Michel Zummer – President, Canadian Rheumatology Association

Team 5 – Access to Medications

Aslam Anis* – Health Economist, University of British Columbia
Nick Bansback – Health Economist, University of British Columbia
Sheila Brien – Person with Osteoporosis, Ontario
Vivian Bykerk* – Rheumatologist, University of Toronto
Brian Feldman – Paediatric Rheumatologist / Researcher, University of Toronto
Samantha Fong – Pharmacist, The Ottawa Hospital
Catherine Hofstetter – Person with Arthritis, Ontario
Jean Légaré – Person with Arthritis, Quebec
Muhammad Mamdani – Pharmacist / Health Economist / Researcher, University of Toronto
Carlo Marra – Pharmacist, University of British Columbia
Janet Pope – Rheumatologist / Researcher, University of Western Ontario
William Tholl – Canadian Medical Association
Barbara Wellis – The Arthritis Society

Team 6 – Access to Surgery

Paul Dieppe – Rheumatologist / Researcher, University of Bristol, England
Michael Dunbar* – Orthopaedic Surgeon / Researcher, Dalhousie University
Ken Faber – Associate Professor of Surgery, University of Western Ontario
Bev Greenwood – President, Canadian Orthopaedic Nurses Association
Gillian Hawker* – Rheumatologist / Researcher, University of Toronto
Mary Kim – Person with Arthritis, Ontario
Hans Kreder* – Orthopaedic Surgeon / Researcher, University of Toronto
Kellie Leitch – Paediatric Orthopaedic Surgeon, University of Western Ontario
Brendan Lewis – Orthopaedic Surgeon / Researcher, Memorial University of Newfoundland
Judy MacNeil – Family Physician, Nova Scotia
Ren Mann – President, Canadian Anesthesiologists' Society
Bill Rennie – Orthopaedic Surgeon, University of Manitoba

Claudia Sanmartin – Statistics Canada, Health Analysis and Measurement Group

Linda Wilhelm – Person with Arthritis, New Brunswick

Tracy Wilson – Orthopaedic Surgeon, Thunder Bay Regional Health Sciences Centre

Team 7 – Participation

Catherine Backman* – Occupational Therapist / Researcher, University of British Columbia, and Canadian Association of Occupational Therapists

Dorcas Beaton – Occupational Therapist / Researcher, St Michael's Hospital and University of Toronto

Pierre Côté – Chiropractor / Researcher, Institute for Work and Health and University of Toronto

Debbie Da Costa – Psychologist / Researcher, McGill University

Aileen Davis – Physical Therapist / Researcher, University of Toronto

Monique Gignac* – Health Psychology / Researcher, ACREU and University of Toronto

Sheila Renton – Occupational Therapist, The Arthritis Society

Pam Sherwin – Parent of Child with Arthritis, Children's Arthritis Foundation

Gillian Taylor – Nursing Coordinator, Montreal Children's Hospital

Team 8 – General Public and Consumer Specific Awareness

Corrie Billedeau – Person with Arthritis, Manitoba

Joyce Greene – Person with Arthritis, Manitoba

Jean-Michel Halfon* – Pfizer Canada Inc.

Laurie Hurley – Senior Director of Arthritis Programs, The Arthritis Society

Cheryl Koehn* – Person with Arthritis, British Columbia

Allen Lehman – Trainee, University of British Columbia

Bernard Prigent – Pfizer Canada Inc.

Andy Thompson* – Rheumatologist, University of Western Ontario

Lori Tucker – Paediatric Rheumatologist, British Columbia

Team 9 – Health Professionals Education

Lori Albert – Rheumatologist, University of Toronto

Mary Bell – Rheumatologist / Researcher, University of Toronto

Kathleen Bell-Irving – Family Physician, University of British Columbia

Angela Busch – Physical Therapist, University of Saskatchewan

Alfred Cividino* – Rheumatologist, McMaster University

Ieva Fraser – The Arthritis Program, Southlake Regional Health Centre

Mike Gilbert – Orthopaedic Surgeon, University of British Columbia

Catherine Hofstetter – Person with Arthritis, Ontario

Susan Humphrey-Murto* – Rheumatologist, University of Ottawa
Gay Kuchta Paediatric – Occupational Therapist, Mary Pack Arthritis Program,
Vancouver Coastal Health
Bianca Lang – Paediatric Rheumatologist, Dalhousie University
Meridith Marks – Rehabilitation Medicine, University of Ottawa
Chris Penney – Rheumatologist, University of Calgary
Sheila Renton – Occupational Therapist, The Arthritis Society
Evelyn Sutton – Rheumatologist, Dalhousie University
Angèle Turcotte – Rheumatologist, Quebec City
Jeffrey Turnbull – Chair, Department of Medicine, University of Ottawa
Veronica Wadey – Orthopaedic Surgeon, Laval University
Jean Wessel – Physical Therapist, McMaster University
Marie Westby – Physiotherapist, Mary Pack Arthritis Program, Vancouver
Coastal Health / PhD student, University of British Columbia

Government Relations Team

Jeremy Adams – Senior Consultant, Enterprise Canada
Gilles Boire – Rheumatologist, Sherbrooke University
Arthur Bookman – Rheumatologist, University of Toronto
Sheila Brien – Person with Osteoporosis, Canadian Osteoporosis Patient
Network
Beverly Bryd – The Arthritis Society, Newfoundland Division
Andy Chabot – The Arthritis Society, Quebec
Anne Dooley* - Person with Rheumatoid Arthritis, Saskatchewan
John Esdaile – Scientific Director, Arthritis Research Centre of Canada
Alana Essery* - The Arthritis Society, Prince Edward Island
John Fleming – President and C.E.O., The Arthritis Society of Canada
Elaine Flis – Consultant, Enterprise Canada
Barb Fox – President and C.E.O., Enterprise Canada
Joyce Greene – Aboriginal Person with Arthritis, Canadian Arthritis Network
Consumer Advisory Council
Gillian Hawker – Rheumatologist / Researcher, University of Toronto
Catherine Hofstetter* – Person with Rheumatoid Arthritis, Canadian Arthritis
Patient Alliance
Beth Kidd* – The Arthritis Society, Alberta Division
Cheryl Koehn* – Summit Co-Chair, Arthritis Consumer Experts
Graeme Kohler – The Arthritis Society, Nova Scotia Division
Jean Légaré* – Person with Rheumatoid Arthritis / Co-Chair, Canadian Arthritis
Network Consumer Advisory Council
Dianne Mosher – Rheumatologist, Dalhousie University
Colleen Murray – Person with Arthritis, Canadian Arthritis Patient Alliance

Tom Noseworthy – Professor and Director of the Centre for Health Policy Studies, University of Calgary
Bob Offer – Community Rheumatologist, British Columbia
Barbara Oke-Kennedy – Site manager for the Dartmouth General Hospital, Nova Scotia
Vivian Randall – Person with Rheumatoid Arthritis, Newfoundland
Bill Rennie – Chair, Alliance for the Canadian Arthritis Program / Orthopaedic Surgeon
Pam Sherwin – Parent of Child with Arthritis, Children's Arthritis Foundation
Jo-Anne Sobie* - The Arthritis Society, Ontario Division
Heather Temple – The Arthritis Society, Manitoba Division
Peter Tugwell – Rheumatologist / Researcher, University of Ottawa
Verena Wardley - The Arthritis Society, Calgary Division
Gordon Whitehead* - Person with Rheumatoid Arthritis, Consumer Advisory Council of the Arthritis Research Centre
John Weir – President, Enterprise Canada
Marceline Zimmer – The Arthritis Society, Saskatchewan Division
Michel Zimmer* - Rheumatologist / President, Canadian Rheumatology Association

* *Denotes team leader/co-leader*

Appendix III - Support

Platinum Level

Merck Frosst Canada, Canadian Rheumatology Association, Abbott Canada, Schering Canada

Gold Level

Canadian Arthritis Network, Institute of Musculoskeletal Health and Arthritis, The Arthritis Society of Canada

Silver Level

Amgen Canada Inc., Health Canada, Pfizer Canada Inc., Wyeth Pharmaceuticals

Bronze Level

Better Bone Health (Procter & Gamble Pharmaceuticals/sanofi-aventis), Wright Biomet, Bristol-Myers Squibb, Hoffmann-La Roche Ltd., Janssen-Ortho Inc., Juvent, MEDEC, Ostek, Servier, Smith & Nephew Inc., Synthes, The Alliance for Medical Technology, Inc., Zimmer, Inc.

Appendix IV – Agenda

Summit on Standards for Arthritis Prevention and Care

October 31 - November 3, 2005

MONDAY, OCTOBER 31

6:00 p.m. **REGISTRATION**
Drawing Room Foyer

7:00 p.m. **WELCOMING RECEPTION**
Drawing Room Foyer

TUESDAY, NOVEMBER 1

Simultaneous translation will be available for all plenary sessions

7:30 a.m. **REGISTRATION**
Drawing Room Foyer

CONTINENTAL BREAKFAST
Laurier Room

9:10 a.m. **OPENING SESSION – WHY WE'RE HERE**
Ballroom

- **Introduction**
Michael Rowland, Summit Facilitator
- **The Arthritis Experience**
Cheryl Koehn, Summit Co-Chair

9:35 a.m. **GETTING STARTED/SUMMIT OVERVIEW**
Michael Rowland, Summit Facilitator

9:45 a.m. **KEYNOTE: NATIONAL STANDARDS**

- **The Need for Evidence-Based Health Care**

Dr. Matthew H. Liang, Rheumatologist/Researcher, Harvard Medical School; Professor of Health Policy and Management, Harvard School of Public Health; Member of the National Arthritis and Musculoskeletal and Skin Diseases Advisory Council

10:10 a.m. *Break*

10:30 a.m. **GOVERNMENT OF CANADA**

The Hon. Dr. Carolyn Bennett, Minister of State (Public Health)

10:45 a.m. **STANDARDS OVERVIEW**

- **Alliance for the Canadian Arthritis Program's Strategy**

Dr. Gillian Hawker, Summit Co-Chair

- **Standards Framework and Process**

Dr. John Esdaile, Summit Co-Chair

- **Overview of Recommended Standards**

- **Arthritis Awareness** – Dr. Monique Gignac, Health Psychologist/Researcher, University of Toronto, and Mr. Jean Légaré, Person with Arthritis, Patient Partners in Arthritis

- **Arthritis Prevention** – Dr. Juliette (Archie) Cooper, Occupational Therapist/Researcher, University of Manitoba

- **Arthritis Management and Models of Care** – Dr. Claire Bombardier, Rheumatologist / Researcher, University of Toronto

11:40a.m. *Break*

12:00 p.m. **LUNCH**
Drawing Room

1:00 p.m. **WORKING SESSIONS:
SUPPORT FOR STANDARDS AND IDENTIFICATION OF GAPS**

- **Introduction**
Michael Rowland, Summit Facilitator
Drawing Room

Participants will be able to attend two different working sessions, one in Session 'A' and one in Session 'B'

1:10 p.m. **WORKING SESSION 'A'**

Participants attend pre-selected working sessions in breakout groups organized by standard areas. Team leaders will present the proposed standards. Facilitators will lead discussion of:

- Support for the recommended standards
- Gaps where additional research and standards are required

Topics/Breakout Rooms

Awareness

1. General Public and Consumer Specific Awareness – *Renaissance Room (Mezzanine)*
2. Health Professionals Education – *Macdonald Room (Mezzanine)*
3. Participation – *Tudor Room (First Floor)*

Prevention

4. Physical Activity – *L'Orangerie (Mezzanine)*
5. Injury Prevention – *Palladian Room (Mezzanine)*

Management and Models of Care

6. Access to a Diagnosis – *Canadian Room (Lower Level)*
7. Manpower and Models of Care – *Laurier Room (Ground Floor)*
8. Access to Medications – *Ballroom (Ground Floor)*
9. Access to Surgery – *Burgundy Room (Mezzanine)*

3:00 p.m.

BREAK

Participants move to second Working Session

3:30 p.m.

WORKING SESSION 'B'

Repeat of Working Session 'A' (same breakout rooms as above)

5:00 p.m.

END OF WORKING SESSIONS

Free time

7:00 p.m.

DINNER

Ballroom

- **Keynote Address – Senator Pat Carney**
Introduced by Dr. John Esdaile

WEDNESDAY, NOVEMBER 2

7:00 a.m.

CONTINENTAL BREAKFAST

Laurier Room

8:00 a.m.

DAY 2 INTRODUCTION

Ballroom

- **Overview of Day's Themes**
Colleen Maloney, Canadian Arthritis Patient Alliance (CAPA)
- **Government of Canada**
Hon. Stephen Owen, Minister of Western Economic Diversification and Minister of State (Sport)

8:20 a.m. **SUMMARY OF DAY 1 WORKING SESSION RESULTS**

Michael Rowland, Summit Facilitator

8:35 a.m. **WORKING SESSIONS:
IMPLEMENTATION STRATEGIES**

• **Introduction**

Michael Rowland, Summit Facilitator

Participants will be able to attend two different working sessions, one in Session 'C' and one in Session 'D'

8:45 a.m. **WORKING SESSION 'C'**

Organized by standard area, participants attend pre-selected working sessions in breakout groups on how to implement the standards. Facilitators will lead discussion of:

- Barriers and facilitators
- Implementation strategies
- Implementation responsibilities

Topics / Breakout Rooms

Awareness

1. Participation – *Tudor Room (First Floor)*
2. General Public and Consumer Specific Awareness – *Drawing Room (Ground Floor)*
3. Health Professionals Education – *Macdonald Room (Mezzanine)*

Prevention

4. Physical Activity – *L'Orangerie (Mezzanine)*
5. Injury Prevention – *Palladian Room (Mezzanine)*

Management and Models of Care

6. Access to a Diagnosis – *Canadian Room (Lower Level)*
7. Manpower and Models of Care – *Laurier Room (Ground Floor)*
8. Access to Medications – *Adam Room (Ground Floor)*
9. Access to Surgery – *Burgundy Room (Mezzanine)*

- 10:15 a.m. *Break – Participants move to second Working Session*
- 10:45 a.m. **WORKING SESSION 'D'**
- Repeat of Working Session 'C' (same breakout rooms as above)***
- 12:15 p.m. *Break*
- 12:45 p.m. **LUNCH**
Ballroom
- 1:45 p.m. **SUMMARY OF IMPLEMENTATION SESSIONS**
Michael Rowland, Summit Facilitator
Ballroom
- 2:15 p.m. **DEVELOPING AN ACTION PLAN – WHAT HAPPENS NEXT**
Dr. Cy Frank, Institute of Musculoskeletal Health and Arthritis
Ballroom
- 2:30 p.m. *Break*
- 2:45 p.m. **PLENARY DISCUSSION**
Michael Rowland, Summit Facilitator
- 3:45 p.m. **CLOSING SESSION**
Ballroom
- **Closing Remarks**
Dr. Dianne Mosher, Summit Co-Chair
Logan Graham, person with juvenile idiopathic arthritis
- 4:00 p.m. **SUMMIT ADJOURNS**

THURSDAY, NOVEMBER 3

Follow-up and debriefing meetings – Summit organizers

- 10:30 a.m. **MEDIA BRIEFING**

Summit on
Standards for Arthritis
Prevention and Care
November 1-3, 2005



Colloque sur les
normes en matière de
prévention et de
traitement de l'arthrite
Du 1^{er} au 3 novembre 2005



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